

AAKP PATIENT PLAN[®]



AAKP PATIENT PLAN

*Providing
Today's
Patients
with
Answers
for
Tomorrow*

STABILIZATION

*Phase
Three*

3

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

The AAKP Patient Plan© Team spent countless hours developing this program and making it a reality. Their devotion to the program ensured its success. The Team members included: Brenda Dyson (patient), Frank Soldovere (professional), Judy Weintraub, MS (patient), Bonny Wilburn (patient), Manuel Zapata (patient) and Rosa Rivera-Mizzoni, MSW, LCSW – Team Leader.

We thank our writers, Kim Amtmann-Buettner and Craig Becker, MSW, LCSW who took all of our thoughts and ideas and weaved them into the great written word.

We appreciate the dedication the Florida ESRD Network (Network 7), Network 8 serving Alabama, Mississippi and Tennessee, and The Renal Network (Network 9/10) serving Indiana, Kentucky, Ohio and Illinois gave to this project. They provided us with educational material to supplement our writing and encouraged AAKP in this project from its inception.

To our sponsors, Amgen, Inc., Baxter Healthcare, Fresenius Medical Care, Kidney Care Foundation, Shire and Sigma Tau Pharmaceuticals, thank you for the generous sponsorships that provided patients with this very important resource.

Last, but certainly not least, thank you to our fellow patients, who told AAKP exactly what you needed and wanted to help you and your family as you experienced the journey with kidney disease.

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AAKP PATIENT PLAN[®]

PHASE 3: STABILIZATION

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 are 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 have already taken the journey you're about to take. We think the knowledge and experience we have 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 is also much more. The series of books and newsletters 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: Access and Initiation

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 to 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 healthcare 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 3: Stabilization

During this phase, you've settled into the routine of your treatments and medications. You've caught your breath and know what effects ESRD and its treatment have on your life and how it's affecting your family, friends, employment and overall health. As in the other phases of the AAKP Patient Plan[©], each of the pieces of this adjustment phase will be broken into parts. This way you can read it at your own speed and go to the information most important to you. Phase 1 is described as being similar to when you're on a road trip and your car is getting close to empty...you start looking around 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 starting off on the trip. Phase 3 is the time when you're on your trip, have a pretty good idea of where you're going and the car is set on cruise control. Just because you're cruising along the highway, however, doesn't mean you don't have to keep reading the signs and checking the map from time to time. As with any trip, there will be some detours and a few traffic jams. The AAKP Patient Plan[©] can be your road map as you continue your journey with end-stage renal disease (ESRD). Remember, you're not on this trip alone; there are many people who will help you along the way. 🌐

– OPTIMAL DIALYSIS –



What Is Optimal Dialysis?

Whether you're on hemodialysis or peritoneal dialysis, or whether you go to a dialysis center or have your treatments at home, there are many things you can do to keep yourself healthy. At this stage, you're probably into the swing of things and the treatments have become a fairly normal thing for you. This is a time to make sure you keep doing what your healthcare team recommends.



A Friendly Note: I bet you're feeling better now than you did a while ago. You may even be thinking that you can slack off a bit or take a break from parts of your treatment plan. You may even want to cheat on your diet. These feelings are normal and I understand that continuing to follow your prescribed treatments, medications, nutritional and exercise guidelines can be challenging. You must remember though, with ESRD the decision to "cheat" can be life threatening.

Understanding your treatments and laboratory results can help keep you healthy. The National Kidney Foundation (NKF), along with others in the renal community, created a set of guidelines called the Dialysis Outcome Quality Initiative (DOQI). These are known as the NKF-DOQI guidelines. They are not intended to define a standard of care, but to provide information that assists you, your doctor and your healthcare team in making decisions about your treatment. The guidelines are available to your doctor or dialysis center. The American Association of Kidney Patients has educational materials about these guidelines. The goal of creating the guidelines was to standardize care for people on dialysis throughout the United States. If you have any questions about these guidelines, you should speak to your doctor or other members on the healthcare team. The guidelines are divided into four sections: hemodialysis, peritoneal dialysis, anemia management and access care. (A handy chart located in the Phase 3 newsletter lists those guidelines that have the greatest impact on your care.) This program is designed to help you get the most from your treatment, feel better and live longer.

As we discussed in Phase 1 and Phase 2, the dialyzer works like an artificial kidney. It strains out the toxins and extra fluid that build up when your kidneys aren't working. As you know, hemodialysis lasts for a few hours a day and a few days a week. Dialysis doesn't completely replace your original kidneys' function. Remember, your kidneys worked 24 hours a day, seven days a week. The length of your treatment is prescribed by your nephrologist and depends on your body size, laboratory results and medical condition. You'll do your best and stay the healthiest when you follow your renal diet, take prescribed medications and spend the full-prescribed time on dialysis.

A Friendly Note: You may feel better after a dialysis treatment, but let's face it, the time you spend dialyzing can be boring. You may be thinking about cutting your time short. How much can it hurt anyway, right? This is the wrong attitude to take. It's really important that you stay on the machine for your full-prescribed time. It's not worth it to cheat.



Research shows that people feel better and live longer when they receive adequate dialysis. Before you started dialysis, you may have experienced nausea, forgetfulness, swelling, a “tin taste” in your mouth, bad breath and the feeling of being exhausted. Now that you have been on dialysis for a while, these feelings should have gone away. Even though they may be gone, you may not be getting adequate dialysis. In the long run, if you don't get enough dialysis, you may again start to feel tired or weak and your energy level may decrease. If this continues, you can be at a higher risk for infection and prolonged bleeding. The bottom line is, without adequate dialysis, your quality of life will be less and your life can be shortened.

How Do I Know If I'm Receiving Enough Hemodialysis?

The hemodialysis treatments you're receiving replace only a small part (less than 15 percent) of the normal function of your kidneys. If you don't get enough of the treatment, your blood will retain too much of the body's waste products that cause uremia and you will always feel sick. However, some people who are underdialyzed experience no symptoms.

If you're being underdialyzed you can expect to experience many symptoms such as:

- weakness and tiredness all the time
- loss of real weight
- poor appetite
- nausea
- a taste of ammonia in your mouth
- feeling better than usual at the end of your treatment
- yellow skin color
- inflammation of the heart

You will also be at a higher risk for infections and prolonged bleeding. It's also important to know that in some cases you can be underdialyzed without experiencing the most severe symptoms of uremia. Lesser symptoms are often overlooked or denied.

On the other hand, if you are well dialyzed you will experience the following:

- a sense of feeling good,
- good appetite with more normal weight,
- feeling like the dialysis is not necessary when the treatment is due,
- no yellow skin.

Once a month, the dialysis staff draws blood before and after your treatment to send to a lab. Your lab tests show how well your dialysis treatment is cleaning your blood. The measurement of how well your dialysis is working is called your “delivered dose” of dialysis. Your delivered dose is determined by calculating how much urea is removed from your body during a dialysis treatment. There are two ways to measure how much urea is removed from your body during a dialysis treatment: Urea Reduction Ratio (URR) and Kt/V (pronounced kay tee over vee). If you’re receiving adequate hemodialysis, your URR should be 65% or higher, and your Kt/V should be 1.2 or higher.

Although the URR usually doesn’t appear on your lab report, it’s easy to figure out yourself. Find the pre-dialysis BUN (blood urea nitrogen) and post-dialysis BUN numbers on your lab report, then:

1. Subtract the post-dialysis BUN from the pre-dialysis BUN to get how much BUN was reduced.
2. Divide this figure by the pre-dialysis BUN to get the “ratio.”
3. Multiply by 100 to get the percentage.

Formula

$$\frac{\text{PREBUN} - \text{POSTBUN}}{\text{PREBUN}} \times 100 = \text{URR PERCENT}$$

Example

$$\frac{94 - 32}{94} \times 100 = 65.9\%$$

If your URR or Kt/V falls below the accepted values, your doctor should look for possible errors in the way your treatments are given. He can:

- increase the amount of dialysis by increasing the size of the dialyzer,
- increase your blood flow through the machine,
- lengthen your treatment time.

If your dialyzer is being reused, the dialyzer needs to be rechecked before each treatment to be sure it is still functioning correctly. If it is not, a new dialyzer must be used.

How Do I Know If I'm Receiving Enough Peritoneal Dialysis?

In peritoneal dialysis (PD), a dialysis prescription is related to the number of bags used per day, the amount of fluids in the bags, the dextrose concentration and how long the dialysate stays within the peritoneal cavity. As with hemodialysis, the term used to measure this dose is called Kt/V. If you're on peritoneal dialysis, you'll have blood drawn during your monthly appointment. Peritoneal dialysis uses only Kt/V to determine how much urea is removed from your body. For Continuous Ambulatory Peritoneal Dialysis (CAPD), this value should be at least 2.0 per week.

To achieve a target of Kt/V of 2.0 per week several steps may be necessary including increasing the volume of dialysate that is placed in the peritoneum. This is the single most efficient way to increase Kt/V. Another method may be to increase the number of exchanges you do each day. The final option might be to combine daytime exchanges with a machine doing many exchanges at night, thus combining CAPD with Continuous Cycling Peritoneal Dialysis (CCPD).

Kidney function persists for six months or more after initiation of dialysis in many PD patients. This residual kidney function is exceedingly important. In large people and most men, PD might not give adequate dialysis without this residual kidney function. Therefore, because of its importance residual kidney function must be occasionally measured, along with the dose of dialysis, to make sure that a total delivered dose is adequate. Determining the amount of remaining kidney function is done through a 24-hour urine collection.

You may also have a Peritoneal Equilibration Test, PET, to measure how well your peritoneal membrane functions. The PET is also used to adjust the PD

prescription. Membrane function influences the amount of time dialysate stays in your belly. The amount of clearance during an exchange depends on the transport rate or speed your peritoneal membrane allows urea, creatinine, etc. to move from your blood across the peritoneal membrane into the dialysate. Generally, peritoneal membrane functions remains the same over time but may change if:

- a) you have a serious infection surrounding your exit site or in your belly,
- b) you have peritonitis several times in one or two years or,
- c) you have been on peritoneal dialysis for several years.

The box below describes the different Kt/V values for the various peritoneal dialysis treatment options. You want to make sure you reach, at a minimum, these levels to ensure you're getting enough dialysis.

Kt/V Values for Peritoneal Dialysis

Peritoneal Treatment	Kt/V
CAPD with fluid always in belly	2.0 or more
APD, Automated Peritoneal Dialysis	more than 2.0
CCPD, fluid in the belly during the day	2.1 or more
NIPD, dry belly during the day	2.2 or more

These minimum measurements are set as a national standard. Your nephrologist may have set a higher dialysis goal for your health because of your individual medical condition. You want to avoid numbers that are lower than these standards. If your numbers are below the standard, ask your healthcare professional, "Why?" If you have questions about the measurement numbers your treatment facility has, talk to your doctor. Remember, reaching or exceeding these goals can help you to have a longer, healthier life.

How Does My Doctor Prescribe My Treatment?

By measuring and monitoring your delivered dose of dialysis, your dialysis team can plan your treatment and check for errors that might stop you from reaching your target delivered dose. You'll be weighed before and after each hemodialysis treatment. Your blood pressure will be monitored during hemodialysis. If you're unable to reach your target URR or Kt/V, your dialy-

sis prescription may be changed. Your hemodialysis prescription is made up of three parts:

- The size and kind of dialyzer you need.
- How fast your blood and dialysate flow through the dialysis machine.
- How long each treatment should last.

There are some medical problems or conditions that can stop you from meeting your hemodialysis adequacy goal. If your URR or Kt/V is below the target level, your dialysis care team should check to make sure:

- Your access and dialyzer are working well.
- Your dialysate and blood flow rates are not too slow.
- Your blood samples were taken correctly.
- You've been to all of your treatments for the full treatment time.

A Friendly Note: Now that you know what your URR and Kt/V should be, are you getting adequate dialysis? If you're not reaching the right numbers, ask your doctor why. You've got to remember that this is your health! There's nothing wrong with questioning your doctor. My doctor appreciated that I understood what was important for my health.



If you're on peritoneal dialysis, your healthcare team will check to make sure:

- You're doing all of your exchanges as prescribed.
- You're collecting your urine and dialysate samples correctly.
- Your peritoneal membrane is working well. Remember that if you've had infections, your peritoneal membrane can become scarred and not work as well as it once did.
- Your remaining kidney function hasn't decreased. If it has, you may need to increase the number or size of the exchanges you use each day, or change to another treatment type.

If your treatment team has reviewed the checklist above and your Kt/V is below your goal, talk to your doctor, nurse and dietitian. Together you can work to create a plan that will keep you at your healthiest.

A Friendly Note: It's really important that you meet the dialysis goals we just talked about. It's up to you to make sure you're getting adequate dialysis. This means no cheating on your diet and definitely not cutting your prescribed dialysis time short.



HEMODIALYSIS CHART FOR URR

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
90%												
85%												
80%												
75%												
70%												
65%												
60%												
55%												
50%												
45%												
40%												

HEMODIALYSIS CHART FOR K_T/V

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
1.8												
1.7												
1.6												
1.5												
1.4												
1.3												
1.2												
1.1												
1.0												
0.9												
0.8												

PERITONEAL DIALYSIS CHART FOR K_T/V

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
2.6												
2.5												
2.4												
2.3												
2.2												
2.1												
2.0												
1.9												
1.8												
1.7												
1.6												

Once a month ask your doctor, nurse or dietitian for your URR or K_t/V number. Keep a record of your adequacy number by putting an X in the box on the chart where your measurement number falls. If your X falls in the gray shaded area, you should talk to your nephrologist, nurse or dietitian.

A Friendly Note: These charts are great to keep an eye on your progress. I've kept my K_t/V chart in my notebook. I believe one of the reasons I do well on dialysis is because I've taken an active role in my healthcare. You can find your own chart in the appendix of this book.



Why Is Nutrition Important To Dialysis?

Maintaining proper nutrition can affect your health. Research shows that malnourished patients are likely to spend more time in the hospital and die earlier. Proper nutrition and adequate dialysis are equally important to the quality and length of your life. Your monthly blood work tests for albumin. It appears on your lab report and provides a valuable check on your nutritional status. Your serum albumin should be above 3.8 g/dl. It's extremely important for you to make sure you are getting enough nutrition. If you're maintaining proper nutrition and being well dialyzed, you should not be los-

ing weight, or suffering from a poor appetite. If you're well dialyzed and are still losing weight then another cause should be sought.

What Is Anemia?

Because you have ESRD, you may have a low red blood cell count or anemia. This happens because your kidneys are no longer making a hormone called erythropoietin (EPO). EPO tells your body to make red blood cells. Red blood cells carry oxygen to all parts of your body. When you have ESRD, your kidneys may not make enough EPO, which can lead to a drop in your red blood cell counts and anemia. Anemia can cause you to feel tired, look pale, lose your appetite, feel cold, have trouble sleeping and have a decreased energy level. If you've been diagnosed with anemia, your doctor will do a few tests to determine causes of your anemia. Some of the possible causes of anemia may be blood loss, an inflammation in your body, poor diet or too little iron, folic acid or vitamin B12 in your body. Your anemia will be treated with a man-made form of EPO called EPOETIN ALFA, also known as EPOGEN[®].

How Do I Treat Anemia?

This man-made EPO works just like the hormone that healthy kidneys make. EPOGEN[®] is given as an injection or in your bloodline during hemodialysis. You can learn to give yourself shots. You'll probably need to take EPOGEN[®] for as long as you're on dialysis. The amount and frequency of EPO injections depend on how much you weigh and how well you respond to treatment. They can vary from once a week to three times per week. Your doctor will watch your response to treatment by checking your hematocrit or hemoglobin every one or two weeks. Your hematocrit is a measure of the number of red blood cells in your blood. Depending on how your body responds to the injections, your dose or frequency may have to be modified. Once you reach the optimal range for your hematocrit, which is between 33 and 36 percent, your blood may only be checked every two to four weeks. Hemoglobin measures the amount of iron in your red blood cells and should be between 11 and 12 to feel your best.

Iron is also needed to make red blood cells. Once you start taking EPO, your body will make more red blood cells, and your body's iron stores will be used up faster. In addition, if you're on hemodialysis, a small amount of blood is left in your dialyzer after each treatment. Over time, this can also lead to a low red blood cell count, anemia and a decrease in the amount of iron in your body.

Will EPO Cure My Anemia?

EPOGEN® alone can't treat anemia. If you're taking EPO injections, you'll also need to take extra iron. There are many over the counter vitamins and supplements that contain iron, however if you take oral iron, you will most likely have a prescription for high dosage iron. The most effective way to receive the iron you'll need is by an intravenous (IV) injection. This will be given in your hemodialysis line or, if you're on peritoneal dialysis, during clinic visits. If you take iron in a pill form, be sure you take it on an empty stomach at least two hours before or after eating or taking other medications. This will enable your body to absorb iron more effectively.

A Friendly Note: By now, you may be wondering why you need to keep an eye on all of this stuff. The reason you need to keep track of this is because if you want to be as healthy as you can be, you've got to know about your disease and its impact on your body. Your healthcare team is there to advise you and help you when possible, but they don't go home with you each night. That means the responsibility is in your hands. You are the team leader.



Why Is My Hemodialysis Access Maintenance Important?

As you know, if you're on hemodialysis you have either a fistula, a graft or a catheter and if you're on peritoneal dialysis you have a catheter. You've learned to care for your access on a daily basis. Failure to check and care for your access can become life threatening. Whether you have a fistula, graft, or catheter, your access site is referred to as your "lifeline." It's important to care for it properly to ensure your dialysis treatments can go on as scheduled.

A Friendly Note: I bet now that you've been on dialysis for some time, you're thinking it'll be OK to cheat "a little" on the care of your access. It gets tiresome always having to clean it and check it, doesn't it? Well, I can tell you from experience the little inconvenience you're experiencing now is much better than running into problems with your access. The access is your lifeline. If something goes wrong with it, how do you think you'll receive your dialysis treatments? Take the time to "pamper" your access. A few minutes here and there can save you a lifetime of troubles.



What Type Of Things With My Access Should I Be Watching For?

If you're on hemodialysis and have a graft or fistula, your access should be checked for blood flow problems and early signs of infection each time you have a treatment. Signs of adequate blood flow are when there is a "buzzing" or "rushing" feeling and a pulse, which can be felt in your access. If a hemodialysis access is not working properly, the cause is usually a steno-

sis. A stenosis is a narrowing in the width of a blood vessel. Any narrowing leading to, through, or from the access can cause a problem. If it's severe enough, it can slow down the access, allowing it to clot. The most common sites of narrowing are listed below:

1. Artery leading to the access

Usually seen in people with arteriosclerotic disease involving small arteries, such as diabetics and long-term smokers.

2. Arterial connection to veins (anastomosis)

This is the connection surgically joining the superficial veins of the arm or the artificial graft with the artery.

3. In the veins or graft leading from the arterial anastomosis

Stenosis here can come from poor needle sticking or a leakage of blood from the access into the arm, causing a hemotoma or bruise.

4. Venous connection with the graft

This is the most common site of blood flow obstruction. The cause of these stenoses are not clear, but may be related to tissue reaction to turbulent blood flow.

5. Anywhere in the native veins after the fistula anastomosis or after the venous connection with a graft

Usually due to previous catheters placed for IV infusions that have damaged the blood vessels. This is a major complication of subclavian catheters used for dialysis, but less often seen with catheters placed in the internal jugular.

Your access is designed to deliver enough blood so that dialysis can be effective. This is the blood that will be removed by dialysis. The reading on the blood flow gauge on your dialysis machine should be 400 to 500 ml/min. Your artery must deliver more than 400 to 500 ml/min. to the access to prevent recirculation of blood or collapse of the arterial flow. Your healthcare professionals can use various machines or even simple evaluation methods to see if your access is functioning well. The best test you can do is to make

sure you feel or hear the rumbling sound your access makes. If there is any change in the sound or feel of your access, report it to your doctor immediately.

Even though you may take great care of your access, there may be times when your access will clot or become infected. If your access clots, you may need to go to the hospital to have the clot removed. Usually, people who have a clot removed don't have to stay overnight in the hospital. If your access becomes infected, your doctor will prescribe antibiotics. Although signs of infection may disappear after a couple of days, it's important to take your antibiotics as they're prescribed and until they're gone. If you don't do this, the infection may return and be harder to treat. You may also risk the possibility of your access failing.

Why Is My Peritoneal Access Maintenance Important?

Peritoneal dialysis patients play a greater role in the day-to-day care of their access than do hemodialysis patients. Catheters must be cleaned daily. You also must monitor your access very carefully for signs of infection. If your catheter exit site feels tender, shows redness, or shows yellowish drainage or pus, you may have an exit site infection and need to talk to your doctor immediately.

Common Complications of PD Catheters

- Infection either at the exit site or in the tunnel,
- Peritonitis,
- Poor flow,
- Bleeding.

Infection

Infection is the most common complication of PD catheters. Chances are you will experience a catheter-related infection at some time during your dialysis experience. Proper catheter care can greatly reduce the risk of this serious problem. Be sure you:

- Wash hands before handling the catheter,
- Wear a surgical mask during exchanges,
- Clean exit site daily as instructed by your nurse,
- Perform exchanges in a clean, dry, well lit area,
- Inspect all bags of dialysate for signs of contamination (cloudiness) before use,

-
- Inspect dialysate after use for signs of infection (blood, cloudiness, fibrin strands),
 - Report any sign of infection to your physician immediately.

Peritonitis

Peritonitis is an infection in your peritoneal cavity. It produces fever, abdominal pain, a feeling of general illness, nausea and vomiting. The earliest sign of peritonitis may be clouding of the dialysate draining from the abdomen. Peritonitis can be treated with antibiotics at home, but more advanced cases require hospitalization.



A Friendly Note: A serious case of peritonitis can endanger your life. Report any symptoms of early infection immediately to your physician. Remember, it's easier to treat an early infection and you'll feel better quicker.

Poor Catheter Flow

Poor catheter flow is frustrating as it prolongs exchanges and decreases the efficiency of dialysis. Outflow (draining) is more commonly affected than inflow (filling). Common flow problems occur from kinks in the catheter, blood clots or fibrin in the catheter, movement of the catheter or blockage by abdominal organs. You and your doctor can find the problem and usually correct it without causing you to change treatment options.

Bleeding

Bleeding from the PD catheter is most commonly due to fat clinging to the catheter tip when the fat is irritated during exchanges. Bleeding may also be unrelated to the PD catheter, such as bleeding from an ovarian cyst in women. In either case, your doctor must investigate it.

Should I Exercise?

Exercise is important for everyone to stay fit and healthy, and that's especially true when you have ESRD. You may say that you're too sick, tired or weak to exercise, but in fact, exercise may be just what your body needs. Exercise helps keep your muscles from becoming weak and joints from getting stiff. Exercise has many benefits. It reduces depression, anxiety, stress and your cholesterol level. It helps to control your blood sugar level and strengthens your heart. You should check with your doctor before starting an exercise program to see if there are any limitations or suggestions. Your doctor can help you develop an exercise plan, taking into account your physical needs and abilities. Exercise will play a big part in living a better, healthier, more satisfying life.

Creating an exercise program doesn't mean you need to join a gym. An exercise program can be as simple as going for a walk, swimming or gardening. Doing something that isn't hard on your joints is the best kind of exercise. Some dialysis centers have exercise cycles you can ride while you're dialyzing. Ask your healthcare team if your center has an exercise program. Take advantage of the programs that may already be in place either at your dialysis center or at your local community center such as the YMCA and YWCA.

A Friendly Note: Find a buddy to go walking with you, or find someone who's willing to go swimming. It's really helpful if you exercise with someone else. It gives you the motivation you may need. My motto is "stay active, stay busy and stay fit!"



What Can I Do To Make Sure I'm Getting Adequate Dialysis?

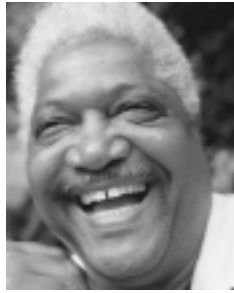
A Friendly Note: Don't cheat yourself out of feeling better, stronger and living longer! Make sure you're receiving adequate dialysis! You play an important role in making sure that you receive adequate dialysis.



CHECKLIST FOR ADEQUATE DIALYSIS

- ✓ Follow your diet and fluid restrictions. Your dietitian can help you and give you suggestions.
- ✓ Take all of your medicines as they're prescribed. Taking your medicines can help you feel more energetic so you can return to your normal activities. If you have questions, talk to your pharmacist or doctor.
- ✓ Check your access each day and before each treatment. Daily care and monitoring of your access is essential to keeping your "lifeline" working as long as possible. If you suspect any problems, call your doctor.
- ✓ Exercise on a regular basis. Remember to talk to your doctor before starting an exercise program so you can find a program that's just right for you.
- ✓ Always attend each scheduled treatment for the full time that's prescribed. Missing a few minutes each time can add up and cause your body harm over a period of time.
- ✓ Follow the advice of your dialysis staff on taking care of yourself. They're there to help you take care of yourself and do well on your treatment.
- ✓ Check your URR or Kt/V adequacy numbers every month. Knowing these important numbers can tell you how much dialysis you're actually getting.
- ✓ Keep a record of your numbers and blood chemistries. Talk to your dialysis care team if they're lower or higher than the goal. ●

– OPTIMAL TRANSPLANT –



What's One Of The Most Important Things I Should Remember About My Kidney?

A lot of time and effort went into finding the best kidney match for your transplant. It's now important to make sure you keep your new kidney healthy and working properly. As we discussed in Phase 2, the closer doctors match the new kidney in blood and tissue type, the better the chance it will be accepted by 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 side effects, which include a decreased immune system, weight gain, facial hair, stretch marks, skin discoloration, and fuller cheeks and face. There are also long-term effects of taking the anti-rejection medications, which include increased risk of skin cancer and other cancers, serious infections, diabetes and bone disease.



A Friendly Note: No matter what type of side effects you have, you must remember all of the medicines work together to help prevent rejection. If you want to keep your kidney, you have to take your medications in the right amount (determined by your doctor) for as long as you have it.

Missing even one dose can be harmful to you and the health of your kidney. You may be in danger of losing your kidney if you frequently forget to take your medications or choose to stop taking them. If this happens, you'll need to go back on dialysis. By doing this, you're also risking your chance to be considered for another transplant.

What Is Acute Rejection?

Within the first three to four months after you receive a transplant, there's a high risk of an acute rejection episode. Acute rejection can usually be successfully treated with intravenous (IV) immunosuppressive drugs. If you do experience an acute rejection episode, you can expect to be hospitalized for a period of time while IV medications are used to fight the rejection. Signs of an acute rejection may include:

- A decrease in the amount of urine you produce,
- Fever,
- Pain or swelling around your transplant site,
- Fluid retention (which can cause a sudden weight gain or swollen feet, hands or eyelids).

In addition to the common signs and symptoms, an acute rejection may also occur with no signs or symptoms. It may only be detected through blood tests that check your creatinine level.

Because of the high risk of acute rejection in the first three or four weeks after discharge from the hospital, you will likely see your doctor and have blood tests three times a week. After that, you'll have tests once a week for another three or four weeks and then once every two weeks. The medical team will continue to cut back on the frequency of your visits depending on how well your transplanted kidney is working and how well you're doing. In addition to checking your blood work, your doctors will want to make sure your incision is healing and you're not having any problems or concerns with your transplant.

A Friendly Note: If you think something isn't right or if you have any questions, call your doctor right away. Your transplant team would rather be called and tell you nothing is wrong, then run the risk of delaying the treatment of a potentially serious problem. If you become sick with any new illness, fever or bad feeling that lasts for four hours or more, contact your transplant center in the fifth hour of illness.



After a transplant, you may feel good and think you can skip or put off clinic appointments. It's important to keep your appointments. Through these frequent appointments, your transplant team can monitor your blood work and treat any possible signs of an acute rejection or infection before your body starts to show the signs or symptoms. Remember, catching problems early can make all the difference in how well you do. If problems go unchecked, you run the risk of losing your transplanted kidney or becoming seriously ill.

A Friendly Note: This is another great opportunity to use a notebook and keep track of your progress. Record your blood results and compare them from month to month. A handy chart is located in the appendix.



How Long Will My Transplanted Kidney Work?

We've come a long way since kidney transplantation first began in the 1960s. Half of the kidneys from a living donor are functioning more than 14 years after the transplant surgery. Half of the cadaveric kidneys function for eight years or more. Although there has been a great deal of progress in treating acute rejection problems, there hasn't been a change in the rate of kidney loss from chronic rejection. Chronic rejection is a slow process where your transplanted kidney begins to slow down in its function and the amount of

urine may decrease. This isn't something that happens overnight. It may be years before the kidney fails and you need dialysis or another transplant.

It's believed, but not proven, that chronic rejection is a kind of immune response in which the small arteries in the kidney transplant are slowly subjected to a scarring process similar to the blockage of blood flow that occurs in arteriosclerosis (coronary artery disease is an example.) Some doctors believe that chronic rejection is not an immune reaction, but is caused by damaging extra blood flow through a single kidney making the kidney work as if there were two kidneys. Kidneys from well-matched living related donors also risk chronic rejection though the rate of loss is slower.

What Are Some Of The Physical Changes I'll Notice?

As we discussed in Phase 2, there are many physical changes that happen when you first have a transplant. After you've had your kidney for several months, you'll notice some of these changes have been reduced.



A Friendly Note: Sometimes, the change in your appearance is a tough adjustment to make. One of the hardest for you may be the weight gain. Because of the high dosages of medication you're given in the first few months, you may gain some weight. This isn't something abnormal, and you're not the first person to go through it. If it's really upsetting you, talk to your healthcare team. Your dietitian can offer a lot of help in this area.

Several things can cause weight gain. First, you're probably feeling better so your appetite returns. Next, you have less diet restrictions and more freedom to eat different foods. Last, the steroids you're prescribed have the side effect of stimulating your appetite. When you combine these things with your freedom from dialysis, you're at risk for gaining unwanted weight. Many people gain around 25 pounds during the first year after a transplant. If you don't watch your diet, you may experience an unhealthy weight gain and/or you may develop:

- Diabetes
- High blood pressure
- High cholesterol

If side effects occur, there are medications that can treat diabetes, high blood pressure and high cholesterol. However, it's best to never let these side effects occur. It's important to watch your diet, keep your weight under control and exercise regularly.

A Friendly Note: The best way to make positive changes in your health is to make sure you get involved. Realize now that you may need to change your diet a little and start (or restart) an exercise program. Don't wait for problems to develop. Get involved and make a commitment to live healthier and avoid problems and their side effects.



To avoid or minimize the effects of weight gain, high cholesterol and high blood pressure, change your diet and exercise patterns before problems start. Make changes in your diet at the time of your transplant. Making minor changes in your diet can minimize the side effects of weight gain and increased cholesterol and blood pressure. This will help lead to a longer, healthier life for you and your kidney. Here are a few hints:

- Change from regular to diet soda or better yet eliminate soda altogether,
- Broil or bake foods instead of frying,
- Avoid sweets or use sugar substitutes,
- Reduce the amount of butter, margarine, oil and other fats in your diet,
- Avoid high calorie/high fat snacks. Eat healthy snacks like raw vegetables or fruits.

You should also begin (or continue) an exercise program. Walking each day for 15 to 30 minutes can make a difference. It can be as simple as going to your local shopping mall and walking. An exercise plan doesn't mean you need to join a gym or buy expensive exercise equipment for your home. Your local YMCA and YWCA have various programs, and there are hospitals and clinics that have exercise facilities and classes. You may find it helpful to motivate yourself by picking an exercise plan that's enjoyable. It's also a good idea to start out slow and set smaller, more reasonable goals for your exercise. Above all, have a positive attitude toward exercising and don't overestimate your limitations. 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, more satisfying life.

A Friendly Note: Simple exercise can have a major impact. I found that parking my car far from a store's door encouraged me to get an extra workout. You can try things like getting off the subway one stop before your usual destination and walking, playing catch with a child, taking the steps instead of an elevator or riding a bike instead of driving.



What Healthcare Professionals Should I Tell About My Transplant?

You should tell your primary physician and any other medical personnel about your transplant, your medications and any changes in your medical status. It's important to keep these people updated and remind them about your medical condition and your status after your transplant. This includes all medical people you have contact with including your dentist, family medical doctor or primary physician, and any specialists you may see such as an allergist, OB/GYN or other specialty physicians. This is important because it allows them to take into account your physical status, immune system and medication reactions as they treat you. Updates should be given each time you see someone who is a medical professional. In an emergency, it's also important to tell medical personnel. You should carry a medic alert card or wear a medic alert bracelet to let people know you have a transplant.



A Friendly Note: Carrying an emergency card in your wallet is a great idea. It not only lets people know you have a transplant, it also lets them know what type of medications you're taking and if you have any other health conditions. You can make your own card by using an index card and writing all of your health information. If you have any changes in your medicines, be sure to change your card. If you're not sure what to put on the card, take a look at our sample.

Sample Emergency Card:

NAME: _____
MEDICAL HISTORY: _____ _____
ALLERGIES: _____ _____
MEDICATIONS: _____ _____
DOCTOR'S NAME: _____
PHONE NUMBER: _____
FAMILY CONTACT NAME: _____
PHONE NUMBER: _____

– FAMILY, FRIENDS AND YOUR SOCIAL LIFE –



How Can I Handle The Stress?

Stress is a part of everyone's life, even if you don't have ESRD. The challenge we all face is how to improve our overall health by reducing the stress in our lives. In today's world, many people are selling their "secrets" to a better life. The bookstores are filled with self-help books. You can listen to motivational speakers on tape. There are support groups for many issues.

A Friendly Note: I've said this before in Phases 1 and 2, religion is sometimes helpful. Churches and synagogues are reporting all-time high memberships. These may be helpful to you with your continuing adjustment to ESRD. Wherever you find and feel a sense of support or encouragement however, grab and embrace it. This can be your key for leading a healthier and happier life. Having a positive attitude and a good outlook on life can take you a long way toward living a healthy life.



Whether you have a transplant or you're on dialysis, your body has experienced many changes since you began treatment. You may have had surgery, you may have had an access or catheter placed, your medications may have caused side effects or you may have changed your life to accommodate treatments. We're not minimizing the changes you, your body, your family and your friends have experienced. We are however, encouraging you to have a healthy perspective and positive outlook. As we said in Phase 2, finding a mentor may be helpful to you. Finding the right mentor can help you to understand you're not the only one going through these changes. You may join a support group for patients and families or you can join a local chapter of AAKP. Finding the right support can help you to adjust to the life changing effects of ESRD and to put things into perspective.

A Friendly Note: Once you've settled into your routine and have become comfortable with your ESRD and its treatment, you may want to take on the role of being a mentor to someone who has recently been diagnosed with ESRD. The knowledge you've learned can help someone else ease through some of the difficult changes that you've already gone through. Your mentor was helpful to you, so why not help other people and show them the road to successfully coping with ESRD.



When Will Things Get Back To "Normal?"

As you regain control of your life and work ESRD into your daily pattern of living, many normal feelings, wishes and desires return. As you now know, you may experience some physical changes with ESRD. These can be caused

by inadequate dialysis, medication side effects and hormonal changes. The changes may or may not affect your sexual interest and ability. If you're going through difficulties because you've lost your sexual interest or for males, if you can't maintain an erect penis, talk to your doctor. A change in your treatment or medication may be all that's needed. Sometimes it may be helpful to talk to a therapist or counselor who specializes in sexuality.



A Friendly Note: Don't be ashamed to talk about sexual difficulties. Many people with ESRD go through the exact same thing. Any member of your healthcare team will understand the importance of this topic to you and will know where to refer you, if necessary. Also, don't forget to talk to your partner about any feelings you're having. Sometimes talking it over with the one you love can help you solve problems with your sex life.

When you're preparing to be intimate with your partner, remember to focus on all aspects involved with a sexual relationship. Many people find that the act of cuddling, massaging and foreplay can help with sexual difficulties. Men who have erectile dysfunction can discuss with their doctor the possibility of using a prescription drug to help maintain their erection (see the question below).

What Treatments Are Available For Erectile Dysfunction?

Over the years, there have been various methods for treating impotence (erectile dysfunction). Initially, the solution to this problem included inserting plastic rods or inflatable balloons into the shaft sometimes controlled by a valve sewn into the scrotum. Later, suction devices were used to force blood into the venous spaces in the penis. Current therapy is less stressful and more effective than ever before. In the early part of the 1990s, a new class of hormones called prostaglandins became available for self injection into the penis. This treatment later improved to have the prostaglandins pushed into the opening at the end of the penis without injection. For about one-third of those with impotence, prostaglandin therapy proved to work.

Another recent advance with penile dysfunction is the use of a pill. Sildenafil, sold under the trade name Viagra[®], has made a big impact on the medical and social scene. In a dose of 25-100 mg taken about 60 minutes before attempting sex, Viagra[®] strengthens and prolongs erections permitting the user to return to normal sexual relationships. In clinical trials, three-quarters of the subjects reported improved sexual intimacy. Patients on dialysis or with a functioning kidney transplant were not included in these studies. However, small studies of ESRD patients given Viagra[®] have been reported

with positive reports from more than half the subjects and their female partners. No unpleasant side effects were noted. Both diabetic and nondiabetic men gave enthusiastic accounts of how Viagra® helped their lives.

Worry over heart attacks is the main concern when prescribing Viagra®. Men who have angina under treatment with nitroglycerine or similar drugs may be at extra risk of sudden death from a heart attack when taking Viagra®.

Should I Take Viagra®?

Considering the very small number of deaths in men given Viagra®, any risk appears small compared with the possibility of benefit. If you don't have active angina and you've talked to your doctor to see if there's another cause of your erectile dysfunction (medications, poor dialysis, etc.), this is a treatment option you may wish to consider. Talk to your doctor to see if this is an option for you.

I Have A Transplant, Can I Have Sex?

After receiving a kidney transplant, you may fear that having intercourse may damage your kidney. You shouldn't have sexual relations immediately following your surgery, but with time you can safely return to normal practices. Talk to your nephrologist and transplant team to find out when you can begin intercourse again and if there are any precautions you need to take. 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, makes it extremely important to be careful and to take precautions against sexually transmitted diseases (STDs). If you contract a STD, you may have to add more medications to your daily care routine. If you contract Human Immunosuppressive Virus (HIV), you may not be considered as a candidate for 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. Not all STDs have physical symptoms, however, should you have any unusual discharge or odor, you need to see your doctor immediately. An STD or infection can be dangerous if left untreated.

It is also extremely important for women to have yearly pap exams. Such tests can ensure that STDs or changes in cells that can lead to cancer have not occurred.

If I'm Starting A New Relationship, How Do I Talk About My ESRD?

If you're single and looking for a relationship, you may not know when to tell this person about your ESRD or the physical changes in your body. Your concerns and questions are normal. How you approach these issues is as individual as you are. The first step is trusting that the person you've chosen to be with is someone who cares about you and your feelings. An open line of communication is really important. Pick a time when you feel comfortable and share your feelings and concerns with this person. By telling him or her about your physical changes and your feelings about it, you're reducing the fear levels which may interfere when the relationship becomes more intimate. After you've explained ESRD and its impact on your body, be sure to listen to what he or she has to say. There will probably be questions and some concern that he or she may hurt you during sex. Together you can work through this.

It's also important for you and your partner to discuss the risks of pregnancy, STDs, and how to use protection and contraceptives to avoid any health risks for you. You can lead a normal, healthy and satisfying sex life by talking about your needs, your condition and keeping yourself safe and protected.

How Do I Accept ESRD Into My Normal Life?

As you've adjusted to ESRD, you've had to bring medication and treatment schedules into your life. It's important to remember that although dialysis is needed to keep you alive, your life is not dialysis. You can still work, volunteer and enjoy many of the activities or jobs you enjoyed prior to ESRD. Your dialysis center or medical treatment facility can do their best to work with you to schedule appointments or dialysis treatments that take into account your lifestyle. It's the goal of your healthcare team to keep you strong and healthy from an emotional, physical and financial point of view. You're encouraged to keep doing the things you enjoy.



A Friendly Note: Now you're at the stage where you're getting more comfortable with ESRD. One of the keys to succeeding is to stay fit and keep an active life. If you're on dialysis, remember dialysis isn't what defines your life. Dialysis is only part of your life!

For most people, it's a challenge to incorporate self care, clinic appointments and treatments into a daily routine. If you're a single parent, it can be chal-

lenging to schedule daycare around your clinic appointments or dialysis schedule. Make use of community resources such as daycare facilities, your local church or synagogue, friends or family members. There are many resources available and your social worker can help you connect with these.

A Friendly Note: It's OK to tell people that you're overwhelmed or you're not feeling well. It's also OK to ask for help from your family and friends. It doesn't matter if you have ESRD or not, things get to people. If you're at that point, ask for help. People are usually more than willing to help, if they know there is something they can do.



What Do I Do If I'm Still Having Problems Adjusting To ESRD?

The reaction and adjustment to ESRD is very individual. The many demands on your time, finances and relationships are as individual as you are. Each medical facility has a social worker who's available to help you and your family with the many adjustments of ESRD. The social worker can link you with different resources including financial and insurance assistance, transportation, assistance with medication costs, homemaker services, employment and job retraining. Beyond the concrete resources, the social worker may also work with you and your family through counseling. Counseling doesn't mean you aren't coping well, but instead can help you and your family communicate your feelings and frustrations. It can also help you discover solutions to some common concerns that arise with ESRD. Just as it's been a process for you to incorporate ESRD into your life, it's also been a life-altering event for your family and friends. They too have been adjusting to ESRD in your life and in theirs. ESRD and its adjustments take an emotional toll on you and your family. You may have had many heart-felt discussions with your family and friends when you were diagnosed and began treatment, but as time goes on, the adjustment may be more difficult for the people in your life. Take time to enjoy the non-ESRD parts of your life with your family too. Spend time together not discussing health concerns. Outings, family events, social situations should be times to just have fun and enjoy life.

A Friendly Note: As you have experienced stress and the feelings of being overwhelmed, your family has gone through the same emotions. Your family and friends have given you support and encouragement as you adjusted to ESRD. Have you given them anything back? Sometimes family members need support too. They're also going through changes. Let your family and friends know you care about the effect ESRD has had on their life and that you appreciate their support. Remember, you can keep your relationship strong with good communication. Don't be afraid to share your feelings. Let them know how much you love them, and how much they've helped you succeed. ●



– WORK, EMPLOYMENT AND VOLUNTEERING –



Now that you've been on dialysis or had a transplant for a while, you're probably getting into the swing of things and getting back into life. It's normal for you to take a break from work during your initial adjustment to ESRD and its treatment. After the initial break, it's time to return to work, a job or some personally fulfilling activity. Being active and productive doesn't necessarily mean you have full-time employment. Your job can be a homemaker, volunteer, student or another desired activity. We tend to describe ourselves by our job, whether it's a homemaker, student, office worker, truck driver, teacher, administrator or volunteer. Because "what you do" plays such a key role in your life, it's important to keep doing something to keep busy, even if it isn't what you did before dialysis.

What Is The Americans With Disabilities Act?

The Americans with Disabilities Act (ADA) provides for job rights for disabled Americans. People with ESRD are considered disabled and thus the ADA applies to you. The ADA limits what you can be asked during an employment interview, prohibits pre-employment physicals, provides for "reasonable accommodation" for persons with disabilities and empowers the Equal Employment Opportunity Commission to investigate possible violations of the Act.

The ADA bars pre-employment medical examinations; it does, however, permit drug testing. An employment medical examination is permitted after a job offer has been made and before the first day of work. This examination must be done on all new employees regardless of their disabilities. The ADA allows questions regarding your ability to perform the job in question. You can't be asked questions about your disability or its severity, only your ability to do the job.

The ADA defines "reasonable accommodation as: "(A) making existing facilities used by employees readily accessible and usable by individuals with disabilities; and (B) job restructuring, part-time or modified work schedule, reassignment to a vacant position, acquisition or modification of existing equipment or devices, appropriate adjustment or modifications of examination, training materials or policies, ... and other similar accommodations for individuals with disabilities."

This could include making accommodations for dialysis and doctor appointments; however, you may have to make up any time taken off from work. It

could also include giving you a quiet and clean room to do peritoneal exchanges during work hours.

For specific information on the American with Disabilities Act, contact AAKP at 800-749-2257.

What Happens If I Can't Work?

If you're unable to continue with your pre-dialysis employment, your social worker can help you find alternatives. You may pursue other job opportunities or take advantage of job retraining programs. This may be a good time to go to school or begin an educational program.

A Friendly Note: Going back to school may not sound like a great idea to you. You're probably worried about the hours needed for studying. Have you considered that if you're on dialysis, you have built in study time several hours per week while you're dialyzing? Don't worry, you'll know when the time is right to get back into your job or pursue other options. The important thing is that you remain active and busy.



When you don't stay busy and active, it's easy to slip into a "sick role." Keeping active and having a healthy attitude can keep you feeling better. If you can't return to work or school, pick daily routines you can stick with, such as walking around the neighborhood, starting a hobby that you can do daily, or taking community classes such as cooking or woodworking. You might visit places in your town, such as museums, nature trails, zoos or libraries. If you have school-age children, get involved in the PTA. By volunteering, you're able to spend time with your child and help other children and families.

Being retired isn't an excuse to be inactive. Retirement means you can now pick what you want to do to be active. Pursue passions: art, bowling, swimming, volunteering or reading to others at schools or libraries. Use your imagination! Try things you never had time for when you were working. People who stay active tend to have better blood pressure control, are less depressed and healthier overall. Get out there and live your life around your treatment and medication schedules. ●

– LEGAL RESPONSIBILITIES –



We've discussed your rights and responsibilities in detail in both Phase 1 and Phase 2. One of the rights briefly discussed is your right to have access to your medical records. Remember, you have the right to look at your medical records at any time. Each facility may have its own policy on how that occurs. Many places want to have a nurse with you to answer any questions or explain abbreviations or medical jargon. Your treatment facility can't give out any portion of your medical records or disclose any medical information without your permission.

What Are The ESRD Networks And How Can They Help Me?

After Congress amended the Social Security Act in 1972 to provide Medicare to people with ESRD, they created groups of representatives from the kidney community to make sure people were receiving quality care. They divided the country into sections called Networks. These Networks, referred to as "ESRD Networks," are contracted through the Health Care Financing Administration (HCFA). Each Network has employees including a director, a nurse, and a social worker. Many networks employ people with ESRD. Each network also has volunteer committees including: a medical review board, a grievance committees and a patient advisory committee. Patients serve on such committee and boards. Because Medicare is a federal program, the Networks work with, and for, HCFA. HCFA works with the ESRD Network Organizations to ensure that people who are on Medicare get quality care. They also make sure that if you're having problems with your care, such problems are quickly resolved. If you have questions or problems with the care you're receiving, you can call your Network for assistance. Phase 1 of your AAKP Patient Plan© includes the name and phone number of the Network for your geographical area.

How Do I Report A Grievance To The Network?

Each Network maintains a grievance process enabling patients to voice concerns about a dialysis provider. Section 1881 of the Social Security Act was amended by the Omnibus Budget Reconciliation Act of 1989 to provide the Networks with both confidentiality in the medical review process and a limitation on liability. It permits Networks to directly investigate grievances, make decisions about the quality of care provided to patients and act as facilitators. The Networks are required to provide all patients with the grievance process for their jurisdiction. If you have never received this process, by

either a patient newsletter, mailings, posting at your facility or during a patient conference, you have the right to call and ask for a copy of the process.

There is a standard procedure all Networks use in handling and resolving patient grievances. The procedure includes:

- You or a representative may file a complaint with the Network,
- Anonymous complaints are accepted,
- Whenever possible, grievances need to be confirmed in writing, although it may also be taken over the phone or in person,
- All Network grievances are strictly confidential,
- The Network investigation is expected to be concluded within 90 days. For a grievance that is determined to be a serious and immediate threat, the investigation will be completed within 60 days,
- After the investigation has been completed, the patient or representative will be notified in writing whether or not the problem was verified. It will also indicate if the grievance was resolved or if the facility is implementing an improvement plan.

In addition to the Network grievance procedures, all dialysis facilities are required to have facility grievance protocols. These protocols should be posted or given to all patients.

You may also call your State Survey Agency to complain about your care. Your call, along with your identity, will be kept private. You can call 1-800-MEDICARE (1-800-633-4227) to find out the phone number for your state's survey agency. You can also visit www.medicare.gov on the internet for more information. 🌐

– CONCLUSION –

You've already learned a lot since you began treatment for ESRD, but there are probably still some questions to be answered. Please don't hesitate to repeat your questions until you have answers you understand. 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 that 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. Your ESRD Network is there to help you. Your family and friends care about you. Remember, you aren't alone! There are people along the way who will work 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 your journey with ESRD.



*A Friendly Note: You're well on your way! Congratulations on learning all you can to stay healthy and lead a normal lifestyle. You should be feeling very proud of yourself and your accomplishments. When you're ready to receive **Phase 4: Ongoing Treatment**, return the postage paid 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 receive 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. ●*



AAKP EXISTS

*to serve the needs
and interests of kidney
patients and their
families.*

MEMBERSHIP

Membership Application

I am not interested in membership at this time, however I would like to receive a complimentary package of information.

To join the AAKP, complete this form and send it with your check to:

American Association of Kidney Patients
3505 E Frontage Rd, Ste 315
Tampa, Florida 33607

Membership Information:

Name:

Street Address:

City: State:

Zip:

- Transplant Hemodialysis CAPD
 CCPD Family Member Pre-ESRD
 Other _____

I am already a member of AAKP, but I would like to make a donation of \$

Indicate your AAKP membership category below:

- Patient/Family member (\$25)
 Professional member (\$35)
 Sustaining (\$100)
 Institutional member (\$150)
 Life Member (\$1,000)

Check Enclosed (payable to AAKP)

Please charge my credit card:

- Visa MasterCard

Account Number

Expiration Date

Signature

AAKP was founded in 1969 by kidney patients for kidney patients. We continue to be the only organization directed by patients for patients. AAKP is devoted to the interests and concerns of dialysis and transplant patients.

As a member you will meet people with similar experiences. You will learn about kidney disease, how to control it and who to turn to for help. In other words, we are here to help you with the answers and guidance you need to live a full and productive life.

HOW YOU CAN JOIN AAKP

Patient/family membership in AAKP is \$25 annually. Professional membership is also available for \$35 per year. Please contact AAKP at 813-636-8100 for international rates. To join us, just fill out the membership application form and send it with your check or Visa/MasterCard information to AAKP. For immediate membership, call AAKP at (800)749-AAKP. Please have your Visa/MasterCard information ready.

HOW AAKP HELPS YOU

AAKP offers you the following benefits:

- Subscription to AAKP's magazine, *aakpRENALIFE*.
- An opportunity to subscribe to the *AAKP Renal Flash*, an electronic newsletter transmitted once a month using the technology of the Internet.
- A web site (www.aakp.org) displaying useful healthcare information and providing links to other renal related sites.
- A membership packet filled with a wide range of informational brochures on issues affecting the care and treatment of kidney patients.
- An opportunity to attend our annual convention, a four day event featuring seminars addressing treatment options, rehabilitation, and psychological and social concerns of renal disease patients.
- Local chapters in your community that provide social and educational support to you and your family with meetings, newsletters and group activities.
- Special interest brochures that address changing medical technology.
- Assurance that AAKP is representing your interests by defending the Medicare ESRD Program.

GLOSSARY

GLOSSARY

Acute Rejection: A form of kidney rejection. Occurs with some kidney transplant recipients shortly after receiving their transplant. The rejection episode happens quickly and can usually be reversed.

Albumin: A protein found in the blood and when found in the urine, can be a sign of renal impairment (kidneys are not working well).

Anastomosis: The surgical connection of the superficial veins of the arm, or the artificial graft, with the artery.

Anemia: The condition of having too few red blood cells. If the blood is low on red blood cells, the body does not get enough oxygen. *See also Epogen.*

Bladder: The balloon-shaped organ inside the pelvis that holds urine.

Catheter: (1) Sterile tubing that is inserted into a vein in the neck or chest to allow for temporary hemodialysis. (2) Sterile tubing that is surgically placed in the abdomen that allows for exchanges for peritoneal dialysis. (3) sterile tube placed in the bladder to drain urine.

Creatinine Clearance: Test measuring how well the kidneys are removing creatinine from the body.

Creatinine: Normal waste product in the body from meat protein and muscle activity. The kidneys remove creatinine from the blood. *See also Creatinine Clearance.*

Dialysis: The process of cleaning wastes from the blood artificially. *See also Hemodialysis and Peritoneal Dialysis.*

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

EPOGEN® (Epoetin Alfa): A medication that assists your body in producing red blood cells. The medication acts the same way as the natural human hormone erythropoietin. When someone experiences kidney failure, the body does not produce erythropoietin the same way it did when the kidneys functioned normally.

Erectile Dysfunction: *See Impotence.*

GLOSSARY

Erythropoietin (EPO): A hormone made by the kidneys to help form red blood cells. Lack of this hormone may lead to anemia.

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.

Hypertension: High blood pressure, which can be caused either by too much fluid in the blood vessels or by narrowing of the blood vessels.

Impotence: The inability to produce an erect penis for sexual activity.

Intravenous (IV): The process of receiving medication through a catheter inserted in a vein.

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

Kt/V: A measurement of dialysis dose. A formula used to calculate adequate dialysis for both hemodialysis and peritoneal dialysis patients. *See also URR.*

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

Peritoneal Dialysis: 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 “dissolved” in the dialysate. The dialysate is then drained from the belly, removing the extra fluids and wastes from the body.

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

GLOSSARY

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

Renal: A term referring to the kidneys.

Residual Kidney Function: The remaining kidney function that eventually decreases over time.

Stenosis: A narrowing in the width of a blood vessel.

Transplant: The surgical procedure of placing a kidney from a donor into the recipient.

Urea Reduction Ratio (URR): A measurement of dialysis dose. A formula used to calculate adequate dialysis for hemodialysis patients.

Urethra: The tube that carries urine from the bladder to the outside of the body.

Urine: Liquid waste product filtered from the blood by the kidneys, stored in the bladder and removed from the body through the urethra by the urination process.

APPENDIX

MY HEMODIALYSIS CHART FOR URR

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
90%												
85%												
80%												
75%												
70%												
65%												
60%												
55%												
50%												
45%												
40%												

MY HEMODIALYSIS CHART FOR K_T/V

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
1.8												
1.7												
1.6												
1.5												
1.4												
1.3												
1.2												
1.1												
1.0												
0.9												
0.8												

MY PERITONEAL DIALYSIS CHART FOR K_T/V

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
2.6												
2.5												
2.4												
2.3												
2.2												
2.1												
2.0												
1.9												
1.8												
1.7												
1.6												

MY TRANSPLANT CHEMISTRY CHART

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Creatinine												
BUN												
Sodium												
Potassium												
Chloride												
Calcium												
Carbon Dioxide												
Glucose												
Albumin												
WBC												
Remoglobin												
Hematocrit												

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

- ✓ Is my URR 65% or higher or my Kt/V 1.2 or higher on a regular basis (hemodialysis)?
- ✓ Is my measured weekly Kt/V 2.0 or higher (peritoneal dialysis)?
- ✓ What must be done to increase these values?
- ✓ How many uses of my dialyzer (hemodialysis) will ensure that my URR is always 65% or higher?
- ✓ Is my serum albumin 3.8 g/dl or higher?
- ✓ What is my hematocrit and hemoglobin?
- ✓ As a transplant recipient, how can I make changes in my diet to keep my cholesterol and weight down?
- ✓ How do I talk to my new partner about my kidney disease?
- ✓ Can I go back to work?

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