

AAKP PATIENT PLAN

Phase 2

Getting Help and Starting Dialysis

The Independent Voice of Kidney Patients Since 1969™



The American Association of Kidney Patients wishes to thank all the patients, family members, professionals and organizations who gave generously of their time and resources in order to provide all patients with the AAKP Patient Plan©.

The AAKP Patient Plan© Team and the AAKP Medical Advisory Board spent countless hours updating this program and bringing the latest in medical research to this project. Our sincere thanks goes to Stephen Z. Fadem, MD; Eli A. Friedman, MD; Christopher R. Blagg, MD; Thomas A. Golper, MD; Richard S. Goldman, MD; Keith C. Norris, MD; Thomas G. Peters, MD; Leslie Wong, MD; Tejas P. Desai, MD; Renee Bova-Collis, MSW, LSCW and Dori Schatell, MS. They provided us with educational material to supplement our writing and encouraged AAKP in this project from its inception.

Please note, the material in the AAKP Patient Plan® series is intended for educational purposes only. Individuals are encouraged to consult their physician and health care team for medical information specific to their care.

This activity is supported by an educational donation by **AMGEN®**

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*The **Phase 2 Patient to Patient** newsletter is available on our Web site at www.aakp.org. For more information, contact AAKP at (800) 749-2257 or e-mail us at info@aakp.org.*

PRE-TEST

The American Association of Kidney Patients (AAKP) is a national non-profit organization dedicated to improving the quality of life for kidney patients and family members through education, advocacy and fostering patient communities. Kidney disease affects 26 million Americans. The AAKP Patient Plan[©] is design to address questions and concerns at the various phases of the disease process. The purpose of the following test is to determine your basic understanding of the materials presented. This is a multiple choice test. Please select the best possible answer to each question.

Once you complete the questionnaire, please return it to the American Association of Kidney Patients at 2701 N. Rocky Point Drive, Suite 150, Tampa, Florida 33607.

1. What are the components of caring for a renal access site? (Please select all that apply)
 - ☐ Touch for pulse, tenderness and temperature,
 - ☐ Look at your skin color, swelling or drainage,
 - ☐ Care to keep your access clean and protected,
 - ☐ Wear tight clothes
2. What may happen when an alarm sounds on a dialysis machine? (Please select all that apply)
 - ☐ You will let your nurses or doctor know immediately so that they can usually address it quickly and easily
 - ☐ You may experience muscle cramps or there can be a sudden drop in your blood pressure (hypotension)
 - ☐ You may have water or chemical balances in your body that change quickly
 - ☐ You may feel dizzy, weak or sick to your stomach.
3. Which of the following are considerations for choosing home dialysis? (Please select all that apply)
 - ☐ Training can be provided to you, typically while you are receiving regular treatments in a dialysis center
 - ☐ Compared to a dialysis center where nurses and technicians help to put you on and take you off the machine, at home you will be doing this with assistance from someone else who can help you when needed.
 - ☐ You will need to become comfortable with sticking yourself
 - ☐ The home dialysis machine is too complicated to use and understand.

If you can drive a car, then you can drive a dialysis machine. With both, you have to learn how to use them safely and what to do when problems occur.
4. Continuous Cycling Peritoneal Dialysis is done at home with a machine called a cyclor.
 - ☐ True
 - ☐ False
5. From the following options, what are some of the changes that can happen after the first few peritoneal dialysis treatment? (Please select all that apply)
 - ☐ Less nausea
 - ☐ Less feelings of exhaustion
 - ☐ An increased “tin taste” in your mouth Typically this symptom begins to fade rather than increase
 - ☐ Less forgetfulness

PRE-TEST

6. People can live a happy and full life on one kidney.
- ☐ True
 - ☐ False
7. From the following options, what are the three kinds of kidney transplants (Please select all that apply)
- ☐ Living related, which involves a blood relative (e.g., mother, father, sister, brother, child, cousin, uncle, aunt) who agrees to give you a kidney.
 - ☐ Living unrelated, which is a person who is not a “blood relative” (e.g., spouses, friends, distant cousins and others) who agrees to give you a kidney that is matched for you.
 - ☐ Animal, which comes from another species where a kidney is matched for you. Animal kidneys are not matched for human transplantation.
 - ☐ Cadaveric, which comes from persons who have recently died and whose family has donated their organs (such as lungs, heart and kidney) for others to use.
8. From the following options, what are potential sexual intimacy challenges related to kidney disease? (Please select all that apply)
- ☐ Men may become unable to get or maintain an erection (erectile dysfunction)
 - ☐ Women with ESRD may experience vaginal dryness causing painful intercourse.
 - ☐ Both men and women may experience a decrease in the desire for sex.
 - ☐ Both men and women may feel that the placement of the access has made them feel “less desirable.”
9. From the following options, which types of exercise are good for people with End-Stage Renal Disease (ESRD)? (Please select all that apply)
- ☐ Strengthening exercises that help make your muscles stronger with the use of weights or other resistance techniques.
 - ☐ Flexibility/stretching exercises that help you move more easily.
 - ☐ Vigorous exercise that includes lifting heavy weights and a high heart rate
 - ☐ Cardiovascular exercises or aerobics that help strengthen your heart and lungs.
10. From the following options, what are the formal components of advance care planning? (Please select all that apply)
- ☐ Selection of a Healthcare Surrogate or Proxy (also called Durable Medical Power Of Attorney)
 - ☐ End of Life Planning
 - ☐ Telling people your wishes regarding your future care if you become unable to make or communicate your decisions.
 - ☐ Written and signed Advance Directives (sometimes called a Living Will)

Please tear questionnaire from the booklet and return it to: AAKP, 2701 N. Rocky Point Drive, Suite 150, Tampa, Florida 33607. Please see page 55 for the answers. Please do not make any changes to the answers after reviewing the answers on page 55 and sending in your pre-test to the AAKP office.

AAKP Patient Plan[©]

Phase 2: Getting Help and Starting Dialysis

Since you first heard the words “end-stage renal disease” (ESRD) and “kidney failure,” you have probably been wondering what happens now... this is a typical reaction. Everyone facing kidney disease has concerns and questions about the future. The future may seem uncertain and dreams and plans changed. But there is help available.

The American Association of Kidney Patients (AAKP) is here to be your guide. As the only national organization directed by kidney patients for kidney patients, we’re in a unique position to understand the needs and concerns of kidney patients. It’s our mission to help fellow kidney patients and their families deal with the physical, emotional and social impacts of kidney disease. We want to help you achieve the best possible quality of health and quality of life.

As ESRD patients, we’ve already taken the journey you are about to take. We think the knowledge and experience we’ve gained along the way can be of great value to you and your family. This is why we developed the AAKP Patient Plan[©].

The AAKP Patient Plan[©] can be thought of as a road map or travel guide. But it’s also much more. The series of books will tell you what to expect, what your needs will be, who will help you, what you need to know and how to make your journey a success.

The AAKP Patient Plan[©] is designed to address questions and concerns at the various phases of the disease process. We have divided the plan into phases to guide you through the treatment process. The phases include:

Phase 1: Diagnosis and Treatment Options

Phase 2: Getting Help and Starting Dialysis

Phase 3: Stabilization

Phase 4: Ongoing Treatment

During each of these phases, you can keep control of your life by staying active and learning as much as you can about the disease and treatment. Being told you have a chronic illness changes your life. As fellow patients, we know that learning what to expect and what your options are will help you be less afraid and more hopeful. The more you know, the better able you are to make choices that are best for you and your family.



A Friendly Note: Throughout this book, you’ll see my comments. I’m here to remind you that you’re not alone in this journey. You have a support team of health care professionals, family and friends – consider AAKP as one of your friends. Also, speaking from experience, it’s good to know you’re not the first person to go through this.

Phase 2: Getting Help and Starting Dialysis

This phase is during a time when you make your choice for a treatment type and get use to your new routine. During this phase, you're catching your breath and looking around to see what effect ESRD and its treatment will have on your life. You want to know how it'll affect your family, friends, employment and overall health. Just like Phase 1, each of the pieces in this adjustment phase will be broken into parts. This lets you read it at your own speed and go to the information that is most important to you at this time. Phase 1 is described as being similar to when you're on a road trip and your car's gas tank is getting close to empty...you start looking at the road map and street signs to find a gas station when you need it. Phase 2 is like finding a gas station, stopping to fill up and beginning the trip. The AAKP Patient Plan[©] is your road map as you continue your journey with ESRD. Remember, you're not alone on this trip; there are many people who will help you along the way. 🌍

– THE DIALYSIS UNIT –



What's Going To Happen When I Start Hemodialysis?

As we discussed in Phase 1, hemodialysis is the most common method for treating ESRD. Hemodialysis is a way to clean your blood using a special filter called a dialyzer. The dialyzer works like an artificial kidney, straining out the toxins and extra fluid that build up when your kidneys aren't working properly. The artificial kidney doesn't completely replace your original kidney's function. Your kidneys once worked 24 hours a day seven days a week. Dialysis only happens for a few hours a day and a few days a week.

Every dialysis unit looks and runs differently, but there are some common elements and themes you'll find in almost every unit. For many people, it's helpful to tour a dialysis unit before beginning treatment. It's a way to see how a unit looks, sounds and smells before you begin treatment. Although you may have toured a unit when you were choosing a treatment option, you may want to tour it again now that you're starting the treatment.



A Friendly Note: When touring a unit, you may find it helpful to bring family or friends with you. When I took my spouse, it was nice to have an extra set of eyes and ears helping me ask questions. I also valued the support I received during this transition. By touring the dialysis unit it showed me what to expect. When you know what awaits you, things don't feel as overwhelming.

Most dialysis centers are designed as an open area with reclining chairs along the wall and a dialysis machine beside each chair. There are usually televisions at each chair.



A Friendly Note: The units may be noisy with the sounds of televisions, people talking and alarms beeping. Don't be frightened when you hear the sound of an alarm. Each dialysis machine has gauges and alarms that constantly monitor your blood pressure, how quickly your blood moves through the tubing and how much water is removed. These alarms are sensitive and are set to sound before a problem begins. This merely means alarms will beep often and a possible problem will be avoided. Hearing the alarms sound doesn't equal an emergency or life threatening condition. The alarms are a safeguard to let the staff know there might be a problem before the problem develops.

Who Will Care For Me While I'm Dialyzing?

There are many people who are in the centers providing care and helping you receive the treatment and resources you need to be healthy. Your medications and treatments will be reviewed and adjustments may be made in your care and treatment plan. Your doctor should also discuss your interest in receiving a kidney transplant or transferring to a home dialysis modality. In addition, he or she should be available for any psychosocial needs.

If you don't see your nephrologist at least once a month, request that you do. If, after you've requested to see your doctor, nothing changes, talk to the Medical Director or the administrator of your facility. If all else fails, the ESRD Network for your area should be made aware of what is happening. *(Your list of Networks and their roles are located in Phase 1: Diagnosis to Treatment Options.)*

While you're dialyzing, you'll also see nurses and nursing assistants. Nurses may train you for home care (if you decide to dialyze at home) and some self-care. The medications you take at home are very important. The nurse will ask you to bring them to the center and review them with you. Some centers teach self-care techniques so you can do certain procedures yourself. One self-care procedure is inserting your own needles.

Nurses are also a great resource to provide education about ESRD and its treatment. Another job of the nurses is to help solve problems as alarms go off or concerns arise. Nurses supervise the dialysis technicians and nursing assistants. The nursing assistants set up the dialysis machines, access your site and monitor your vital signs during treatment. The technicians also make sure the dialysis machine is working properly and your dialyzer is properly cleaned and stored for your next treatment.

There are dietitians who will review your blood work results and help you to make wise food and beverage choices. They will advise your doctors about medication changes to help you maintain the right level the phosphorus in your blood and other minerals. They will talk with you about your eating and cooking habits, your medications, the amount of fluids you drink and your nutritional needs.

You'll also see social workers who can help you adjust to ESRD and financial concerns related to ESRD. They are available to help make sure that your quality of life remains at the highest level, and will address many of your needs including transportation and health benefits. They can also help you maintain your employment. The dialysis center is filled with people who are there to help you receive the best treatment and care.



A Friendly Note: To stay your healthiest and do your best, you'll want to follow the renal diet, take your prescribed medications, watch your fluid intake and spend the prescribed time on dialysis. I know you're thinking, "Once in a while won't hurt," but it's really not to your benefit to cheat.

What Happens When My Access Is Placed?

One area of great concern for both patients and renal health care professionals is the vascular access. This can be a catheter which is used on a temporary basis. Or it can be a fistula (connecting your own artery to vein) or graft (synthetic tube under the skin) which are both considered permanent. Proper care is necessary to make certain they last long. It is very important for you to know how to best care for your access.

You will probably have your initial access placed before going to the dialysis center. You may only have a catheter which is a temporary access. You may already be on dialysis but need to have a new access. It's important to understand how the renal care team helps decide what type of access is best. The surgeon, working closely with both the nephrologist and you, usually makes the final decision where an access can be placed and the type. It's preferred to make the fistula or graft on the arm that you don't use a lot, the "non-dominant arm." So if you're a right-handed person it's better to have the access in your left arm. The surgeon will try to make a fistula if he or she can. If you have small veins or other medical problems a fistula may not work. The surgeon will then make a graft.

Sometimes special tests will be ordered to help determine the best type of access and best place to put the access. These tests are also done if there are blood flow problems with your access. The most common tests are called "venography" or "venogram" and a "doppler exam." Other tests may need to be done as well.

There are two main types of permanent vascular access; the fistula and the graft. The fistula is considered the best vascular access. Fistulas are the preferred vascular access for long-term dialysis patients because they last longer than any other vascular access and are less prone to infection and clotting. To make a fistula, your own artery and vein are connected together under your skin.

If a fistula can't be done, then a graft is the next best access. To make a graft, a piece of special tubing is placed under your skin and connects your artery and vein together.

Sometimes after the operation to place the access, a patient has to wait until it can be used. A temporary catheter can be used for dialysis until the fistula or graft is ready. Also, if the fistula or graft is infected or clotted, a catheter may need to be used until the fistula or graft is fixed. A temporary catheter usually may be used for up to about three weeks. A special temporary catheter often called a “permacath” may be used for several months. Catheters are usually placed on the side of the neck or under the collarbone.

Your access should be placed as early as possible. If possible, it should be done several months before you start dialysis. A new fistula usually takes three to four months before it can be used. To help the fistula work better, your doctor will have you do certain arm exercises (usually squeezing a ball). A graft can usually be used in three weeks. No special exercises are necessary to help the graft work. To have your access placed, you will have surgery, usually as an outpatient.

Adequate care of each hemodialysis patient requires close monitoring to make certain the vascular access is working. A proper working vascular access should have enough blood flow for an adequate dialysis treatment. It should also last long, and have no or few complications, like infections and clotting. Problems with the vascular access may be the most common reason to place dialysis patients in the hospital.

For more information on your hemodialysis access, call AAKP at (800) 749-2257 to order a copy of “Understanding Your Hemodialysis Access Options.”

Is There Anything Special I Have To Do With My Access?

Whether you have a fistula or graft, your access site is often called your “lifeline.” It’s important to care for your access properly to ensure your dialysis treatments go as scheduled. Each time you have a treatment, your access should be checked for blood flow problems and early signs of infection. Signs of adequate blood flow are when there is a “buzzing” or “rushing” feeling and a pulse can be felt in your access. If these signs aren’t in place, your nephrologist and dialysis unit should be called as soon as possible. Clotting and infection are easier to treat when they’re found early. Early signs of infection may be redness, swelling or warmth to the touch. The area around your access should be kept clean and dry between treatments. Daily care and monitoring of your access are essential to keeping your “lifeline” working as long as possible.

Providing a little “TLC” to your access on a daily basis will help eliminate problems, or at least catch problems early to avoid more complications. The “TLC’s” of caring for your access are as follows:

Touch for pulse, tenderness and temperature,

Look at your skin color, swelling or drainage,

Care to keep your access clean and protected, no resting on arm, no heavy lifting, watch your weight, keep clothes loose and no tight jewelry.

Also, be careful not to bump or cut your access. You don't want anyone taking your blood pressure, drawing blood or putting an IV into your arm or leg that has the access site.

What Happens To The Tubing After I Finish My Dialysis Treatment?

After your dialysis is completed, the tubing that carried your blood is thrown away. However, the dialyzer may be cleaned and processed. Some dialyzers reuse the tubing, however it is not near as common as it once was. The dialyzer reuse process involves your dialyzer being labeled as yours and then cleaned by the dialysis technician. Your dialyzer won't be shared with other patients. The cleaning process involves hooking your dialyzer to a cleaning machine. The automated system flushes your dialyzer with water and a sanitizing fluid. During this cleaning process, after your dialyzer is flushed, negative pressure is applied to make sure the fibers are cleaned. Once a dialyzer is cleaned and sanitized, it's stored for your next dialysis treatment. During the reuse and cleaning process, each dialyzer is checked to make sure there isn't any leakage. It's also tested for volume and pressure capabilities. As long as a dialyzer passes those tests, it can be used for another treatment. You may prefer to reuse your dialyzer if you have reactions to the first use of a new dialyzer. You may also decide that you don't want to reuse your dialyzer. AAKP strongly urges you to discuss your options with your doctor to help decide what's best for you. You have every right to decide what is best for you.



What Does It Mean When An Alarm On The Dialysis Machine Starts To Sound?

A Friendly Note: Earlier you learned about the gauges and alarms on the dialysis machines. The alarms help prevent possible problems. But, there are times when people do have problems while on dialysis. I'm telling you this not to scare you, but rather to inform you about all aspects of dialysis. It's important to be educated on this subject because there are some things you can do, such as following your diet, to avoid some of the difficulties.

An alarm sounds when you have problems on dialysis. It's usually because the water or chemical balances in your body change quickly. When this happens, you can have muscle cramps or there can be a sudden drop in your blood pressure (hypotension). If you experience hypotension, it can make you feel dizzy, weak or sick to your stomach. If you're having any of these problems during your treatment, let your nurses or doctor know immediately. Many times, the problems can be treated quickly and easily. Most people find that by following the proper diet and taking all the prescribed medicines, they can avoid problems during dialysis.

What Will Happen To Me After My First Few Treatments?

A Friendly Note: Some people expect that after their first treatment, they'll feel great. But, you may not start feeling better until after a few treatments. Remember, it took a while for the toxins to build up in your body. This means it'll take a while for those toxins to clear out of your system. I'll warn you, you won't feel 10 years younger or have more energy than you did before you became sick, but usually after a few treatments you'll begin to feel better.

After the first few treatments, many of the symptoms of ESRD begin to lessen. Some of the symptoms you may notice disappearing include: feelings of nausea, forgetfulness, swelling, the "tin taste" in your mouth, bad breath and the feeling of being exhausted.

A Friendly Note: How you'll feel after your treatments is as individual as you are. Some people feel tired or weak right after getting off of the dialysis machine, others may not think as clearly as usual. Yet, there are others who feel good and are ready to get on with their day. As you work into the routine of dialysis, you'll discover how you feel after treatment and develop ways to plan your days depending on how you feel.

Can I Cut My Dialysis Treatments Short?

Although you may feel better after hemodialysis, the actual treatments can be boring and tiresome. For that reason, you may want to cut your dialysis short. We can't urge you enough to have all of your scheduled treatments for the full scheduled time. Studies show that people who receive complete dialysis treatments are more likely to live longer and feel better. Because of these studies, many nephrologists prescribe and highly recommend four or more hours of dialysis three times per week. It's really important for you to receive adequate dialysis. Don't let your dialysis facility cheat you out of



adequate treatment, and don't cheat yourself out of feeling better, stronger and living longer! In Phase 3, Stabilization, we'll talk more about guidelines that help you know if you are getting adequate dialysis.



Would It Help To Talk To Someone Else?

A Friendly Note: Talking to someone who has gone through what you're going through can be very helpful. It lets you know you're not alone. You'll also find out you're not the first one to have the feelings that you're probably experiencing. Take the time and look into getting a mentor.

Finding a mentor may be helpful to you as you begin dialysis. Your nephrologist, nurse, dietitian or social worker knows the other people in your dialysis facility. They can help match you with someone who has similar experiences. Finding the right mentor can help ease your transition and let you know your feelings are normal. If for some reason you don't click with the person who serves as your mentor, go back to the staff and ask to meet someone different.

In addition to a mentor, there are usually support groups available for you and your family. These can be a valuable resource. The American Association of Kidney Patients has a nationwide listing of support groups on its website. Visit www.aakp.org/outreach. There is also information on how you can start your own support group.



A Friendly Note: Another source of strength and support for many people is their religion and faith. Don't underestimate the comfort of prayer and community involvement that can come from your religious affiliation. 🌍

– HOME CARE –



I've Chosen Home Hemodialysis, Now What?

Medicare requires all dialysis facilities to ensure that all patients are told about all treatment options, including home hemodialysis, peritoneal dialysis, and kidney transplantation and that this be documented. If you are interested in home hemodialysis (HHD) or peritoneal dialysis (PD) and the facility you are at does not provide training for either of these treatments, they are required

to give you information as to the nearest facilities where such training can be provided to you.

There are different ways to do hemodialysis at home - during the day or overnight, three times a week or more frequently, as short daily or long nightly treatment. Remember that HHD has been shown to give the best results in terms of patient survival, fewer complications, better quality of life and great opportunity for rehabilitation. However, HHD is not for everyone. Two things in particular sometimes stop patients from considering this treatment.

1. **Sticking yourself with a needle.** However, with training, no one will be able to do this better than the patient.
2. **The machine looks complicated to use.** If you can drive a car, you can operate a home dialysis machine. With both, you have to learn how to use them safely and what to do when problems occur. You don't need to know what is under the hood in either case.

Training generally takes between four and 12 weeks. Training is done while you are receiving regular treatments in the center. Remember, a good dialysis patient, whether in a center or at home, should learn as much as they can about their disease and its treatment and take as much responsibility for their own care as they can. In a center nurses and technicians help to put you on and take you off the machine. At home you will be doing this with assistance from someone else (family member or friend) who can help you when needed. You and a helper will receive complete training to perform the dialysis treatments. Each time you're receiving treatment in the center during training, you and your helper will gradually take on more responsibility for your dialysis. Once you, your helper and the training staff are confident in your abilities to manage dialysis safely at home you can begin home dialysis.

To learn more about types of hemodialysis, call AAKP at (800) 749 – 2257 to order your copy of "Understanding Your Hemodialysis Options."

How Do I Choose A Helper?

You'll need to choose a helper you can count on. They will need to be in the home while you are dialyzing and be able to give you whatever assistance

you may need each time you dialyze. Training will prepare you both to understand the dialysis machine, and how to safely perform the steps of dialysis treatment at home. If your spouse or a family member is the person you choose, you may need to set aside personal feelings during the treatment. Fighting or arguing, while you are dialyzing isn't good for either of you. It's important for you to choose someone with whom you can work and who can stay calm and help you to solve problems when they arise.



A Friendly Note: It's important to remember that the person you have as your dialysis helper potentially is taking on a big responsibility. They will help you connect to your blood access site, assist as needed with the dialysis, help you monitor the treatment and must be able to help with problems and respond to emergencies. Again, it is important that you do as much of the treatment yourself as you are able to. The role of your helper can be stressful, and this stress can spill over into your relationship. Relationship problems must be worked out before they get out of control.

If I Dialyze At Home, Does That Mean There's No One Else To Help Me?

Remember that while you dialyze at home you have telephone access to an experienced dialysis nurse at the training center 24 hours a day, seven days a week. You still have access to the same professionals as a patient who dialyzes in a facility. There is a nephrologist, nurse, social worker and dietitian available to answer your questions and concerns. You can see them during a routine clinic visit or office visit, set up a special appointment or call on the phone. If you have equipment problems the nurse can make arrangements for equipment servicing or repair and can arrange for dialysis in the facility if needed while your machine is being fixed. Thus there are many people still there to help you solve problems as issues or concerns arise. Both you and your helper are trained to recognize and respond to routine dialysis problems that may occur during the treatment. If either of you is unsure how to solve a problem, remember there is a nurse on call 24 hours a day, seven days a week to help you.



A Friendly Note: Speaking from experience, most problems you may have while dialyzing at home can be solved over the phone. But if you find yourself in an emergency, call 911 and be sure to let your emergency response team know you have ESRD, are on hemodialysis, and have a blood access site. This team may need information about your treatment schedule, who is your nephrologist, your medications, and any recent blood chemistry records.

What Will I Have To Do To The Dialysis Machine To Make Sure It's Ready For Each Treatment?

When you dialyze at home, you are responsible for many of the things that people in the dialysis center would do. You'll be responsible for making sure your machine is working properly. You'll have to make sure you have the needed equipment and supplies. After the treatment is completed, you will also be responsible for cleaning up and disposing of the used supplies. When dialysis is done at home, your equipment and supplies are delivered to your home. A large number of supplies are needed each month, including the tubing for the dialysis machine, dialysate, sterile bandages and your dialyzer. You'll need to have a space in your home set aside for storing the supplies and your dialysis machine.

A Friendly Note: An inventory list of all your supplies can make things easier on you. This way you can mark down what has been used, and you'll know what needs to be ordered for the next month. When you create your inventory list, always remember to have extra supplies on hand in case of an emergency.



I've Chosen Peritoneal Dialysis. What Can I Expect?

As we discussed in Phase 1, peritoneal dialysis (PD) is quite different from hemodialysis. It doesn't use an "artificial kidney" or dialyzer. PD uses a space in your belly called the peritoneal cavity. With PD your peritoneal cavity is filled with a "germ free" (sterile) liquid called dialysate, which enters your abdomen through a catheter. This catheter is placed during outpatient surgery. The liquid sits (dwells) in your peritoneal cavity while waste products and fluids move from your blood through the peritoneal membrane into the dialysate. This membrane acts like a strainer and keeps the good things in your body and only lets the toxins and extra fluid go through. No dialysis can do this perfectly so some of the good things are removed with the toxins. The dialysate, along with the toxins and extra fluid, are then drained. The peritoneal cavity is then filled with the clean dialysate and the process begins again. Each time the dialysate is drained and refilled, it's called an "exchange." The number of times you exchange fluid depends on which type of PD you choose, how much residual kidney function remains and on your prescription. Just as with hemodialysis, your nephrologist determines the prescription for how many exchanges you perform a day and the volume size of the dialysate. However, unlike HHD, you do not need a partner.

Do I Have To Worry About Any Kind Of Infection Or Germs?

Yes, infection is a possibility with PD. Preventing an infection is really important. When germs get into your peritoneal cavity, they can cause an infection. This infection is called peritonitis. Peritonitis will make you feel sick. You'll experience abdominal pain and sometimes a fever.



A Friendly Note: Most germs and infections that cause peritonitis can be treated with antibiotics. However, there are some infections that are very hard to treat. Therefore, as soon as you notice symptoms of peritonitis, let your doctor know. The earlier it's caught, the the better the outcome.

Each time you have peritonitis, it can cause scarring in your peritoneal membrane. The more scarring you have, the harder it is for your peritoneal membrane to “strain” waste products and water. Your dialysis quality decreases as the difficulty of straining wastes increases. If the peritoneal membrane becomes too scarred, you may have to change to hemodialysis because PD will no longer work for you.

As we discussed in Phase 1, there are several types of PD. One is continuous ambulatory peritoneal dialysis (CAPD), and another is continuous cycling peritoneal dialysis (CCPD). Anytime a machine called a cyclor is used, the PD is called APD, automated PD. So CCPD is a form of APD. Both are continuous, which means they give you around the clock treatment. This “around the clock” treatment is more similar to how healthy kidneys work.

What Is Continuous Ambulatory Peritoneal Dialysis?

CAPD can be done in any place that's clean and well lit. Exchanges are usually done every four to eight hours during the day. The only equipment you need is a bag full of dialysate fluid and the plastic tubing that comes attached to the bag. CAPD uses gravity to drain and fill the abdomen with dialysate. In a sterile manner you connect the dialysate bag and tubing to your catheter. The dialysate bag is hung above your head on a hook or pole. This bag remains clamped until later. The solution that's been sitting (dwelling) in your peritoneal cavity is drained out through tubing connected to an empty bag on the floor. That bag fills from your peritoneal cavity with your body's toxins and fluid collected in the dialysate. When you finish draining, the bottom tubing is clamped and you open the clamp on the tubing attached to the clean dialysate bag. The dialysate flows into the peritoneal cavity by elevating the bag above your head and letting the

fluid drain in by gravity. Once you have filled your peritoneal cavity with clean dialysate, you can detach the tubing, and empty the used dialysate into the toilet. The clean fluid sits in the peritoneal cavity for about four to eight hours. During this time you're free to go about your regular activities. Each exchange takes about 30 minutes to complete. Most people begin their exchanges in the morning and then end their day with one just before bedtime.

What Is Continuous Cycling Peritoneal Dialysis?

Continuous Cycling Peritoneal Dialysis (CCPD) is a form of Automated Peritoneal Dialysis (APD). It is done at home with a machine called a cycler. The exchanges occur at night while you sleep. The catheter is connected to the cycler tubing. For eight to 10 hours each night, the machine fills and drains the dialysate from the peritoneal cavity automatically, hence the name. The cycler machine keeps repeating this process throughout the night. In the morning, clean dialysate is left in the peritoneal cavity after you disconnect from the machine. One or two manual exchanges may be prescribed during the day. This is the most common form of PD in the US.

What is Nocturnal Intermittent Peritoneal Dialysis?

Nocturnal Intermittent Peritoneal Dialysis (NIPD) is almost exactly like CCPD except that no dialysate is left in the peritoneal cavity at the end of the nightly cycling. This allows the abdomen to be empty during the day. This can only be performed when there is enough residual kidney function to clean the blood. In this situation, the residual kidney function plus the nightly cycling adequately clean the blood. Over time, NIPD is converted to CCPD as residual kidney function is lost.

What Is It Going To Be Like When I Start Peritoneal Dialysis?

A Friendly Note: Having flexibility and freedom are benefits to performing treatments at home or work. But, it's important to remember that doing treatments on your own, or with a family member, can sometimes be difficult. You may feel like it's adding extra stress to your life and relationships. You may feel as if it's hard for you to carve out time at work or home where it's quiet and uninterrupted to perform the exchanges. If you start to notice that these issues are getting to you, just remember you're doing this for your health. It's worth it to take the time. Eventually, you'll get used to the idea of taking 30 minute "breaks" here and there to perform an exchange.



During your training for PD, you'll learn to solve common problems. Just as with HHD, there is a nurse on-call 24 hours a day, seven days a week. If you're concerned about something, don't hesitate to call. In addition to the nurse who is on-call, there's a social worker and dietitian available to you. If you have a question or concern, you can request to see any of them when you see your nephrologist and treatment team. The social worker and dietitian are also available by phone if an issue arises between clinic appointments.



A Friendly Note: Although most problems can be solved over the phone, if you find yourself in an emergency, call 911. Be sure to let your emergency response team know you have ESRD and are on peritoneal dialysis. The team may need your treatment schedule, nephrologist's name, medications and any recent blood chemistry records. Make many notes to yourself and your medical team. Don't trust your memory and end up frustrated. Notes work!

What Type Of Supplies Will I Need To Store At Home?

When you're on PD, you'll have a lot of supplies to store in your home. There's enough plastic tubing and bags of dialysate for a month's worth of exchanges.



A Friendly Note: You're going to be responsible for keeping track of your supplies and ordering them each month. Your PD nurse will teach you how to order and keep track of your supplies. Don't worry, as time goes by, you'll get used to the system and be able to make arrangements on your own, including travel and vacations.

Will It Help To Talk To Someone Else?



A Friendly Note: In the hemodialysis section, we talked about the benefits of talking to someone else about their experiences. PD and HHD aren't any different in this regard. When you're first starting out, it is helpful to talk to someone who has been through what you're experiencing. It's very helpful to find a mentor.

Finding a mentor may be helpful as you begin dialysis. Your nephrologist, nurses or social worker know the other people in your treatment facility and can help match you with someone who is also on PD. Finding the right mentor can help you know your feelings are normal.

There are several kidney support groups across the country available to patients and caregivers. Visit the AAKP website, www.aakp.org/outreach to find a support group near you. There is also information on how you can start your own support group.

– TRANSPLANTATION –



When a kidney from another person is surgically placed into someone whose kidneys have failed, it's called a kidney transplant. Only one kidney is placed during a transplant. One healthy kidney can do the work of two. The transplant involves an operation, which usually takes about three hours. Once you have the operation, you'll need to take medications for the entire time you have a functioning transplanted kidney. These medicines help your body accept the kidney and are called anti-rejection medicines. They are also known as immunosuppressive medications.

The anti-rejection medicines have some side effects. However, these side effects are usually manageable. A few of the most common side effects are:

- high blood pressure
- a decrease in your body's immune system
- weight gain
- raised cholesterol
- stomach ulcers
- facial hair
- stretch marks
- fullness in your face
- darkened skin
- diabetes



A Friendly Note: The side effects listed are common, but not everyone who has a transplant experiences all of the side effects. Some people have very few side effects.

The challenging schedule of transplant medications and their side effects are discussed in more detail in the “medications” section of this phase.

What's The First Step In Getting A Transplant?

Before you can have a transplant, you must be evaluated at a transplant center. Doctors, nurses and social workers will talk with you and give you medical tests to decide if a transplant will work for you. They'll also look at how well you're currently following your dialysis and/or medication schedule. These professionals can answer any questions you have about medications, surgery and care. As the anti-rejection medicines are quite expensive, transplant coordinators want to make sure you explore any needed support to assist you. Another factor is your blood and tissue type. The closer your blood and tissue type match the new kidney, the better the chance the new kidney will be accepted in your body and begin working.

What Are The Different Types Of Transplants?

There are three kinds of kidney transplants: living related, living unrelated and cadaveric. Each has the potential to work so long as tests indicate that the chances of early rejection are low.

A living-related donor is a blood relative (mother, father, sister, brother, child, cousin, uncle, aunt) who agrees to give you a kidney. It's important to remember just because a person is a relative does not mean the kidney will be a match. Blood tests will determine if the kidney is a good match for you.

A living-unrelated donor is a person who is not a "blood relative." Such persons include spouses, friends, distant cousins and others. The person is tested for blood and tissue type. The unrelated donor is tested just as a related donor is, and blood tests determine how well the unrelated donor's kidney may be matched for you. During the last several years, this has become a more common type of transplant.

Cadaveric kidneys come from persons who have recently died and whose family has donated their organs (such as lungs, heart and kidney) for others to use. This is the most common type of transplant today. All organs in America are managed through a national waiting list. When a kidney becomes available, your blood and tissue type are compared to that of the donor. Finding just the right kidney may take a short time or several years. Based upon these and a number of other factors, a computerized system ultimately matches all cadaveric organs with appropriate patients in need.

What Is The Transplant Process Like For A Living Kidney Donor?

Whether you're receiving a transplant from a relative or a friend, the donation process is the same. Just as you go through special testing and evaluations so does your potential donor. The tests for the donor include a past medical history, physical examination, routine blood and urine tests, special x-ray studies, and some psychosocial and financial counseling. If it's decided that someone is a suitable donor that means the person has one kidney suitable for donation and another kidney healthy enough for the person to live with only one kidney. The risk of complications to the donor is low when a thorough evaluation is performed.

A Friendly Note: It's important to remember that the health of the person giving you a kidney is just as important as your health for receiving the kidney. Just like your transplant team tells you what to expect after you receive the kidney, your donor is also prepared for how he or she will feel after donating a kidney. As with any operation, there are possible complications. After surgery, the donor can have bleeding, pain, bloodclots, infection or other problems. Most donors never experience these and have a



short hospitalization and rapid recovery.

What Type Of Pain Is Involved For The Donor And How Long Is The Hospital Stay?

For the kidney donor, postoperative pain and discomfort depend in part upon the kind of operation performed. There are several newer approaches to removing a kidney from the living donor for transplantation. Among these are laparoscopic or modified (hand assisted) laparoscopic techniques, operations which approach the kidney through very small incisions, and modifications of larger operative procedures used in the past. In most centers, the donor operation allows for hospitalization of only a few days. Pain control may be applied through special techniques such as epidural medication delivery or placement of small temporary tubes near the area of kidney removal. The kidney donor will need to be away from work for several days to several weeks depending upon the specific job. Most donors should not lift heavy objects for several weeks, but can return to moderately vigorous walking and exercising as recovery progress.



A Friendly Note: When someone donates a kidney to you, sometimes that person begins to feel a special type of bond with you. After all, you two now share kidneys that are related – in a sense. It's possible that if the kidney doesn't work, however, the donor may feel guilty that he did something wrong. You may also feel guilty because someone gave up a kidney, but you couldn't get it to work. These feelings are natural. The best thing you can do is talk to someone, like your social worker, about what you're feeling.

What Happens When I Receive A Transplant?

When a living donation occurs, there are usually two transplant teams operating at the same time. One team of surgeons operates on the donor and removes the kidney (this process is called a nephrectomy). In a separate operating room, another team transplants the kidney into you. The donated kidney is usually placed into the front part of the body near your hip in your lower abdomen. Usually your old kidneys are not removed. Once the operation is done, your new kidney may begin working immediately or it may take a few days or even weeks. If it takes awhile for your kidney to start working, you may need to have dialysis. Once it starts working, however, you'll no longer need dialysis.



A Friendly Note: You should know, there are times when a transplanted kidney never starts working. If this happens to you, you'll need to stay on dialysis. The transplanted kidney may have to be removed if your doctor thinks it's a source of infection or poses a health threat to you.

What Type Of Pain Is Involved And How Long Will I Be In The Hospital?

As with any surgery, there is a certain amount of pain or discomfort that's normal. Your doctors will prescribe pain medication for you. Your pain should gradually lessen each day and pretty much disappear within three to four weeks. You'll probably be in the hospital for about seven to 14 days.

A Friendly Note: Don't worry if after your transplant you notice little tinges of pain from time to time. You may experience occasional, brief pain for several months when you move a certain way or sit or stand in a specific position. This is normal. Just remember, you went through major surgery and your body needs time to heal itself.



What Will I Experience Emotionally When I Receive A Transplant?

A Friendly Note: A transplant is going to fill you with a lot of different feelings. A variety of situations may influence these feelings. You may expect your new kidney to begin working right away but if this doesn't happen, you may feel devastated. When the new kidney does begin working, you may feel a whole new set of emotions like excitement and relief. All of these feelings are to be expected shortly after a transplant. And, most importantly, they're normal.

The first few months after your transplant may be the most emotionally difficult. There are many transitions that happen after a transplant. Your body changes as it adapts to your new kidney and the medicines that are necessary after a transplant. Your transplant team may adjust medicines so they work best for you. You may see new doctors on your medical team. You will no longer see the social worker from your dialysis unit. You may see a transplant physician instead of your dialysis doctor. All of these changes can seem overwhelming and it may be helpful to talk to someone who has gone through this before. You may want to consider talking to your new social worker, nurse or doctor to see if there's someone with a similar experience.

A Friendly Note: It really helps to talk to someone who has gone through the transplant process and understands the roller coaster of emotions. No matter how much you read and are prepared by medical professionals, hearing first hand from a person who has gone through the experience lets you know you're normal. You may also gain a sense of peace through your religious affiliation. Prayer and support from your religious community can help you during this time.

– QUALITY OF LIFE ISSUES –



What About Sexual Intimacy?

A Friendly Note: Sexuality may be a subject that is difficult for some people to discuss. You may not feel comfortable discussing sexual issues with anyone other than your spouse. Sometimes, you may not even feel comfortable talking about sex with your spouse. One of the best pieces of advice you'll get in this section is that open communication is extremely important when dealing with most quality of life issues, including

sexuality. I understand why you may not want to talk about sex. Many were brought up to keep it behind closed doors. But your doctor can't help if he or she doesn't know there is a problem. Sexual difficulties can be common in people with ESRD. That's why it's important to talk about it. Sometimes a simple adjustment of medicines can help the problem. If you are uncomfortable talking about the subject, a reasonable way to open a discussion about a sexual problem is to say to the doctor "I am usually pretty uncomfortable talking about sex with anyone, but I have noticed some changes that I want to ask you about."

If you're like most people with ESRD, you've experienced a lot of changes in your life since the diagnosis. From the initial stages of kidney failure to choosing a treatment option to having an access placed to beginning a medical regime, you've had a lot of things on your mind. These changes may have caused you to concentrate on your health much more than you have in the past. When we are preoccupied by problems and concerns, it is common to have a decreased desire for sex. Some people have even commented that the placement of the access has made them feel "less desirable." If you've gone through this, your feelings are normal.

Many people, as they age, develop sexual problems whether they are healthy or not. People with ESRD, diabetes, heart disease, and hypertension are even more likely to have sexual changes. In other words, if you are experiencing these problems, you are not alone. Common sexual changes in men with ESRD include the inability to get or maintain an erection (erectile dysfunction) and delayed or inability to have an orgasm. Women with ESRD may experience vaginal dryness causing painful intercourse. Both men and women with ESRD commonly experience a decrease in the desire for sex. What can you do about these common issues?

- Tell your spouse or partner that your desire for sex has been affected by your illness. Tell them it isn't anyone's fault and that your love for them has not changed.
- When beginning sexual intimacy, take your time. Don't rush. Consider more holding each other, cuddling, touching, messaging and manual stimulation before intercourse.

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- Ask for a private conversation then tell your doctor, nurse, or social worker about the problem. Describe the problem any way that is comfortable. Using slang words, pictures or pointing to areas of your body are okay. Describing the problem is **ALL THAT IS IMPORTANT**. Ask “why is this happening,” “what can we do about it,” and “what will happen in the future?”
 - Review a list of your medications with your doctor, nurse or social worker. Changes in some medications, particularly medicines used to treat hypertension, can improve sexual function in men.
 - If you are a woman, consider a referral to a gynecologist to explore the usefulness of hormone therapy. Also consider using an over-the-counter lubricant to make intercourse easier and more pleasurable.
 - If you are a man, consider a referral to a urologist for diagnosis and treatment of erectile dysfunction. Alternatively, you might consider asking one of your doctors or nurse practitioners if they might evaluate you for medication to treat erectile dysfunction.
 - Couples may also benefit from a referral to a qualified sex counselor.

Remember, if you have concerns about your ability to maintain intimacy and a satisfying sexual relationship, talk with the social worker, doctor or nurse in your facility. If you don’t talk about it, the problem may never be solved.

Finally, some people who have received a transplant fear that by having intercourse, they may damage their new kidney. Like any physical activity after surgery, there should be temporary limitations on sexual activity to allow the incisions to heal. Ask your nephrologist or transplant team when you can safely resume a normal sex life. Please know that you’re not alone in your concerns and there are people who can help you regain intimacy and a fulfilling sex life.

What About Sexually Transmitted Diseases?

Having ESRD, it’s extremely important to be careful and take precautions against sexually transmitted diseases (STDs). If you contract an STD, you may have to add more medications to your daily care routine. It’s also important to know if you contract Human Immunodeficiency Virus (HIV), it may delay a transplant or limit the availability of a transplant. For these reasons, protecting yourself from STDs is a responsibility you need to take seriously. Choosing abstinence or using condoms and practicing safe-sex techniques are ways to reduce the spread of STDs. If you have questions or need information on any of these techniques, talk to your doctor, nurse or social worker. You can also call the public health clinic nearest you for additional information.

Can I Have A Child?

Some of the physical changes related to ESRD make it less likely a woman will become pregnant, although it does happen. If pregnancy occurs, more frequent hemodialysis (often daily) is common. Miscarriages are very common in pregnant women with ESRD. Women or their partners should continue to use birth control to prevent pregnancy. Pregnancy after transplant can and does occur. Men on dialysis can father children. Sperm counts, however, often decrease after months or years on dialysis, which may make it difficult for partners wishing to become pregnant. You should consult with a gynecologist or urologist if you need to discuss fertility and family planning concerns.

Before you decide to become pregnant and have children, talk to a nephrologist who has experience in this area. This is important in your family planning efforts because each time you dialyze, your baby does too. This may have some long-term effects on you and your baby. If you're on peritoneal dialysis, you may be switched to hemodialysis to allow the baby more room to grow.

You and your spouse may feel disappointed if you can't physically have children. However, there are other ways to bring children into your family. Adoption, foster parenting, becoming a Big Brother/Sister, mentoring in schools are all ideas.

If you decide you don't want to become pregnant and have children, be sure to take the necessary precautions and use some form of birth control. Your doctor can talk to you about which contraceptives are available and effective for you. 🌐

- EXERCISE -



Exercise is important for everyone to stay fit and healthy. This is especially true when you have ESRD.

A Friendly Note: I used to make a funny face every time someone mentioned exercise to me. I wasn't feeling well and always seemed to be tired. I didn't think I had the energy to exercise. Actually, exercise is exactly what my body needed. It made me feel better and it has helped to keep my muscles from weakening and my joints from stiffening.



Exercise has many benefits for people with ESRD:

- It makes your heart stronger 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.

What Type Of Exercise Program Should I Use?

A regular exercise program can help you feel healthy again. This, however, isn't a suggestion to go out and set a world record. Exercise should be done in moderation. Check with your doctor before starting an exercise program to see if you have any limitations. Your doctor can help you develop an exercise plan that will take into account your physical needs and abilities.

Types of exercise good for people with ESRD include:

- *Flexibility/stretching exercises* - help you move more easily.
- *Strengthening exercises* - help make your muscles stronger with the use of weights or other resistance techniques.
- *Cardiovascular exercises or aerobics* - help strengthen your heart and lungs. It improves your circulation and endurance.

An exercise plan doesn't mean you need to join a gym or buy some fancy exercise equipment for your home. There are dialysis centers that have exercise programs. Your local YMCA and YWCA have various programs. Hospitals and clinics also have exercise facilities and classes. It can even be as simple as going to your local shopping mall and walking. Whatever exercise plan you decide to try, be sure to check with your doctor. Exercise will play a big part on your road to a better, healthier and more satisfying life.

A Friendly Note: Pick an exercise plan that's enjoyable. This will help motivate you so you'll keep up with the program. It's also a good idea to set reasonable goals for your exercise. Then when you reach those goals you'll feel really good about yourself and the exercise program. After I had been exercising for a while I was able to take a look at how much I had achieved. The whole time I had been keeping a progress report. This would be a good idea for you, too.



- ADVANCE CARE PLANNING -



A Friendly Note: This is a difficult section for some people. It's one of those topics you may not have thought too much about before you were diagnosed with ESRD. As you're reading this section, don't become depressed thinking that because you're an ESRD patient something terrible is going to happen. Think of this information as a future plan. After all, everyone needs a plan whether or not they have ESRD. Remember, making plans for the end of your life no more causes you to die than buying automobile insurance causes you to have a car accident!

Since you were diagnosed with ESRD, you've had to think about a lot of issues and make a lot of decisions. You're now in a phase of your care when most people feel they're regaining control of their health and life. One of the ways to hold on to the control of your body and your future is to tell people your wishes regarding your future care if you become unable to make or communicate your decisions. These choices are best made when you can take your time thinking about them instead of when you are in the middle of a crisis. Like car insurance and health insurance, advance directives are better to have long before you need them.

Who Can Help With Advance Care Planning?

- Your dialysis facility social worker,
- Your dialysis staff,
- Your doctors and nurses,
- Your lawyer (although a lawyer is not necessary for your advance care planning).

What Is Advance Care Planning?

Advance Care Planning includes:

1. Written and signed Advance Directives (sometimes called a Living Will),
2. Selection of a Healthcare Surrogate or Proxy (also called Durable Medical Power Of Attorney), and
3. End of Life Planning.

You can change these plans anytime you want. In fact, many people change their advance care plans whenever their medical condition changes. Your dialysis facility is required to tell you about their policies regarding honoring your advance directives. If they don't honor your wishes, they must provide you with a list of other dialysis facilities that will honor your wishes. If you tell a nurse or doctor in the dialysis facility what you do or don't want done in the event you cannot make those decisions yourself in the future, the staff can record your wishes in your medical record. Although not as helpful as written directives, telling the staff can still be helpful in the event of a crisis.

Once you have completed your advance care planning, the dialysis facility is required to have your wishes entered into your medical record.

Advance Directives or Living Wills are different in every state. Advance Directives include instructions for selecting the circumstances when and how you want the advance directives to be used. With written advanced directives you can add your own personal wishes, learn how to change your mind, how to make the document legal, and what to do with the document after your directives are completed. Then you just fill in the blanks, and check the boxes. Remember to sign the paper and have it signed (witnessed) by two other adults.

Some of the medical circumstances and medical treatments that are often considered in advance directives are:

CIRCUMSTANCES:

“If you become incapacitated with a terminal illness, end stage illness, or persistent vegetative state, you DO or DO NOT want the following treatments:”

TREATMENTS:

- CPR (Cardiopulmonary Resuscitation):
If you suddenly die (heart and breathing stop), CPR is a way to try to restore your life. CPR consists of several emergency treatments. CPR means forcefully compressing your chest wall in an attempt to get enough oxygen to your brain to prevent brain damage. CPR means attempting to restart your heart by giving strong medicines intravenously or directly into your heart. CPR means using strong electrical shocks applied to your chest to try to start your heart. CPR means giving “artificial respiration,” or in other words breathing for you by mouth-to-mouth breathing or with a breathing machine.

You can limit CPR or choose alternatives to CPR. CPR can be limited to “intravenous medicines to try to help your heart start and work normally” ONLY. In other words, do not use chest compression or artificial breathing. You can choose “do not use electrical shocks to try to start my heart.” You can also choose “do not intubate” (intubate means inserting a breathing tube either through your nose or down your throat and into your lungs. The tube is attached to an artificial breathing machine, called a respirator). Finally, the alternatives to CPR are “AND” – “Allow Natural Death” or sometimes called “DNR” – “Do Not Resuscitate.”

- Mechanical or artificial respiration: breathing done for a person by a machine, called a respirator.
- Medicines that could keep a person alive by treating infections, an irregular heart beat or high or low blood pressure.

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- Tube feedings: a way to give liquid food through a tube inserted through your nose into your stomach or directly through the belly wall skin into the stomach.
 - Total Parenteral Nutrition (TPN): a way to give liquid food intravenously through a large vein in the neck or chest when a person can't eat by mouth or feeding tube.
 - Blood transfusions: do you want them or not.
 - Surgery: do you want it or not.
 - Dialysis: do you want to stop dialysis if you don't have a good chance of recovering with the quality of life you want.
 - Comfort Measures Only (also known as Supportive Care): These are active, purposeful treatments designed to keep you comfortable while awaiting a natural death.

Ask your dialysis staff to give you a copy of your state's advance directives form so that you can fill it in. You can also get a copy of your state's advance directives on the internet (www.caringinfo.org or www.kidneyeol.org). Someone in the dialysis facility, often a social worker, is available to help you with the process and answer any questions you might have.

HEALTH CARE PROXY:

The second part of advance planning is selection of a health care proxy or surrogate (sometimes called a medical power of attorney or durable, medical power of attorney). This person should agree to implement your decisions about treatment if you are incapacitated. You should write this person's name in your advanced directives. Then, you should have the person sign indicating they agree to be your proxy. You should sign the paper too. Make certain that you tell your proxy what kinds of treatment you want done if you become seriously ill and cannot communicate your wishes about the care you want to receive. (See next page for things to say to help discuss advance care planning). If you have written, signed, advance directives, the proxy's job is easier. All the proxy needs to do is give your advance directives to the doctors and nurses providing the care.

It is essential that your health care proxy understands what you want done if you lose the ability to make or communicate your decisions. Your proxy need not be afraid of making wrong decisions if the proxy merely tells the medical staff what you said you wanted.

END OF LIFE PLANNING:

The third part of advance care planning is called end of life planning. These plans are your thoughts, feelings and decisions about where you want to die when the time comes (for example "I want everything done and it is ok if I die in an intensive care unit;" or "When it is my turn to die, I want to die in my own home, in my own bed;" or "I want to be in a quiet room, in a clean, comfortable bed, surrounded by my family. A hospice facility is ok if

it provides those things.”). You should know that choosing hospice services at home or in a hospice facility, means you don’t want to have any pain and discomfort when it is your turn to die. Using hospice care does NOT mean you are “quitting.” It simply means you want your care givers to provide you with the best possible comfort and conditions for your death.

During your end of life planning you should also consider any existential (thinking about your life), spiritual, or religious support you want when it is your turn to die.

Advance directives, proxy selection and end of life planning may not be easy subjects to think about, let alone talk to your spouse, family and friends about! There are some good questions that can help you to think about advance care planning and begin to make some decisions. These questions are helpful for talking with your doctors, nurses, family and friends too.

SOME HELPFUL QUESTIONS FOR THINKING AND TALKING ABOUT ADVANCE CARE PLANNING:

- “If you had to choose between being kept alive as long as possible regardless of personal suffering or living a shorter time to avoid suffering which would you choose?”
- “Will this treatment prolong my life and maintain my quality of life, or merely delay my death?”
- “If you become unable to make decisions for yourself, whom do you want to carry out your preferences for you?”
- Under what circumstances, if any, would you want to stop dialysis?”
- “If your heart stops beating or you stop breathing, would you want to allow natural death?”
- “Under what circumstances, if any, would you NOT want to be kept alive with medical means such as cardiopulmonary resuscitation, a feeding tube, or mechanical ventilation?”
- “Where do you prefer to die and who do you wish to be with you when you die?”

A Friendly Note: Once you’ve made your advance directive decisions and completed the forms, make several copies and give them to your doctors, family and friends. You’ll want to make a list of the people who have copies. If you change your mind about your wishes at any time, they can be cancelled or changed. To be on the safe side, if you change your advance directive, you’ll want to notify all the people you gave copies to. Ask them to destroy those copies and give them your new wishes.



- WORK & EMPLOYMENT -



What About My Job?

A Friendly Note: ESRD and its treatment have changed many areas of your life. Another area of your life that you may be worried about is your job. Let's face it, your job not only pays the bills, but it may provide you and your family with insurance. A job also helps to identify you. My job is very important to me, not only because of the financial aspects but also because it has become a part of my daily and weekly routines for so many years. When I started hemodialysis, I needed time to adjust, but I'm glad I went back to work. It put normal routines back in my life. Most people who are on dialysis suggest that taking a brief leave of absence while adjusting to dialysis is better than applying for disability. I happen to agree.

The Federal Family and Medical Leave Act allows persons with serious health conditions including kidney failure to qualify for up to 12 weeks of unpaid leave. While on leave, your employer is required to hold your present job or a similar job with the same pay, benefits and working conditions. Your employer is required to maintain group health coverage, although you may be charged for the insurance premiums. If a spouse, parent or child is needed to help care for a person with a serious medical condition, they too may be able to take unpaid leave under the Family and Medical Leave Act. There are three conditions to be eligible.

To qualify for leave, a person must:

- Work for a company with 50 or more employees
- Have been working for your current employer for at least 12 months
- Have worked at least 1,250 hours in that 12-month period

The leave may be used all at one time, or it can be used as a reduced number of hours each day or in small time frames of an hour (if the payroll system tracks time in shorter units). Some employers require you to use vacation time and/or sick days first. That varies from employer to employer. With the federal supports that are in place, it can allow you to stay employed and maintain some level of activity. 🌍

- TRAVEL -



Can I Travel When I'm On Dialysis?

As you begin to feel better and regain strength and energy, you'll realize your life is getting back to normal. You may decide you'd like to go on a trip, visit family and friends or travel for business.

A Friendly Note: Just because you have ESRD and are on dialysis, doesn't mean everything must come to a stop. If you want to take a trip and go on vacation, GO — NOTHING IS STOPPING YOU. The only difference is you're going to have to plan a little more and make a few extra arrangements. Other dialysis patients travel all the time and they travel all over the place, including overseas and on cruise ships.



How Do I Arrange For Hemodialysis When I'm Traveling?

Whether you have private insurance or Medicare, be sure to check to see if the cost for dialysis is covered where you're traveling. Medicare doesn't pay for treatments outside of the United States. If you're paying with cash for your treatment while away from home, be sure to let the facility know you're paying for it yourself. You may get a better rate.

A Friendly Note: As you travel, remember each facility has its own way of providing care and treatment. The dialysis units may have different procedures. The facility in which you usually dialyze, may allow you to eat while you're dialyzing, but the unit you go to when you're on vacation may not let you. Different things work for different units. You'll learn that as you travel more. It's interesting to learn how units operate in different areas of the country and world.

When you're planning your vacation, you'll want to take a look at possible dialysis units that are close to where you're vacationing. Your dialysis unit can give you a list of treatment facilities to call in the area you're visiting. You can call the out-of-town facility and make the needed arrangements. By arranging it yourself, it allows you to set up a location and a schedule that best meets your needs during travel.

You can set up the dialysis schedule on your own, but you may need the help of your dialysis unit when it comes to the paperwork. Copies of your medical records must be faxed to the facility you'll be visiting. Your dialysis facility will take care of this for you. About two weeks before your trip, check with your unit to make sure the needed paperwork was sent. Also, check with the unit you'll be visiting to make sure they have everything they'll need.

I'm On Peritoneal Dialysis. Can I Travel?

When you're on peritoneal dialysis, you'll need to arrange for your supplies to be sent ahead of time to your destination. You can call your supplier and order the amount of supplies you'll need. Your supplier will deliver the supplies to your travel location instead of your home. This means you won't have to worry about carrying extra suitcases filled with heavy supplies. You will however, still want to carry one or two extra dialysate bags and needed supplies, in case you need them en route. If you're on CCPD, you can have your cycler machine delivered to your travel spot as well. As with hemodialysis, you have to plan ahead. ESRD doesn't mean you're unable to travel and vacation with family and friends.

Does Medicare Cover My Dialysis When I'm Traveling Outside Of The Country?

Medicare doesn't cover the cost of supplies or treatments while you're out of the United States. Some patients' private insurance will cover 80 percent and the individual pays the other 20 percent. However, some countries will only accept cash payments from foreign travelers. Be sure to research the areas you'll be visiting and understand the payment procedure before you arrive.

Is There Anything Special I Have To Do If I'm Traveling Outside Of The Country?

When you travel abroad, there are often special vaccines that are needed for all visitors. There are some shots that can't be given to transplant recipients or for people with certain health conditions who are on dialysis. Therefore, before you plan a trip outside of the U.S., you should talk to your nephrologist. 🌐

- MEDICATIONS -



How Important Are The Medicines My Doctor Has Prescribed?

A Friendly Note: In Phase 1 we talked about how you would feel when your kidneys stopped working. We also explained the effects on your body. If you're like most people, you want to feel better. One of the ways to do that is to receive adequate dialysis. You'll also need to take your medicines, watch your diet and exercise regularly. These are simple keys that will help you feel your best.



It's your right and responsibility to understand what medicines you're taking, why you're taking them and how you're supposed to take them. For example, some medicines should be taken with meals and other medicines should be taken on an empty stomach. It's important to tell your medical team of any changes in your medications and treatment plan. A change in any of your medicines can affect other areas of your treatment.

What Type Of Medications Will I Need To Take When I'm On Dialysis?

When you have kidney failure, medications may be prescribed to help your body make red blood cells, control blood pressure, and help replace vitamins and minerals. Other medicines will keep your bones strong, get rid of phosphorus that builds up when your kidneys are not working, and treat infections or other illnesses you may have. Below is a list of some of the common medications for people who are on dialysis.

- **Iron** is used to help your body make red blood cells.
- **Blood pressure medicine** is used to keep your blood pressure under control. If it is not controlled, you could have a heart attack or a stroke.
- **Vitamins** are used to help replace the vitamins and minerals that are lost during dialysis. You may also need vitamins because of your dietary restrictions.
- **Calcium** helps keep your bones strong and your heart muscles healthy.
- **Phosphate binders** help your body bind to the phosphorus from the foods you eat.
- **Epogen® or EPO** is used to stimulate the production of red blood cells. You may need this to help treat anemia, which is often associated with kidney disease.
- **Carnitor®** may be used to replace carnitine deficiency. Carnitine is a natural substance that helps the body's cells produce energy. It also helps to remove the waste products from our cells. Some patients may lose carnitine during each dialysis session.
- **Antibiotics** help your body fight infections. When your kidneys are not

working, antibiotics can build up in your body, so if another doctor gives you an antibiotic, be sure to ask your nephrologist if the dose is okay.

Can I Take Over-The-Counter Medicines?

Because you have kidney failure, you need to be careful what over-the-counter medicines you take. This also includes “home remedies.” These medicines or remedies can react with your prescription drugs and can make you sick or could even be life threatening. Make sure you tell your medical team about all medicines and remedies you’re taking. Here are some common medicines you’ll want to avoid:

- **Alka-Seltzer®**, baking soda or other bubbling remedies. These are high in sodium.
- **Milk of Magnesia** or antacids containing magnesium. Magnesium can build up and cause neurological problems.
- **Aspirin**, unless ordered by the doctor. Aspirin can affect the clotting abilities of the blood and may cause too much bleeding.
- **Enemas and laxatives** should be avoided.
- **Vitamins or food supplements** may have potassium and magnesium in them.
- **Any “cure all” remedies, herbal medicines and over-the-counter medicines** that have not first been discussed with your nephrologist.

What Type Of Medications Will I Need When I Have A Transplant?

As we briefly discussed in the transplantation section, the closer the new kidney matches your blood and tissue type, the better the chance the new kidney will be accepted into your body and begin working. No matter how close the transplanted kidney matches your blood and tissue type, you’ll have to take several medications to keep your body from rejecting your new kidney. These medicines may have some side effects. Regardless of the side effects, it’s important to remember that all of the medicines work together to help prevent rejection. Your medicines will need to be taken in the right amount according to how they’re prescribed for as long as you have your new kidney. Missing even one dose can be harmful to you and you can risk losing your new kidney.



A Friendly Note: You don’t want to forget to take your medicines or just stop taking them because you don’t like the side effects. This is dangerous because it will probably cause you to lose your transplanted kidney. If this happens, you’ll need to go back on dialysis. It may also jeopardize your chance to be considered for another transplant.

Your doctor will prescribe medicines that keep your body from rejecting the new kidney. These medicines are called immunosuppressants. They are also known as anti-rejection drugs. When immunosuppressants are working, it means your body's ability to fight off germs is decreased. Because of this, it's easier for you to get infections or tumors. Taking immunosuppressants may change your eyesight, blood pressure and blood sugar levels. Immunosuppressants may also cause problems with your stomach. There are other medicines that you can take to help minimize the stomach problems or ulcers, blood pressure and blood sugar levels.

A Friendly Note: Don't become discouraged by the possible things that might happen because of the immunosuppressants. If you want to keep your new kidney working, this is what needs to be done. But, these side effects are manageable and you may not experience everything we've described. By knowing everything that might happen, you're better prepared.



Steroids may also be prescribed to help with inflammation or swelling. This is your body's natural response to an injury or an invasion. Your body thinks of your new kidney as an invasion and will try to respond. Steroids keep the inflammation in control. In taking these medicines you may have changes in your appearance. These medications may also increase your appetite and create some changes in your mood. Most of these side effects occur right after the transplant when the dose of medicine is the highest. The side effects usually decrease as the medicine dose is lowered. Remember, not everyone has every side effect to a medication. 🌍

- ALTERNATIVE/COMPLIMENTARY AND OTHER MEDICATIONS -



In recent years, there has been a growing trend to explore and use alternative medicine or complementary medicine. These are treatments, which are used in addition to traditional western medicine. Common treatments include acupuncture, herbal remedies, chiropractic therapies, mind-body techniques and others. It also includes over-the-counter medicines. There may be some benefit in these types of treatments and medicines, but it's important to know there may be dangerous side effects when these treatments are combined with your medicines.

These alternative and complementary medicines may also be harmful to people with certain medical conditions. Kidney disease can be one of these conditions. It's important to tell your doctor all of the medical treatments you're taking. Also, before trying any complementary therapies or medicines, check with your nephrologist first. In the Appendix is a table listing commonly used herbal treatments and their potential effects.

Are There Any Vaccinations I Should Receive On A Regular Basis?



A Friendly Note: When the flu, pneumonia and other illnesses hit a healthy person it may not be serious, but with you it can be. When you have ESRD, getting the flu or pneumonia can be serious. It may take a long time to get over the illness or it can cause serious complications. There are a few safety measures you will want to take to keep this from happening. There are several vaccines you should receive. You will also want to keep a current record of all vaccines you have received. This way you will know when it is time to get a new vaccine.

When you have ESRD, your immune system has changed. It may not be as strong as it was before. People with ESRD should receive an annual flu shot. You should also receive a pneumococcal pneumonia vaccine every three to five years. This is opposed to every 10 years for the general population. In addition, there is a vaccine for Hepatitis. Hepatitis B is a disease that affects a person's liver. It is mainly transmitted through blood and blood products. If you get Hepatitis, there is a chance that you may not be eligible for a transplant. It's highly recommended that persons with ESRD receive the Hepatitis vaccine.

In some rare cases, people have allergic reactions to immunizations. This is usually caused by sensitivity to egg protein that is found in some vaccines. If you have a history of severe reactions to eggs or egg protein, you should tell your doctor before getting a vaccination.

What Type Of Immunizations Will I Need Before I Have A Transplant?

If you are thinking about a kidney transplant, you will need to make sure that you are up to date on all of your immunizations. The reason for this is because after you receive the transplant, the medicines you take to prevent rejection, such as steroids and immunosuppressants, can cause the vaccines not to work well. After you receive a transplant, you should never receive a vaccine containing live viruses. This includes polio, measles, mumps, rubella and chicken pox vaccines. Because your immune system is weakened from the anti-rejection medications, these live vaccines can put you at risk of getting the disease they are supposed to prevent. Other people living in your home after you've received a transplant should avoid live vaccines so there is not a risk of spreading the live virus to you. 🌐

- TESTS AND CHEMISTRIES -



What Types Of Blood Tests Are Done When I'm On Dialysis?

Each time you dialyze, you are weighed and there are tests that are done to look at your blood and body chemistries. If you are on peritoneal dialysis, these tests are done once a month when you go to the unit. The blood tests measure the waste products in your blood. It is very important to know your numbers. They are the key to tell if you are receiving enough dialysis. The values are guidelines and may vary from person to person. Use the blood chemistry chart in the appendix to keep track of your numbers each month.

Potassium (K)

Normal value = 3.5-5.4 MEQ/DL

Accepted dialysis normal = 4.0-6.0 MEQ/DL

Potassium regulates muscle action, including the heart.

Symptoms of high levels:

- Irregular heart beats
- Muscle weakness
- In extreme cases, heart attack

Causes of high levels:

- Eating too many foods high in potassium such as bananas and tomatoes

Sodium (Na)

Normal value = 135-147 MEQ/DL

Accepted dialysis normal = 135-147 MEQ/DL

Sodium is necessary for maintaining the body's cells and water.

Symptoms of high levels:

- Thirst
- High blood pressure
- Shortness of breath
- Swelling (edema) in legs, around eyes, fingers and other areas

Causes of high levels:

- Eating too much salt

Phosphorus (P)

Normal value = 2.5-4.5 MG/DL

Accepted dialysis normal = 3.5-5.5 MG/DL

Phosphorus is made by protein breakdown. It's a chemical that works with calcium to keep bones strong. A medicine called a phosphate binder may be taken with meals to control the phosphorus level. Constantly high phosphorus levels lead to bone disease and other symptoms such as bone pain, itchiness and muscle weakness. Recent evidence suggests that a high phosphorus level can lead to blocked blood vessels and heart disease.

Signals/symptoms of high levels:

- Low calcium
- Elevated parathyroid hormone by lowering calcium
- Itchy Skin

Causes of high levels:

- Not taking phosphate binders
- Eating high phosphorus foods- milk, beans, cheese and meats

Glucose**Normal value = 65-115 MG/DL****Accepted dialysis normal = 65-115 MG/DL***Glucose, or blood sugar, is necessary for energy and maintaining normal body tissue.*Symptoms of high levels:

- Excessive thirst

Causes of high levels:

- Diabetes

Hematocrit (HCT or Crit)**Normal value = 38-47 percent for women and 42-50 percent for men****Accepted dialysis normal = 30-36 percent for men and women.****Hemoglobin (Hgb) – more accurate than HCT****Normal value = 12.5-15 for women and 14-16 for men****Accepted dialysis normal = 10-12 men and women.***Hemoglobin is the part of a red blood cell that carries oxygen throughout the body.*Symptoms of low levels:

- Fatigue
- Shortness of breath
- Difficulty exercising

Causes of low levels:

- Decreased production of red blood cells
- Blood loss during or after dialysis
- Shortened survival time of red blood cells

Calcium (Ca)**Normal value = 8.5-10.8 MG/DL****Accepted dialysis normal = 8.4-9.2 MG/DL (per K/DOQI)***Calcium helps keep bones strong and growing.*Symptoms of low levels:

- Muscle twitching and cramping
- Seizures
- Hair loss
- Cataracts

Causes of low levels:

- Eating high phosphorus food
- Not taking phosphate binders
- Low vitamin D

Symptoms of high levels:

- Muscle weakness
- Fatigue
- Abdominal cramps
- Loss of appetite
- Nausea and/or vomiting
- Constipation

Causes of high levels:

- Certain medications
- Too much vitamin D



A Friendly Note: In Phase 3: Stabilization, you will learn more about measuring adequate dialysis and ensuring good quality outcomes. It is helpful to keep a notebook to track your progress and your numbers. This will also help you and your health care team track your progress. It will also help your doctor to know what works best for you. I enjoy looking back to see how well I'm doing and how much progress I've made.

- THE ESRD DIET -



As discussed throughout Phase 1, diet is a key part of living a healthy life with ESRD. Your treatment facility has a renal dietitian who can help you make good food choices and understand your blood chemistries. Your dietitian will help you to plan your diet so you can stay as healthy as possible. In Phase 3 we'll talk more about the specific guidelines for your chemistries and nutrition.

A Friendly Note: Watching what you eat and drink may be one of the most difficult changes you make. The good news is you don't have to do it alone. A dietitian will explain the diet to you and help you make choices for special occasions or when you're dining out. Dietitians are not there to "police" you, but to work with you to make the best choices possible. It's important to be honest about your food likes and dislikes as a way to come up with a food plan that works for you.



When you eat or drink, your body uses everything it needs and the parts of food that aren't needed are removed from your body. Kidneys are also important in keeping water and electrolyte (sodium and potassium) levels balanced. In addition, the kidneys balance minerals such as calcium and phosphorus and regulate hormones including active vitamin D, PTH, and erythropoietin (EPO). Since you no longer have working kidneys, your body can't remove the toxins that are building up in your body.

Eating the wrong foods and fluids can be dangerous. There are many nutrients that can build up in your body that might become life threatening. Although there are certain foods and beverages that are commonly avoided among people with ESRD, what you eat and drink is different depending on the stage of your kidney disease and the kind of treatment you choose. For example, there are medications you may take to treat your ESRD that can cause constipation, which means your stools become hard and infrequent. If this happens to you, you'll want to talk to your doctor or dietitian. Your dietitian may help you to make food choices that can help relieve your constipation and your nephrologist may prescribe stool softeners.

What's My Diet Like If I'm On Hemodialysis?

If you're on hemodialysis, it's important to eat the right foods because your blood is only cleansed three times a week. Waste products and toxins build up in your body between dialysis treatments. The renal dietitian will provide you with a meal plan that includes how many servings from each food group to eat each day.

Protein / Calories

Protein is needed by the body to keep your tissues healthy and replace old or damaged tissue. Each day, protein must be included in your diet for you to stay healthy. Calories are very important too. In order for your body to use the proteins for growth and repair, sufficient calories are needed. Calories are necessary for energy and for maintaining your body weight. Just as fuel gives power to cars, calories fuel your body and give you energy. If you are underweight, the renal dietitian can give you suggestions on increasing calories in your diet.

Potassium

Potassium is a mineral that is vital for regulating your heart. It's found in many of the foods we eat and in some medications. When your kidneys fail, potassium builds up in your blood. A high potassium level is extremely dangerous. It can make your heart stop working.

There are two ways to control your potassium level. The first way is to complete all dialysis treatments. The second is to limit high potassium foods in your diet. The foods that are the most common sources of potassium are fruits, vegetables and dairy products. Limiting high potassium foods can reduce the risk of a weakened heart muscle or heart attack. Some vegetables can be soaked in water for several hours and then rinsed. It has been shown that this process, called "blanching" or "dialyzing," removes a good amount of potassium from the vegetables. Because this procedure doesn't remove all potassium, you still need to be careful of what you eat. Talk to your dietitian and ask him or her to explain blanching in more detail. Another way to cut back on your potassium is to eat canned vegetables and fruits. The canning process reduces the amount of potassium. One thing you have to watch for is the ingredients in salt substitutes. Some of the substitutes have high levels of potassium. Make sure to read the labels carefully. If you are not sure about a salt substitute, ask your dietitian.



A Friendly Note: One of the most important things I've learned is that portion sizes are the key to potassium control. As you're reading about this special diet, it may sound overwhelming, but most foods can be incorporated into your diet with some planning and moderation.

Calcium / Phosphorus

Calcium and phosphorus are minerals found in many foods we eat. They are needed to form bones and keep them strong and healthy. They are also necessary to help nerves and muscles function properly. Phosphorus helps your body make energy. In kidney disease, the kidneys lose their ability to get rid of extra phosphorus from the blood. This also causes the calcium levels to drop. Too little calcium and vitamin D and too much phosphorus

eventually lead to bone disease. In addition to a low phosphorus diet, you will most likely be started on active vitamin D and phosphate binders to prevent bone disease. Foods high in phosphorus include: milk, cheese, nuts, seeds, bran, chocolate, colas, and legumes such as pinto and kidney beans. Various medications such as antacids and supplements, contain large amounts of calcium. Make sure to read all labels carefully and check with your dietitian or doctor before taking any new over-the-counter medications.

Why Is Phosphorous So Important?

If the phosphorus in your blood becomes too high, it will cause your body to pull more calcium from your bones. This is an effort to try to balance things. The problem is as you pull more calcium out of your bones; your bones will get weaker. In addition, this extra calcium and phosphorus can deposit in other areas of your body such as skin, joints, and blood vessels. This can cause other problems such as painful joints, itchy skin, and red eyes. It may also contribute to heart disease.

How Can I Prevent These Problems?

The best way to prevent hyperphosphatemia (excess phosphorus in your blood) is to limit your high phosphorus foods. For a listing of the phosphorous values of everyday foods, see the “AAKP Nutrition Counter: A Reference for the Kidney Patient.”

In addition, take your phosphate binders with each meal. If you snack, talk to your physician about taking additional binders with these snacks. If you only eat once per day, discuss how to change your binder schedule for your meal variations.

A Friendly Note: As there are several types of phosphate binders available, you may wish to discuss with your doctor which one is best for you.



Sodium / Fluid

Fluid balance is one of the jobs healthy kidneys perform. They help keep the body from gaining too much fluid volume, and prevent swelling or puffiness in the feet, ankles, legs, hands or face. When the kidneys lose their ability to flush out extra fluid, the extra water can raise blood pressure, cause strain on the heart, and can make it difficult to breathe. The body tolerates approximately one to two pounds of excess fluid without significant difficulties. Your dietitian will advise you on how much salt and fluid you can have each day.

What's My Diet Like If I'm On Peritoneal Dialysis?

If you are on peritoneal dialysis, your diet may be less restrictive than hemodialysis. However, you will still need to be careful about the amount of fluid, salt, phosphorus and potassium you consume. You may need to eat extra protein in your diet because protein is lost during dialysis exchanges.

The recommended amount will vary from person to person. When you're on peritoneal dialysis, you also have access to a dietitian who can help you understand the diet.

What Can I Do About Being Thirsty?

Although thirst and craving fluid can't be eliminated, there are some tips that can help control it.

- Follow a low sodium diet, because salty foods make you thirsty.
- If you're thirsty, chew gum, or suck on mints or hard candy.
- To quench thirst, try rinsing your mouth with mouthwash or water without swallowing.
- Try to drink from small cups instead of large ones.
- Remember, ice lasts longer in your mouth than liquid. Try freezing your favorite juice or beverage, like lemonade. Keep in mind, however, that ice also needs to be counted as part of your fluid allowance.

What Diet Restrictions Are There With A Transplant?

As we've said before, a transplant is not a cure; it's another treatment option. If you have a successful transplant, you may still need to watch what you eat and drink. Because of side effects from the anti-rejection medicines that you take, you may have to monitor weight and cholesterol levels. The good news is most transplant recipients don't have to limit the phosphorus or potassium in their diet. This allows you to eat more fresh fruits and vegetables. You usually don't have fluid restrictions. One of the side effects of your transplant medications may be an increase in your cholesterol. If so, you'll need to limit your saturated fat intake and choose leaner cuts of meats. Unfortunately, you'll still need to be careful of the amount of sodium you eat. The steroids you take can cause water buildup that can elevate your blood pressure. Again, talk with your dietitian, as recommendations for what you eat and drink will be individualized.

In conclusion, you have already learned a lot, but you probably still have questions. Please don't hesitate to ask questions until you have answers that make sense to you. You have both the right and the responsibility to understand ESRD, the treatment options available to you, and your treatment plan. As confusing as this adjustment may be, the bottom line is there are many people on many levels working to make sure you, receive the care you need. You can receive help and guidance from people at your clinic or dialysis unit. You can be linked with a mentor who is another person with ESRD. You can receive help from people within your community, people who represent your Network, and from your family and friends.

- CONCLUSION -

Remember, you're not alone! There are people along the way who will work together with you to create a safe and caring environment. A place where your questions can be answered, your anxieties lessened, and your concerns put to rest, as you continue on your journey with ESRD.

*A Friendly Note: Congratulations, you've completed the second phase in your journey with kidney disease. You're well on your way. Did you write down all your questions so you can share them with a member of your healthcare team? Remember, it's to your benefit to ask questions, work with your health care team, form an open line of communication with your support team and take an active role in your health. When you're ready to receive **Phase 3: Stabilization**, return the return the postage card to AAKP. But, take your time and make sure you understand what is going on with your health. You'll know when you're ready to move to the next phase. The control to decide when you're ready to receive more information is left in your hands. Good luck and I'll meet you again in the next phase.*



GLOSSARY

GLOSSARY

Access: General term used to describe the site where the needles for the hemodialysis process are connected to your body. *See also* *Fistula and Graft*.

Anti-Rejection: *See* *Immunosuppressive Medications*.

Cadaveric Transplant: An individual who has recently died and his or her organs are donated for transplantation. *See also* *Transplantation*.

Continuous Ambulatory Peritoneal Dialysis (CAPD): The most common type of peritoneal dialysis. With CAPD the blood is always being cleaned. The procedure uses a system of bags and tubing. No machine is required.

Continuous Cycling Peritoneal Dialysis (CCPD): A form of peritoneal dialysis that uses a machine. The machine automatically performs the exchanges while the person sleeps and typically involves three to five exchanges. This is sometimes called Ambulatory Peritoneal Dialysis (APD).

Dialysate: A cleansing liquid used in hemodialysis and peritoneal dialysis.

Dialyzer: A part of the hemodialysis machine that removes wastes and extra fluid from the blood.

Fistula (arteriovenous fistula): Surgical connection of an artery directly to a vein, usually in the forearm, created in patients who will need hemodialysis.

Graft (arteriovenous graft): Surgical connection of an artery and a vein with an artificial tube.

Hemodialysis: The use of a machine to clean wastes from the blood after the kidneys have failed. The blood travels through tubes to a dialyzer, which removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body.

Hyperphosphatemia: The presence of excess phosphate in the blood.

Hypotension: A lower than normal blood pressure. In sudden hypotension the person may feel dizzy, weak or sick to the stomach.

Immune System: The body's defense system for fighting off and protecting itself from viruses and bacteria.

Immunosuppressive Medications: Prescription medications given to transplant recipients to suppress the natural response of the body's immune system.

GLOSSARY

Kidneys: The two bean-shaped organs that filter wastes from the blood. The kidneys are located near the middle of the back.

Living Unrelated Donation: An individual who is willing to donate a kidney, but isn't related to the person needing it. *See also Transplantation.*

Living-Related Donation: An individual who is willing to donate a kidney and is related to the person needing it. *See also Transplantation.*

Nephrologist: A doctor who treats patients with kidney problems and related hypertension.

Nephrectomy: The surgical removal of a kidney.

Peritoneal Cavity: The space in the abdomen that holds the major organs. The inside of this space is lined with the peritoneum.

Peritoneal Dialysis (PD): Cleaning the blood by using the lining of the belly (abdomen) as a filter. A cleansing solution, called dialysate, is drained from a bag into the belly. Fluids and wastes flow through the lining of the belly and remain "trapped" in the dialysate. The dialysate is then drained from the belly, removing the extra fluids and wastes from the body. *See also Continuous Ambulatory Peritoneal Dialysis and Continuous Cycling Peritoneal Dialysis.*

Peritoneal Membrane: A sac, resembling cellophane with holes, which serves as the lining of the abdominal cavity and holds organs in place within the peritoneal cavity.

Peritoneum: The lining of the peritoneal cavity.

Peritonitis: An inflammation of the peritoneal membrane. This inflammation causes an infection in the peritoneal membrane. Peritonitis is treated with antibiotics that are included in a special type of peritoneal dialysate.

Transplantation: The surgical procedure of placing a kidney from a donor to the recipient. There are three types of donations: cadaver, living-related and living unrelated.

APPENDIX

MY IMPORTANT MEDICAL INFORMATION

IMPORTANT MEDICAL INFORMATION	
Primary Doctor Name: _____ Phone number: _____	Dialysis Center Name: _____ Phone Number: _____
Nephrologist (Kidney Doctor) Name: _____ Phone Number: _____	Emergency Contact Name: _____ Phone Number: _____
Nurse Name: _____ Phone Number: _____	Insurance Plan #1 Name: _____ Phone number: _____ Policy number: _____
Dietitian Name: _____ Phone Number: _____	Insurance Plan #2 Name: _____ Phone number: _____ Policy number: _____
Social Worker Name: _____ Phone Number: _____	Other Name: _____ Phone Number: _____
Pharmacy Name: _____ Phone Number: _____	Other Name: _____ Phone Number: _____

QUESTIONS TO ASK YOUR HEALTH CARE TEAM

- ☐ ✓ What exercises can I do now that I have begun dialysis?
- ☐ ✓ I've had a few dialysis treatments and still don't feel like myself, is this normal?
- ☐ ✓ What are the symptoms of peritonitis?
- ☐ ✓ How do I know if my access is functioning well?
- ☐ ✓ Are there any herbs that are safe for me to use?
- ☐ ✓ How do I know if I'm experiencing a rejection of my transplanted kidney?
- ☐ ✓ What do I need to do to plan a vacation?
- ☐ ✓ I'm having difficulties becoming sexually aroused, what is wrong?
- ☐ ✓ What type of access do I have?
- ☐ ✓ Why am I feeling tired all the time?
- ☐ ✓ Can I change my treatment option if I don't like it?
- ☐ ✓ Can I dialyze at home?

[illegible]

HERB	HEALTH CLAIM	NOTES/SAFETY/SIDE EFFECTS
ALOE	Laxative in acute constipation. Not for chronic use. Possible effect on the immune system. Aloe vera gel used externally can assist with healing of burns and wounds.	May cause cramps or diarrhea. Over time may cause electrolyte imbalance and alter absorption of some drugs. Do not use if pregnant or have a GI illness. Daily dose 0.05-0.2 g dry extract. Lethal dose is 1 g/day for several days.
ECHINACEA	May assist in the treatment of upper respiratory tract infections and flu. Best taken at the first signs of cold symptoms to reduce intensity and duration of symptoms. Topically may provide antioxidant protection.	<u>Do not take if you have a transplant.</u> Do not take continuously. Allergic reaction possible. Effects of oral capsules and teas inconsistent and questionable. AIDS patients should not use.
EPHEDRA (May Hung, Ephedrin, Ultimate xhphoria	May be used as a decongestant and a stimulant of the central nervous system. Thought to decrease appetite, but not recommended for weight loss.	<u>It is not recommended for either transplant or dialysis patients.</u> May increase blood pressure, heart rate, heart palpitations and risk of stroke. Caffeine increases effect. Should not be taken by patients with heart disease, high blood pressure, thyroid disease or diabetes. Avoid if using antihypertensive or antidepressant drugs. No more than 24 mg/day. Do not use longer than seven days. Causes dry mouth.
GINKGO BILOBA	Antioxidant, may increase blood flow to your brain and legs. May improve concentration, memory, vertigo, depression and headaches.	Side effects include headache, GI problems dizziness. Patients with bleeding disorders should not take. Overdose may cause irritability restlessness, diarrhea and vomiting. Ginkgo seeds are toxic. Do not use if taking anticoagulants. Must be taken consistently for 12 weeks to be effective.
GARLIC	May improve blood lipid levels and reduce blood pressure in those people with mild hypertension. May increase bleeding or clotting time.	Side effects include GI symptoms, possible odor, allergic reaction. Do not use if taking blood pressure or anticoagulation medications. Dose: 2-4 gm fresh/1-2 cloves or 10 mg allium/4 mg allicium. May have less effect on lipids when used with a modified diet.
GINSENG	May be used as a stimulant or relaxant. Regulates glucose in Type II diabetics. May aid in treatment of anemia, depression and as an appetite stimulant. May enhance immunity.	<u>Do not use if you have a transplant.</u> Side effect include headache insomnia, anxiety, skin rash, morning diarrhea. Limit/avoid intake of caffeine. Diabetics should monitor for possible hypoglycemia. Rare severe side effects. Amounts of ginsenosides varies among brands and preparations.
LICORICE ROOT	Use in the treatment of peptic ulcers. May have anti-inflammatory properties. Often found mixed with other herbs.	Do not take if you have kidney disease, glaucoma, or take blood pressure, Digitalis, corticoid, or diuretic medications. May cause sodium and water retention and excessive potassium losses. Not as effective as prescription medications.
KAVA KAVA	Primarily used as a relaxant, sedative and for sleep enhancement.	Heavy daily use may cause dry, flaky skin, yellowing of the skin and eyes, persistent lethargy. Do not use if you are taking prescription medications for sedation or anxiety. Dose: 45-70 mg kavalactones three times a day for anxiety, 135-210 mg one hour before bedtime for sleep.
ST. JOHN'S WART	Used to treat mild to moderate depression but not severe depression. May also have antiviral, antibacterial, wound-healing activity.	<u>Not recommended for patients experiencing renal failure.</u> Side effects include headache, flu-like symptoms, cough, fatigue, confusion, increased sensitivity to light and GI irritation (may be lessened if taken with food). Do not take with other antidepressant medications. 300 mg three times daily. Must take consistently for four weeks. Inconsistent amounts of active ingredient, hypericin, in most OTC products is a concern.

NOTES

PRE-TEST ANSWERS

1. What are the components of caring for a renal access site? (Please select all that apply)
 - ☒ Touch for pulse, tenderness and temperature,
 - ☒ Look at your skin color, swelling or drainage,
 - ☒ Care to keep your access clean and protected,
 - ☐ Wear tight clothes

2. What may happen when an alarm sounds on a dialysis machine? (Please select all that apply)
 - ☒ You will let your nurses or doctor know immediately so that they can usually address it quickly and easily
 - ☒ You may experience muscle cramps or there can be a sudden drop in your blood pressure (hypotension)
 - ☒ You may have water or chemical balances in your body that change quickly
 - ☒ You may feel dizzy, weak or sick to your stomach.

3. Which of the following are considerations for choosing home dialysis? (Please select all that apply)
 - ☒ Training can be provided to you, typically while you are receiving regular treatments in a dialysis center
 - ☒ Compared to a dialysis center where nurses and technicians help to put you on and take you off the machine, at home you will be doing this with assistance from someone else who can help you when needed.
 - ☒ You will need to become comfortable with sticking yourself
 - ☐ The home dialysis machine is too complicated to use and understand.

If you can drive a car, then you can drive a dialysis machine. With both, you have to learn how to use them safely and what to do when problems occur.

4. Continuous Cycling Peritoneal Dialysis is done at home with a machine called a cycler.
 - ☒ True
 - ☐ False

5. From the following options, what are some of the changes that can happen after the first few peritoneal dialysis treatment? (Please select all that apply)
 - ☒ Less nausea
 - ☒ Less feelings of exhaustion
 - ☐ An increased “tin taste” in your mouth Typically this symptom begins to fade rather than increase
 - ☒ Less forgetfulness

6. People can live a happy and full life on one kidney.
 - ☒ True
 - ☐ False

PRE-TEST ANSWERS

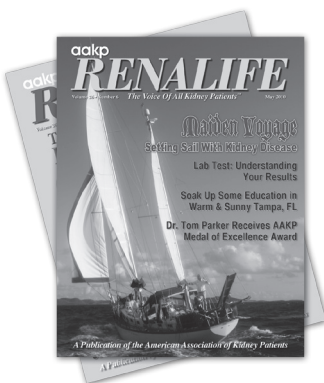
7. From the following options, what are the three kinds of kidney transplants (Please select all that apply)
- ☒ Living related, which involves a blood relative (e.g., mother, father, sister, brother, child, cousin, uncle, aunt) who agrees to give you a kidney.
 - ☒ Living unrelated, which is a person who is not a “blood relative” (e.g., spouses, friends, distant cousins and others) who agrees to give you a kidney that is matched for you.
 - ☐ Animal, which comes from another species where a kidney is matched for you.
Animal kidneys are not matched for human transplantation.
 - ☒ Cadaveric, which comes from persons who have recently died and whose family has donated their organs (such as lungs, heart and kidney) for others to use.
8. From the following options, what are potential sexual intimacy challenges related to kidney disease? (Please select all that apply)
- ☒ Men may become unable to get or maintain an erection (erectile dysfunction)
 - ☒ Women with ESRD may experience vaginal dryness causing painful intercourse.
 - ☒ Both men and women may experience a decrease in the desire for sex.
 - ☒ Both men and women may feel that the placement of the access has made them feel “less desirable.”
9. From the following options, which types of exercise are good for people with End-Stage Renal Disease (ESRD)? (Please select all that apply)
- ☒ Strengthening exercises that help make your muscles stronger with the use of weights or other resistance techniques.
 - ☒ Flexibility/stretching exercises that help you move more easily.
 - ☐ Vigorous exercise that includes lifting heavy weights and a high heart rate
 - ☒ Cardiovascular exercises or aerobics that help strengthen your heart and lungs.
10. From the following options, what are the formal components of advance care planning? (Please select all that apply)
- ☒ Selection of a Healthcare Surrogate or Proxy (also called Durable Medical Power Of Attorney)
 - ☒ End of Life Planning
 - ☐ Telling people your wishes regarding your future care if you become unable to make or communicate your decisions.
 - ☒ Written and signed Advance Directives (sometimes called a Living Will)



The American Association of Kidney Patients (AAKP) is the leader in kidney patient centered education. For more than 40 years, AAKP has provided patients and families the educational tools they need to understand kidney disease and take a more active and informed role in their health care.

Education • Community • Advocacy

Teaching Patients to Take Charge of their Health Care



Patients engaged in their own treatment typically enjoy better treatment outcomes. AAKP uses print, online and live programs to reach the more than 26 million people affected by kidney disease including more than 400,000 people using dialysis as a therapy and more than a 100,000 people living with a kidney transplant.

Social Networks

Building communities among kidney patients, their families, health care professionals and other support groups is a goal of AAKP. AAKP promotes education and fosters conversation that helps improve patients' everyday lives. Support groups, social media, online resources, patient educational meetings and local presentations all provide interactive forums for patients.



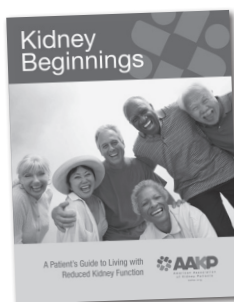
AAKP Online

Kidney disease information is available 24/7 through AAKP.org for anyone with an interest in learning more about kidney disease. The online information covers every modality— Chronic Kidney Disease (CKD), Dialysis and Transplantation.



Educational Brochures

Understanding kidney disease is a critical first step to improving your health. AAKP continually develops high quality, patient friendly materials covering every level of kidney disease. These are patient-focused with language and graphics specifically designed for a non-medical audience.



Advocacy

“Why is public policy important to kidney patients? Because our lives depend on it!”

AAKP believes an informed patient is the best advocate. AAKP actively addresses public policy issues with government officials, including Congress and federal agencies, such as the Centers for Medicare and Medicaid Services (CMS). At the top of AAKP's agenda is QUALITY of health care – from early diagnosis of CKD to improved dialysis facility quality and better management of comorbid conditions, to increasing transplant opportunities.

Take Charge of Your Health Care with AAKP!

Contact us today for more information about services offered by AAKP.

www.aakp.org or call 1-800-749-2257

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