

AAKP PATIENT PLAN.®



AAKP PATIENT PLAN

*Providing
Today's
Patients
with
Answers
for
Tomorrow*

ONGOING
TREATMENT

*Phase
Four*
4

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.

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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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*Your Phase 4 package of the **AAKP Patient Plan**[®] should include the book **Ongoing Treatment** and the **Phase 4 Patient to Patient** newsletter. If you have not received both pieces, please contact AAKP at (800) 749-2257 or e-mail us at AAKPnat@aol.com.*

AAKP PATIENT PLAN[®]

PHASE 4: ONGOING TREATMENT

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’s help available.

The American Association of Kidney Patients (AAKP) is here to be your guide. 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 are 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 roadmap or travel guide. But it’s 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 educational materials that address:

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 with kidney failure. 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 4: Ongoing Treatment

This phase is a time when you've settled into a routine with ESRD and you've been dealing with things for a while. You realize there are things that happen to you that may have nothing to do with ESRD, but affect your life and your treatment options. As in the other phases of the AAKP Patient Plan[®], this phase will be broken into parts so that you can read it at your own speed and go to the information that's 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 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, you 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 doesn't mean you don't have to keep reading the signs and checking back at the map from time to time. As with any trip, there will be some detours and traffic jams. Phase 4 is the time when you know where you're going. You've been cruising along and successfully worked your way through some detours and traffic jams. You may be bored with the same scenery each time you make the trip or there may be things that come up that you weren't expecting, and you're now looking back at the road map to see if there are alternative routes you can take. Keep reading the signs, looking at your map and talking to other people who have made the same trip. We hope this can be your road map as you continue your journey with end-stage renal disease. Remember, you're not on this trip alone, there are many people who will help you along the way. ●

– ONGOING TREATMENT –



A Friendly Note: Over time, you've learned how to make ESRD part of your life. You may have put some things like your job, family and friends on hold while you were adjusting to the daily routines of treating your kidney failure. You've made treatment choices and followed medication and dietary requirements. You've adjusted to ESRD and its treatments. Look back at the notebooks you've kept and see how far you've come. You can be proud of your accomplishments. You've learned how to balance ESRD with your family, friends and work.

Phase 4 is the time to keep your life moving forward. As you've learned, ESRD doesn't define who you are. ESRD and its treatment are only a part of your life. Start planning a future. When you think in terms of long-term goals and dreams, you can keep your mind and heart young and healthy. Now that you're into the routine of ESRD and its treatment, start making short-term and long-term goals. Now may be the time to go back to or continue with school. Start planning for your future. Think about marriage and family and what you want to have happen with your life. If you have children or grandchildren, think about your future with them. This is a good time to really take stock of your life and take control of what you want your future to look like.

I've Made It To This Point, Now What?

Your life continues. As we discussed throughout the AAKP Patient Plan®, there are many people who can help you with your journey with ESRD. There are rehabilitation services that can help you return to school, job retraining programs, exercise options, volunteer activities, mentoring programs and many other opportunities that are available to you. Take advantage of the opportunities that await you. Make a difference in your life and the lives around you. Take advantage of your healthcare team and their knowledge of resources and programs that will help you live life to your full potential.

Will There Be More Changes In My Care?

As you've learned with life, there are always changes – whether or not you have ESRD. Yes, as an ESRD patient you may experience changes. However, changes aren't necessarily bad. Some changes may include:

- A change in your medical status
- Long-term effects of your treatments or medication

-
- Your support system may change
 - A job change or other major change in your life

The changes you experience may be the result of a decision you made. For example, you may be on hemodialysis now, but you might want to switch to peritoneal dialysis or go on the transplant waiting list. Other changes could involve your healthcare team, such as a change in medicines or dialysis time. You may even want or need to change dialysis facilities.

A Friendly Note: As you enter this phase remember, it's OK to look back and "re-learn" about different areas of your care. At some point, you may start to think about changing treatment options. If you make this type of decision, it's a good idea to revisit the different phases of the AAKP Patient Plan® and review the pros and cons of the options. ●



– THE LONG-TERM CARE TEAM –



As you become more and more confident in your care and treatment options, your role changes from someone who is getting to know the team and the treatment process to someone who becomes the team leader. Although the healthcare team that you work with may know more about certain areas of ESRD and its treatment, you're the best expert on you.



A Friendly Note: No matter what phase of care you're in, no other person on the healthcare team can know how the treatments for ESRD are impacting your life like you can. You're the advocate for what's best for you and your family.

How Will My Healthcare Team Change?

Over time, your medical condition will change. As you age and as you continue treatments long term, there will be changes in your body. The core of your healthcare team may expand from your primary doctor and nephrology team to include more specialists. You may see cardiologists (heart doctors), orthopedic physicians (bone doctors), or psychologists or psychiatrists. As you learned in earlier phases, it's important to remind each of your doctors that you have ESRD and the treatment option you're currently using. You may want to ask any specialists to talk to your nephrologist to ensure treatments and medications prescribed won't interfere with your ESRD and its treatment.

Because ESRD is a long-term condition, you may see members of your healthcare team change. As you become familiar with the people on their healthcare team, a relationship and trust begins to grow and mature. As people move forward in their careers, they may move away from your treatment facility.



A Friendly Note: When professionals leave, it can leave you feeling abandoned and hurt. This is a very real loss that many people experience. It's another transition that you must make with ESRD. The one thing you can count on is that you're not alone. Though team members may change, you'll have people available to help you with the many transitions you face.

Just as professionals from your healthcare team may change or leave, there may be other people in your life who have roles that change. You may have a caregiver or spouse who has been with you for a long time who may die or become ill or debilitated. Because you have ESRD, it's sometimes assumed that you'll always be the person who's in the position of needing care and

assistance. In some cases, your friend, spouse or caregiver may be the person who ends up needing to be cared for or may die before you. When that happens, it can cause you to stop and look at what type of treatment you're receiving and if its the best for you in your new situation. 🌐

– LONG-TERM HEALTH ISSUES –



A Friendly Note: When you're on dialysis or have had a transplant for a long period of time, you will most likely develop other health issues. As I've stated throughout these phases, this information isn't meant to scare you. We're giving you this knowledge to educate and prepare you. You're always better off when you know what might happen.

ANEMIA

One effect of ESRD is anemia – a decrease in your red blood cell count. This can occur during any phase of your care and with any treatment option, including transplant. Anemia occurs because your kidneys are no longer making a hormone called Erythropoietin (EPO). This hormone (EPO) is what tells your body to make red blood cells. Red blood cells are what carry oxygen to all parts of your body. A few symptoms of anemia include:

- Feeling tired,
- Having a pale appearance,
- A loss of appetite,
- Feeling cold or chilly,
- Having trouble sleeping, and
- Having a decrease in your energy level.

What Is EPO And How Do I Receive It?

If you've been diagnosed with anemia, your doctor will perform some tests to determine what's causing your anemia. If you are a dialysis patient, your anemia will be treated with a man-made form of EPO called Eproetin Alfa. You may know this as EPOGEN[®].

This man-made EPO works just like the hormone which healthy kidneys make. EPO is given in the form of an injection. Many people learn to give their own shots. It may also be injected or put into your hemodialysis blood-line. You'll most likely need to take EPO for as long as you're on dialysis. The amount and frequency of EPO injections depends on how much you weigh and how well you respond to treatment. The amount you receive can vary from once a week to three times per week. Your doctor will monitor your response to treatment by checking your hematocrit 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 desired hematocrit range, which is between 33-36 percent, your blood may only be checked every two to four weeks.

Is EPO All I Need To Treat Anemia?

Although low levels of erythropoetin are the primary cause of anemia in kidney disease, EPOGEN® alone cannot treat anemia. If your body is deficient in iron. 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 during each treatment. Over time, this can lead to a low red blood cell count, anemia and a decrease in the amount of iron in your body.

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. The most effective way to receive the iron you'll need is by an intravenous (IV) injection. If you take iron in a pill form, you'll need to make 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.

It's important to remember that some medications and antibiotics can reduce the effect of EPO. They can cause your red blood cells to die before they've done their job of bringing oxygen to the different parts of your body. This side effect of your medication isn't easy to predict, so your hematocrit may fall unexpectedly. In addition, the use of the blood thinner, heparin may cause longer bleeding times when your dialysis needles are removed. Either of these may cause your hematocrit to decrease. There may be small changes in your hematocrit that are of no concern. For example, right after a dialysis treatment, your hematocrit may rise by 3 to 4 percent because your blood becomes concentrated during dialysis. It's common for your hematocrit to go up or down by 5 percent or less. If the changes are greater than 5 percent or continue to fall over time, you should talk to your doctor.

BONE DISEASE

If you have kidney failure, you may be affected by bone disease. If you're on dialysis, you've probably been told again and again by your doctor and dietician to keep track of your calcium and phosphorus levels to prevent bone disease. This is important because if your bones become weak, they begin to lose their ability to support your body. In severe cases, as more and

more calcium is lost, the spine becomes curved, the posture stooped and bones begin to break easily. It's important to know that bone loss may begin long before you reach the point of being diagnosed with ESRD. This loss of calcium can happen over a long period of time and may not be noticed for a while.



A Friendly Note: Transplant patients may also have bone disease caused by steroids. You should report joint pain or skeletal problems to your doctor. The saying, “when in doubt, check it out” is a great slogan to keep in mind.

How Can I Prevent Bone Disease?

It's important to keep an eye on your calcium and phosphorus levels. Keeping phosphate levels low isn't just for people who are on dialysis. Even if you're planning on a kidney transplant, it will be difficult to restore the calcium you've lost. Renal transplant recipients often have soft bones before transplantation. In addition, the steroids required after a transplant, decrease the amount of bone you have. To take control of bone loss, keep the phosphate levels in your blood low. Avoid foods that are high in phosphate. You may also take a phosphate binder, such as calcium acetate or calcium carbonate, to lower your phosphate to a safe range. These phosphate binders should always be taken with meals. If you don't take them with your meals, they don't work and may make you feel nauseated.

It may sound easy to follow the recommendations for reducing phosphates and taking binders, but many people say it's hard to do. It's hard because many of your favorite foods are high in phosphorus. Foods such as chocolate, eggs, nuts, dried beans, cheese, milk and cola soft drinks are all high in phosphorus. The phosphate binders can also cause constipation. Because of this, you may decide to stop taking your binders. This may seem like a good decision in the short run, but long-term, it's easier to treat constipation than bone loss. To keep your body strong and healthy, take your binders with meals. Keep some phosphate binders with you for meals away from home or unexpected snacks. For meals at home, leave the bottle of binders on the table where you eat. Despite advances in medicine, treating bone disease remains a challenge. The best treatment for bone disease is prevention.



A Friendly Note: If you want to learn more about phosphate binders, be sure to read the newsletter that accompanies this book.

Exercise is also important in keeping joints from stiffening. You should become involved in a low-impact activity, such as swimming or walking. Be

careful of jogging or running activities, because these can cause joint problems. Check with your doctor before starting any exercise program to be sure it's right for you.

What Can I Do If I Have Bone Disease?

If you've been on dialysis for a number of years and weren't told how to prevent bone disease, or didn't follow your doctor's recommendations, you may have trouble with bone disease. Although it's hard to manage and treat significant bone disease, there are some treatments that may help you. There are medications that can halt further loss of calcium. There are also medications that can bind to aluminum deposits and help remove them from your bones. The loss of calcium from your body can be slowed, but replacing lost calcium in your bones remains a problem with no real solution. If you have bone loss, talk to your doctor to refer you to a bone doctor (orthopedist) who specializes in renal bone disease.

PARATHYROID GLANDS

What Are The Parathyroid Glands?

Knowledge of the parathyroid glands and of the parathyroid hormone, which they produce, is important to all patients with kidney problems. The parathyroid glands most commonly exist as four glands found near (under) the thyroid gland in the front of the neck. On rare occasions, there may be as many as six of these glands and some may even be found in the chest cavity.

The important product of the parathyroid glands is parathyroid hormone (PTH). This hormone keeps blood calcium and phosphate at levels necessary for proper function. The right concentration of calcium, in particular, is essential for many bodily functions. Thus, calcium levels that are too high or too low can have major effects. A small drop in blood calcium will increase the release of PTH from the glands to raise the calcium back to normal. It does this by bringing more calcium into the blood. The major source of replacement calcium is from the diet through the intestinal tract. To get the calcium into the blood from the intestine, PTH stimulates production of active vitamin D into the kidney. The active form of vitamin D acts on the intestine to make it easier for more calcium to be absorbed from food. To complete the loop, calcium and vitamin D suppress PTH in a process called feedback inhibition. When the kidney function is normal, PTH, calcium and active vitamin D are in a natural balance.

How Do The Parathyroid Glands Affect Me As An ESRD Patient?

When the kidneys become even mildly damaged (creatinine levels of 2-3 mg/dl), they may lose the ability to make active vitamin D. Consequently, it becomes harder to gather calcium from the intestine. The parathyroid glands are constantly stimulated to produce PTH and to grow in size. At this point, control of the parathyroid glands is no longer automatic and you and your doctor must become actively involved. The problem of overstimulation of the glands becomes worse as kidney function decreases and phosphate levels rise in the blood because phosphate cannot be excreted by the kidney. Without the intestinal source of calcium, the enlarging parathyroid glands send PTH to bone to get the necessary replacement calcium. The resulting damage to the bones is called kidney bone disease or renal osteodystrophy.

How Do You Treat The Parathyroid Glands?

Treatment is aimed at reducing the overactive parathyroid glands. There are two major parts of this treatment. One is to return the phosphate levels to normal in the blood by (1) reducing the phosphate intake in the diet and (2) by the use of phosphate binders to keep phosphate in the intestine, thus keeping it from entering the blood stream. The other part of the treatment is replacement of vitamin D. This is done by taking medication by mouth (orally) or by receiving it intravenously (IV). The goal is to lower the blood levels of PTH. Problems in achieving this goal will happen if you don't follow a phosphate reducing plan and get enough vitamin D without making the blood calcium level dangerously high. As bone disease worsens, the calcium brought into the blood may not be absorbed by the bone. If this happens, then the calcium levels in your blood easily become too high. A vitamin D like compound is available to lower the PTH levels while causing less of an increase in blood calcium.



A Friendly Note: While you're reading this book, write down any questions you may have. This way you can talk to your doctor about your question and get specific information for your situation.

There are situations when the over-secretion of PTH can't be controlled. When the parathyroid glands can't be shut down even at high normal blood calcium levels, surgery is usually needed. This is especially true if there's advanced bone disease. The surgery is intended to reduce the gland thus reducing the amount of PTH secreted. On rare occasions, this surgery seems to fail when PTH levels remain high in the blood. In this situation, there may be extra glands in the neck or chest which may have to be removed.

While the ability to keep PTH at acceptable levels (about three times normal) has improved over the years, your doctor's clinical skills and your willingness to follow a regimen are very important for success. You must develop habits that help keep blood phosphate levels in their normal range. If you're unable to stop PTH kidney bone disease, you're at a greater risk of abnormal thinning of bone, muscle weakness, arthritis and eventual bone fractures.

MUSCLE CRAMPS

What Causes Muscle Cramps For Hemodialysis Patients?

Muscle cramps during dialysis are a common and frustrating problem. No one knows the exact reason why you get cramps, but it may be caused by less blood flowing to the muscles as fluid is removed during dialysis. The actual loss of fluid might contribute to the decreased blood flow, but also the blood vessels to your muscles may contract (shrink) during dialysis in order to push more blood to your brain and other important organs. Shifts of electrolytes, like sodium and potassium, might also be involved. Either way, the result is painful cramps in the feet, hands, lower legs or thighs and sometimes the abdominal muscles.

How fast and how much fluid is removed can cause cramps. Cramps are more likely to occur when a large amount of fluid is removed during the short time you are on dialysis. Cramps also happen when you get close to your "dry weight" and your blood pressure is lowered.

When cramps occur soon after starting the dialysis treatment or in the middle of the treatment, this could be caused by removing too much fluid during the treatment in order to get you to your "dry weight." The best solution to this problem is to gain less weight between treatments by eating less salt and drinking less water and other liquids. If this isn't possible, you should dialyze for a longer time, so the fluid doesn't have to be removed as quickly.

If the cramps occur close to the end of the treatment, you may actually be having too much fluid removed, causing you to become too dry. This might mean your dry weight is too low. If this is the case, it's better to increase the dry weight or give some saline, rather than shortening the dialysis treatment time. Determining the best dry weight for you is very difficult and your doctor will need to decide what is most appropriate. Remember also, dry weights change from time to time. For example, if you've been ill and not eating well for several days, your dry weight may decrease. On the other hand, if you've

been eating more than usual and not exercising enough, your dry weight could increase.

How Are Muscle Cramps Treated?

Different things are tried to treat cramps when they occur. The first thing your medical team will do is check to make sure your blood pressure isn't too low. If the blood pressure is too low, you'll be given saline to return the blood pressure to normal. Also, they'll usually stop removing fluid during dialysis until the cramps get better. Some dialysis units give concentrated saline, called hypertonic saline, to increase blood flow to the muscles by pulling fluid into the blood vessels and other tissues. Hypertonic saline can be a problem because it can make you very thirsty. It may cause you to drink more fluids after your treatment. If you're already gaining too much fluid between treatments, this only makes the problem worse.

Preventing cramps before they happen is best. The most effective measure is not gaining too much weight between dialysis treatments. Your doctor should carefully keep an eye on your target weight. In addition to these approaches, it may also be helpful to start stretching before your dialysis treatments and to start an exercise program to strengthen the muscles that usually cramp.

HYPERTENSION

Chances are that when you went to see your doctor, you had no idea you had high blood pressure (hypertension). High blood pressure is often defined as 140/90 or higher. The changes that take place with high blood pressure initially occur on a very small scale in your blood vessels, heart and kidneys, among other places. Often these changes take place without you knowing. The good news is you are not alone. There are at least 50 million people in the United States with high blood pressure. The even better news, is together, you and your doctor can take control of this condition before it progresses any further. Medicine, along with exercise and proper diet can help control your blood pressure.

How Did I Get High Blood Pressure?

This is a good question. In 95 percent of the cases the cause is unknown. However, it is known two of the changes in your body that manifest as high blood pressure. These are constriction (tightening) of blood vessels and too much fluid inside the vessels. A molecule in your body called Angiotensin II is one of the primary offenders. Angiotensin II causes a constriction of the

blood vessels. In effect, Angiotensin II creates a situation much like pouring too much water down too small of a tube. This leads to higher pressure in the tube, or in the case of high blood pressure – too much pressure in blood vessels.

How Do I Know If My Medicine Works?

You probably won't know unless you measure your blood pressure. With regular check-ups, your doctor will monitor your blood pressure. Even better, you can learn to take your own blood pressure and monitor your progress yourself! Then, working together as a team, you and your doctor will be able to tell that the medicine is doing its job.

Because most people feel fine, almost 50 percent of them stop taking their medication. This is a mistake. You must remember that you are fighting an invisible enemy that conducts a sneak attack on your body. Slowly but surely, high blood pressure can lead to things like changes in vision, heart failure, heart attacks, strokes and kidney failure. The higher blood pressure makes your body work harder than it should and it may eventually wear out. By taking your medicine, monitoring your blood pressure and keeping appointments with your doctor you may prolong your life up to 10 – 20 years over someone who ignores the hidden enemy!

What Else Can I Do In Addition To Taking Medicine?

Along with taking medication and regular blood pressure readings, changes in your lifestyle can dramatically combat high blood pressure. This is your chance to be the key player in your treatment. Your doctor can only act as your coach and guide for this part.

Some of the best results in lowering blood pressure are associated with reducing body weight. Don't worry, this does not have to be a painful experience. Your doctor can help modify your diet and your activity level without sacrificing everything you enjoy. By eating well and exercising, you may find that you feel better overall. As a bonus, you'll help treat your hypertension. Physical exercise has been shown to lower blood pressure. Exercise also decreases the rate of heart disease, one of the results of hypertension. If you smoke or drink you can really help yourself by cutting back or quitting. Smokers have a higher incidence of harmful hypertension and heart disease. Similarly, heavy alcohol consumption can lead to a stroke, one of the possible outcomes of high blood pressure. For some, changing these habits may be hard. However, as the star player in your own care, you owe it to yourself to control high blood pressure.

NEUROPATHY

What Is Neuropathy?

It is not known why chronic kidney patients get nerve damage, also known as neuropathy, but it may be linked to the buildup of waste products in the blood. To prevent and treat nerve damage, you need to get adequate dialysis and to follow diet guidelines. Symptoms of nerve damage include tingling, burning, numbness, weakness and pain in the hands and feet. Tell your doctor if these symptoms develop. Many long-term dialysis patients suffer from neuropathy.

What Is Carpal Tunnel Syndrome (CTS)?

Carpal Tunnel Syndrome (CTS), a painful condition of the wrist and hand, may affect some hemodialysis patients. Symptoms include pain, numbness, tingling and limited movement of the hand and wrist.

Your doctor may order nerve conduction velocity (NCV) testing to determine whether you have nerve damage of CTS. If there is nerve damage, the test will show the extent of the damage. With early diagnosis of CTS, surgery may relieve the symptoms.

DIALYSIS ASSOCIATED AMYLOIDOSIS

Amyloidosis is a complication of long-term dialysis. The most common symptoms of amyloidosis include pain, numbness and tingling of the hands and wrists known as Carpal Tunnel Syndrome. In addition, as the syndrome progresses, painful arthritis like symptoms can develop in any of the body's joints. In advanced cases the protein that causes this syndrome has been found in blood vessels and major organs causing damage. Deterioration of these organs can result in death. Amyloidosis can be diagnosed with x-rays, bone scans and biopsy.

What Causes Amyloidosis?

The cause of amyloidosis is the buildup of a protein in the body known as B₂M. While many of the body's waste products such as urea and creatinine are easily removed by the dialyzer during hemodialysis because of their small size, B₂M is too large, therefore it cannot be easily removed. While the buildup of this protein is not immediately life threatening it can cause significant disability as time passes. The average time to onset of symptoms in

young individuals is six - eight years after the initiation of hemodialysis therapy, these symptoms can be seen earlier in older individuals.

How Can It Be Prevented?

Kidney transplant is the only treatment that has been shown to significantly stop the progression of the disease. If transplant is not an option, medications such as colchicine and analgesics can reduce symptoms. It's been shown that peritoneal dialysis can slow the progressions of this disease because the peritoneal membrane is more permeable than a dialyzer and can therefore filter B₂M effectively. There are advanced hemodialysis type clearance symptoms in existence which can reduce the buildup of B₂M. However, due to the complexity and expense it is not readily available for all patients. Research is still underway to find ways other than transplant to effectively prevent and treat this complication of long-term dialysis.

SKIN PROBLEMS

Why Does Dialysis Affect My Skin?

Dialysis patients, along with the general population often suffer from skin problems. However, due to the build-up of toxins, various medications and other health conditions, you may find on occasion you suffer from skin problems. It's recommended that you visit a dermatologist at least once a year for a complete check up. Always visit your doctor if you notice any change in your skin.

Why Is My Skin Itchy?

Itching is a fairly common complaint for dialysis patients. You should talk to your doctor about treatment. Some patients find keeping the skin moisturized very helpful. You don't need to spend a lot of money on fancy lotions. Petroleum jelly, baby oil and non-perfumed lotion can be quite helpful, especially if applied right after bathing. Try to use as little soap as possible, as soap dries your skin.

A Friendly Note: Report persistent itching to your nephrologist. Continuous itching could mean your phosphorus levels are too high.



What Is Psoriasis?

Psoriasis is usually silvery scaling patches on the scalp, knees and elbows. The nails, groin, abdomen or back may also be key areas in which the dis-

ease develops. It's often itchy. There are various treatments available, including steroid creams. Some medications you may take as an ESRD patient can worsen the outbreak of Psoriasis, such as beta blockers (blood pressure medicine).

What Is Eczema?

Eczema is a chronic skin disease that causes a rash on various parts of your body. It usually causes the skin to have red patches with scaling. You may have itching. It's important to contact your doctor for medication. Over the long term, if left untreated, eczema can lead to thickened itchy skin that's difficult to treat.

DEPRESSION AND ANXIETY

What Is Depression?

Everyone gets “down in the dumps” or the “blues” on occasion. We can't always be happy and cheerful. You probably felt this way when you were first diagnosed with ESRD. Depression, however, is more than occasional sadness. Long term depression, without any let up in feeling “down,” is called clinical depression. Though it can be serious, it's treatable. If you, or someone you know feels this way, get help.

What Are The Signs Of Depression?

Signs and symptoms can vary among people. Some people continue to appear happy and cheerful even if they're depressed. If you have any of the following symptoms, contact your doctor.

- **Emotions:** Do you feel continuously sad or cry a lot?
- **Appetite/weight:** Have you gained or lost weight?
- **Sleep:** Do you have trouble sleeping or are you sleeping too much? Are you tired all the time, regardless of how much sleep you get?
- **Anger:** Do you find yourself constantly mad or irritable?
- **Outlook:** Have you lost interest in activities that you previously enjoyed?

-
- **Sex:** Have you lost interest in sex?
 - **Self-esteem:** Do you feel worthless, unattractive, excessively guilty or helpless?
 - **Concentration:** Do you have difficulty concentrating, remembering or making decisions?
 - **Anxiety:** Are you nervous, have phobias, delusions or fears?
 - **Suicide:** Have you had thoughts of suicide or attempted suicide?

A Friendly Note: I was embarrassed when I was diagnosed with depression. I thought it was a sign of weakness and that I could just snap out of it. But after seeking help, I realized that there's no reason to think this. Now that I feel better again, I'm glad I talked to my doctor.



How Is Depression Treated?

Different people need different treatment. Talking to a professional may be all you need to feel better, while others may require medications and still others may do best with a combination of counseling and medicines. Therapists are trained to help you recognize and change unhelpful thinking patterns that may cause depression.

Antidepressant drugs may be helpful. These medicines can improve your mood, sleep, appetite and concentration. Many drug therapies may take several weeks to begin working effectively. Like most medicines, there may be side effects. Remember, there are many types of medications and your doctor can help you find the one best for you.

What Is Anxiety?

We all get anxious or nervous at various times and this is normal. If you are bothered by severe and/or frequent anxiety, you may have physical symptoms. These symptoms can include irritable bowels, breathing difficulties, dizziness, sweaty palms or a profound fear of the unknown. Severe anxiety can cause panic attacks.

How Can I Treat Anxiety?

You may find counseling helpful. Your social worker may be able to teach you relaxation techniques that help reduce your stress and anxiety level. Breathing exercises and muscle relaxation can help too. Some patients may

get relief with medicines like anti-anxiety medications or antidepressants. Often a combination of techniques is helpful. Daily exercise, such as walking where you can enjoy the surroundings of your neighborhood, can be beneficial.



A Friendly Reminder: Remember, as patients we have been through many tough situations. It's o.k. to feel scared, nervous or sad. Talking to someone may be just the trick you need to feel yourself again. 🌍

– TRANSPLANT HEALTH ISSUES –



Transplant patients have certain long-term issues that are caused by immunosuppression or the drugs they take.

CHRONIC REJECTION

A Friendly Note: As we talked about in earlier phases, the most common cause of long-term failure of a kidney transplant is chronic rejection. Although there have been advances in treating acute rejection, the medications and treatments for chronic rejection haven't changed the rejection rate. We've said it in the earlier phases, transplantation is not a cure for kidney disease, it's just one of the treatment options.



What Is Chronic Rejection?

Kidney transplant rejection is the result of a complex attack by several kinds of white blood cells that trigger the release of antibodies. It's your body's effort to fight off a foreign object, much like your body tries to fight an infection. When the donor kidney is very different in tissue type (*HLA antigens*) from the recipient or when the recipient has become sensitized by prior exposure to the donor, an immediate rejection (*hyperacute-rejection*) may destroy the transplant within minutes to hours. Fortunately, pre-transplant testing for antibodies has reduced the chance of a hyperacute rejection to less than 1 percent.

Even with the administration of a combination of immunosuppressive drugs, as many as one-third to one-half of kidney transplant recipients undergo an acute rejection within days, to as long as months, after receiving a kidney transplant. Signaled by a fall in urine output, a rise in serum creatinine concentration, and sometimes pain and tenderness in the area of the transplant, an acute rejection is in most cases reversible by treatment with intravenous (IV) corticosteroid drugs and oral medicines. The risk of acute rejection never disappears. Doctors don't completely understand the best way to balance the tug of war between your immune system's effort to remove (reject) the transplanted organ and the medications used to suppress the immune system while still keeping its ability to fight infection intact.

All transplant patients must make efforts to keep a transplant functioning. All of the insults of initial blood supply interruption (when the kidney was first prepared for surgery) and many minimal to severe rejection "episodes" take their toll on kidney function. By about eight years after transplantation, 50 percent of kidneys from cadaver donors are lost, mainly to a process called chronic rejection. 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 narrowing of blood flow that occurs in atherosclerosis (coronary artery disease is an example). So far, however, none of the drug combinations that are successful in reversing an acute rejection have been helpful in chronic rejection. Kidneys from well matched living-related donors also risk chronic rejection, but the rate of loss is slower; 50 percent fail in about 12 years.

What all of this means for patients trying to understand their life with a kidney transplant is that the reality is a transplant is not forever. Younger recipients will probably face recurrence of kidney failure and the need for a second or third kidney transplant or return to dialysis. On the bright side, there are highly promising approaches to medications that may completely turn off the rejection process.

HEART DISEASE



A Friendly Note: This information is being provided to you so you're well educated about all of the possible side effects of kidney transplantation. You may or may not experience these things. Don't let this information scare or discourage you – that's not its purpose.

The most common cause of death for people who've had a renal transplant is heart disease, also called cardiovascular disease. Hypertension (high blood pressure), high cholesterol and diabetes can all lead to heart disease. High blood pressure is a problem that 60 - 80 percent of people experience when they've had a transplant. This high blood pressure may be caused by your immunosuppressive medications. There are medications available to treat high blood pressure. These medications have to be closely monitored because they can raise the blood level of some of your immunosuppressive medications.

WOMEN'S ISSUES

Many female transplant recipients experience changes due to steroid use. Irregular bleeding, heavy periods (menses), continuous spotting and painful cramping can all occur. Talk to your gynecologist about problems you may be having. Some medications may reduce these problems. Before starting any type of birth control or hormone therapy, check with your nephrologist first.

As a female, you should be sure to get a yearly exam that includes a pap test. Because of the suppressed immune system, female transplant recipients are

more vulnerable than other women for cervical cancer, sexually transmitted diseases and infections, especially yeast infections.

CHOLESTEROL LEVELS

If you've had a transplant, you've probably noticed an increase in your cholesterol levels. This is especially true if you're taking a medicine called Cyclosporine. High cholesterol can lead to heart disease. Diet can play a part in lowering your cholesterol, but diet alone usually isn't enough. There are medications that can help lower your cholesterol. While these medications lower your cholesterol, there's also a chance they may damage your muscles. Talk to your doctor about how best to control your cholesterol levels.

DIABETES

You may also develop diabetes as a result of taking steroids. Your diabetes may go away if your doctor is able to lower your steroid dose. If your diabetes doesn't go away, there are some medications that may help. Diabetes can also be controlled through diet and exercise or by taking insulin shots.

CANCER

If you've had a transplant, your risk of skin cancer, especially lymphomas are increased. Because of the increased risk of skin cancer, you should always protect yourself from the sun. Here are a few suggestions:

- Wear a hat with a brim and sunscreen to help protect your skin.
- Always use sunscreen, even on overcast days.
- Apply sunscreen about 20 minutes before you go outside.
- Consider limiting your sun exposure when the ultraviolet (UV) index is seven or higher. You can find this information in your newspaper.
- The sun's strongest hours are between 10 a.m. and 4 p.m. – minimize your exposure during these times.

As a transplant recipient, you should visit a dermatologist (skin doctor) at least once a year. Changes in moles (color, shape and size) as well as skin

appearance should be reported immediately. Talk to your doctor if you notice any of the following:

- asymmetry in the mole (one half doesn't match the other half),
- the edges become ragged, or the color spreads from the border of the mole into the surrounding skin,
- it increases in size quickly,
- it has multiple colors within it,
- there is redness around the mole,
- it begins to ooze or bleed and/or,
- it itches or there is any other feeling of pain. 🌐

– NORMAL AGING FOR DIALYSIS AND TRANSPLANT PATIENTS –



When you live with ESRD for many years, you'll experience normal body changes that come with the aging process. Whether or not you have ESRD, aging is a part of everyone's life. The changes with aging are usually much more gradual, but just as life altering. Both your energy level and physical strength begin to lessen as you age. You may want to talk to your medical team to help sort out what may be physical changes related to inadequate treatment, medical complications, medication side effects or the aging process. This can be confusing to pull apart the different parts of your care, but by talking with your medical team, you can make sure you're staying strong, healthy and fit.

A Friendly Note: One of the best things you can do for yourself is to listen to your body. Listening to your body means you've learned what signs and symptoms to watch for and how to respond to anything that's out of the ordinary.



A good rule of thumb is the following: “when in doubt, check it out.” This doesn't mean you need to be overly cautious or run to your doctor a couple of times a week. It just means to remember that you have an entire team of professionals who are available to help you. In addition to your nephrologist, you can talk to your nurse or your primary care physician. Sometimes a phone call alone can provide you with the answer to your questions or concerns. Remember it's better to have something checked early and be told that there's nothing to worry about than it is to wait. 🌐

– MEDICATION –



A Friendly Note: During the other three phases, we explained some of the medications you'll need to take. Over time, you've probably learned about your medications, their side effects and when you need to take them. You also need to be watchful of many over-the-counter medicines. Just because we have easy access (no prescription necessary) to these medicines, doesn't automatically mean they're OK for us to take.

As a kidney patient, you should be aware of the limits and possible side effects to over-the-counter medications. Below is a summary of the most frequently used non-prescription medicines and some of the problems you should avoid.

ACETAMINOPHEN

Acetaminophen, also known by the brand name Tylenol[®], is one of the most frequently used non-prescription drugs. Acetaminophen is used to relieve pain and reduce fever. Unlike aspirin, it doesn't relieve the redness, stiffness or swelling caused by rheumatoid arthritis. However, it may relieve the pain caused by mild forms of arthritis. Some people, particularly those with other allergies or asthma, may be allergic to acetaminophen. Although acetaminophen is generally a very safe drug, it may cause kidney damage, particularly when taken in large amounts over a long period of time, or when taken in combination with certain other pain medications. For example, medicines like Excedrin[®] contain the combination of aspirin, acetaminophen and caffeine. The chances of side effects are increased in patients with hepatitis or other liver diseases.

It's important not to take more acetaminophen than is recommended on the package label. If too much is taken, liver and kidney damage may occur. If you're taking acetaminophen, you should read the labels of all of your drugs to be sure that other medicines don't also contain acetaminophen.

If you're taking acetaminophen to relieve pain, including arthritis pain, for more than 10 days or if the pain gets worse, new symptoms occur or the painful area is red or swollen, you should check with your doctor. Acetaminophen is also effective for lowering a fever. However, fever is often an important sign of infection in dialysis and transplant patients. If the fever lasts more than 24 hours, gets worse, new symptoms occur, or redness or swelling is present, kidney patients should call their doctor. These could be symptoms of serious infections requiring antibiotic treatment.

Don't drink alcoholic beverages if you're taking acetaminophen. Alcohol and acetaminophen increase the chances of liver damage, particularly if someone is taking acetaminophen regularly over a prolonged period of time and is drinking large amounts of alcohol.

Acetaminophen may interfere with the results of some medical tests and should be stopped for at least three days before the tests are taken. For example, acetaminophen may cause false results with some blood sugar tests. Similarly, caffeine is present in some non-prescription products that also contain acetaminophen, and can interfere with heart tests.

An overdose of acetaminophen can cause liver and kidney failure. Get emergency help immediately if you've taken an overdose, even if there are no symptoms. Signs of severe acetaminophen overdose may not appear until a few days after the overdose.

Symptoms of an acetaminophen overdose include:

- yellow eyes or skin;
- diarrhea;
- increased sweating;
- loss of appetite;
- nausea or vomiting;
- stomach cramps or pain;
- swelling, pain, or tenderness in the upper abdomen or stomach.

Side effects of acetaminophen are rare, when taken in the proper dose. Some side effects may include:

- bloody or black, tarry stools;
- bloody or cloudy urine;
- fever with or without chills (not present before treatment and not caused by the condition being treated);
- pain in lower back or side;
- pinpoint red spots on skin;
- skin rash, hives or itching;
- sores, ulcers or white spots on lips or in mouth;
- sore throat (not present before treatment and not caused by the condition being treated);
- sudden decrease in amount of urine;
- unusual bleeding or bruising;
- unusual tiredness or weakness.

ASPIRIN

Aspirin is also a frequently used non-prescription medication. It has many of the same effects as acetaminophen, but is also useful for treating the pain and swelling of rheumatoid arthritis. Aspirin also acts as a blood thinner by making blood clotting cells, called platelets, less sticky. Small doses of aspirin are frequently used to prevent heart attacks or strokes. It's useful for hemodialysis patients to prevent access clotting. However, the blood thinner effect of aspirin may cause serious bleeding in some people. Because of this, you shouldn't take aspirin for at least five days before any surgery, including dental surgery, unless you're taking it on a doctor's advice.

Just like acetaminophen, some people, particularly those with other allergies or asthma, may be allergic to aspirin. Aspirin can also cause kidney damage, especially when taken in large amounts over a long period of time, or when taken in combination with certain other pain medications. Aspirin can cause gastritis and stomach bleeding, particularly if used in combination with other arthritis medicines. Alcohol can make the stomach problems worse.

Because of the blood thinning effects of aspirin, you shouldn't use it if you're taking other blood thinners without a doctor's supervision. Aspirin can increase the effects of some diabetic medications, but can also prevent gout medicines from working as well as they should. If you have anemia or stomach problems don't take aspirin on a regular basis without a doctor's advice. The chance of serious side effects is increased in patients with kidney and liver diseases. Aspirin can cause false urine sugar test results when taken regularly or in larger doses.

An overdose of aspirin is a very serious condition and you should seek emergency medical attention quickly. Taking an overdose of aspirin may cause unconsciousness or death, especially in young children. Signs of an aspirin overdose include seizures, hearing loss, confusion, ringing or buzzing in the ears, severe drowsiness or tiredness, severe excitement or nervousness, and fast or abnormally deep breathing. Check the labels of other non-prescription drugs to see if they contain aspirin or acetaminophen to avoid overdosing accidentally on these medications.

NONSTEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDs)

Drugs containing ibuprofen, such as Advil® or Aleve®, are used to relieve some symptoms caused by arthritis, such as inflammation, swelling, stiffness

and joint pain. They may also relieve other kinds of pain such as gout attacks or menstrual cramps. They also reduce fever. Both are members of a group of drugs called nonsteroidal anti-inflammatory drugs, or NSAIDs. All of the NSAIDs can cause side effects, especially when used for a long time or in large doses. You shouldn't take these medications, except with the advice of a doctor. They can cause a sudden loss of kidney function in patients with kidney disease. Like aspirin and acetaminophen, they can also damage the kidneys if taken in large amounts over a long period of time.

Although NSAIDs may be used instead of aspirin to treat many of the same medical problems, people who are allergic to aspirin should not use them. NSAIDs may cause a rare but serious type of allergic reaction. This reaction is more common in patients allergic to aspirin. The most serious signs of this reaction are shortness of breath, wheezing or fainting. Other signs may include changes in color of the skin of the face, very fast heartbeat or pulse, hives on the skin and swelling of the eyelids. If these symptoms occur, patients should get emergency medical attention.

Some people who take NSAIDs may become more sensitive to sunlight than they are normally. Exposure to sunlight, even for brief periods, may cause severe sunburn. If you're taking NSAIDs, you should stay out of direct sunlight, wear protective clothing, apply a sun block and never use a sunlamp or tanning bed.

Side effects such as confusion, swelling and worsening kidney function are more common in older patients. Older people are also more likely to develop stomach problems while taking NSAIDs.

NSAIDs may react with other medications or make the side effects of other medicines worse. These effects are particularly important for blood thinners, other pain medications, some antibiotics and transplant drugs - particularly Cyclosporine.

Stomach problems and bleeding ulcers are common side effects. They are more likely to occur if you drink alcohol while taking these medications. Taking more than one NSAID together or with aspirin on a regular basis may increase side effects. The risk of these side effects depends on the dose of each medicine and on how long the medicines are taken together. You should be sure to tell your doctor or dentist that you're taking Advil®, Aleve® or Motrin® before any kind of surgery.

NSAIDs may make you confused, drowsy, dizzy, lightheaded or less alert than normal. They can cause blurred vision or other vision problems. You should call your doctor if you're taking Advil®, Aleve® or other NSAIDs and develop chills, fever, muscle aches or pains, rash or other flu-like symptoms.

COUGH MEDICINES

Cough medicines, like Robitussin® and Robitussin DM®, are among the most frequently used over-the-counter medications. These medicines are generally safe for kidney patients. Some patients use dextromethorphan (DM) to relieve the cough associated with common colds. Dextromethorphan relieves the cough by acting directly on the cough center in the brain. One important side effect is drowsiness, so you need to be careful not to drive a car or operate machinery after taking them. If you have liver disease, you should be particularly careful, because the sedative effects may last much longer and be more severe.

Cough medicines shouldn't be used without the advice of a doctor for chronic coughs that are caused by asthma, emphysema or when there is an unusually large amount of mucus with the cough. Since dextromethorphan decreases coughing, it makes it difficult to get rid of the mucus that collects in the lungs and airways during an asthma attack or in patients with bronchitis.

CALCIUM CARBONATE

Tums® is an example of calcium carbonate. It is frequently used as a calcium supplement and to bind phosphorus to help prevent bones from getting soft. It's also used as an antacid.

The body uses calcium to make strong bones. Patients with kidney disease cannot get rid of phosphorus in the diet from the body normally. When phosphorus builds up, the calcium in the bloodstream decreases and the body takes the needed calcium from the bones, making them softer. Tums® binds some phosphorus in the gut and decreases its absorption from food and, at the same time, increases the amount of calcium absorbed. Tums® should be chewed completely before swallowing for it to work best. Vitamin D also helps prevent calcium loss from bones and increases calcium absorption. You shouldn't use bonemeal or dolomite as a source of calcium. They may contain dangerous amounts of lead.

Calcium supplements can bind other drugs in the gut and decrease their absorption. They should not be taken within one hour of any other medications. If you have kidney stones, you shouldn't take extra calcium and should check with your doctor before taking Tums®.

You shouldn't take calcium supplements if your phosphorus or calcium is too high. When both are elevated, they can cause severe itching, sores, swelling under the skin and heart troubles. You should check with your doctor before taking calcium supplements.

H2-BLOCKERS

The ulcer medications commonly called H2-blockers are available as non-prescription medicines. Pepcid AC® is a brand name example of this type of drug. It's used to treat ulcers and prevent their return, relieve or prevent heartburn, acid indigestion and sour stomach. They work by decreasing the amount of acid produced by the stomach. Although they often work quickly to relieve symptoms, it may take several days for the medicines to have their full effect. These medications are generally safe, but can cause some people to have confusion or dizziness. These side effects are more common in older patients and patients with kidney or liver disease. This is because the kidneys and the liver are important in removing the drugs from the body. People who are allergic to H2-blockers may experience a rash or decreased kidney function.

The H2-blockers can have interactions with other drugs that you may be taking. They can increase the absorption of Cyclosporine, thereby increasing Cyclosporine levels in transplant patients. They may also have effects on asthma medicines, blood thinners and blood pressure medications. Consult your doctors before taking H2-blockers for indigestion or ulcer symptoms because of the important interactions with their other drugs. Furthermore, symptoms occurring for longer than two weeks may need further tests to ensure bleeding ulcers or infections of the stomach are not the cause.

ANTIHISTAMINE

Kidney patients frequently are advised to take antihistamines for symptoms of itching. Benadryl® is an example of an antihistamine. These medications are also used to relieve allergic symptoms. In addition, since Benadryl® may cause drowsiness as a side effect, it can be used to help you sleep. Unfortunately, Benadryl® is not very good at relieving itching for kidney

patients. Older patients are usually more sensitive to the effects of antihistamine. Confusion, difficult or painful urination, dizziness, drowsiness, feeling faint, or dryness of mouth, nose or throat, are side effects that can occur.

Benadryl® should be used cautiously if you're taking other medications known to cause drowsiness. Antihistamines will also add to the effects of alcohol, sedatives, tranquilizers, sleeping medicines, prescription pain medicines or narcotics. You shouldn't drive, use machines, or do anything that could be dangerous after taking Benadryl® or other antihistamines.



A Friendly Note: You're an important part of the healthcare team and treatment decision-making process. It is common to use non-prescription medications to treat certain conditions. Low cost and convenience are important reasons why you may choose over-the-counter medicines. However, you should respect these drugs as serious medicines, understand the risks and side effects of each medication, read the label information carefully and try not to use them too often. You should always inform your doctors of all non-prescription drugs you're taking.

HERBS

Herbal remedies can pose dangerous problems to dialysis and transplant patients. The long-term safety of herbs is unknown and they may pose safety risks for you.

Herbal therapies are becoming more popular as alternative treatments for various ailments including colds, nausea, constipation, insomnia and depression. While some herbs have shown promise, the lack of long-term studies regarding their overall health benefits leaves a lot to the unknown. Doctors don't know how these herbs are removed by the body. This becomes even more of a concern for kidney patients since it's not known how reduced kidney function, dialysis and various medications can impact herbs' effectiveness and safety.



A Friendly Note: Transplant recipients must be extremely cautious about herbs. Any product that claims to boost the immune system can cause rejection. Remember, you take immunosuppressive drugs to suppress your immune system so you won't reject the transplant. Many herbs counter this and can cause devastating effects.

In addition, there are no guarantees or minimal federal regulations to ensure that the purity or potency in the products you purchase are consistent, let alone safe. It's a "buyer beware" market. Use herbs with caution. It is probably best to not use herbs. Find out as much as you can regarding their safety and possible drug interactions, and most importantly, always talk with your

doctor and dietitian before starting any new products. Remember, if it sounds too good to be true...it probably is.

A Friendly Note: Please review Phase 2 for a detailed chart describing herbs and their effects on your health. 🌍



– FAMILY ISSUES –



A Friendly Note: Even though you've reached this phase in your care, your family is still a big part of your treatment. Over time, things in your life may change and you need to always understand how to communicate these changes and feelings with your family.

As discussed in the long-term health issues section, time has a way of marching on. As time continues, it's important for you to stop every now and then to think about what's changed for you and your family as you've been living with ESRD and its treatment. You may have had changes in the make up of your family. You may now be married, divorced, widowed or remarried. How have the changes in your personal life affected your ESRD and its treatment? As new people have come into your life, have you helped them to understand your disease and treatments? It can be overwhelming to consider all of these things, but if you break it down into smaller pieces, it can be much easier to think about.

How Do I Keep The Lines Of Communication Open With My Family?

It's important to talk regularly to your significant other and your family members about your disease, its treatments and how it affects everyone. Just because you've reached this point doesn't mean you no longer need to talk about ESRD. Kidney disease will always be a part of your life and a part of your family members' lives. Open communication is helpful in anyone's life - this isn't something only people with ESRD do. By keeping communication open, you and your loved ones can express frustrations, fears, concerns and joys. Below are a few suggestions to help you in this area.

Create a family tradition. Schedule a night each month when you sit down and talk about events, accomplishments, concerns or fears. This gives everyone a chance to say what's on his or her mind in a safe feeling environment. By making it a tradition, you're setting the tone that communication is important for your family.

Set the environment. Try not to seclude yourself when and if things don't go as planned. If you're going through a tough time, don't block everyone out. Make sure your family members know you want to keep the lines of communication open no matter what's going on in your life.

It's OK to involve a professional. Sometimes it's difficult to communicate. It may feel like no matter what you do it isn't working and tensions or fears are rising. It's OK and healthy to use the services of a counselor, therapist,

psychologist or psychiatrist. Many times it's helpful to have an "outsider" shed light on a situation.

I Have Family Support, But Why Do I Sometimes Still Feel Alone?

No matter how much support you have from family and friends, you may feel that you're alone with your ESRD. This is a natural feeling, especially when you've been treating your ESRD for several years. One of the difficult things about having long-term ESRD is that your life has been dramatically altered for years. Your feelings and how you incorporate the life-changes are unique to you. You may find that some of the people who become important in your life are other people with ESRD who have become long-term survivors. You may find that because they've had similar experiences to you, there's a bond that will develop between you. It will probably be helpful for you to develop relationships with other people who are experiencing the effects of ESRD. Just as with any relationship, there are risks in developing relationships at your treatment facility. The people you become close to may move, have complications or die. Although those friendships can be comforting, they can also be stressful.

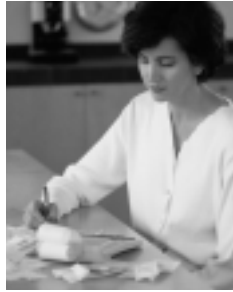
How Do I Tell Someone New In My Life About My ESRD?

This is always a difficult topic for people with ESRD, especially when a new relationship is involved. Don't be ashamed of your kidney failure. It's a part of you, but it doesn't define you. When you feel the time is right, use direct, sincere honesty. Pick a time and place where you won't have many distractions. Simply tell the other person there's something important you'd like to say. Then, explain you are on dialysis or have a transplant and what that means. Tell the person as much as you feel comfortable sharing. For some people, it's helpful to explain how they found out about their kidney failure, what they did to cope and how well they're doing now.

If this is a serious relationship, and the person is interested in learning more about your condition, give him or her copies of the AAKP Patient Plan[®] and any other material you have. It might also be helpful for the person to visit the AAKP Web Site at www.aakp.org and learn more about how people live healthy, normal lives with ESRD.

As you've learned with ESRD, the more you talk about it the easier it becomes. It's the same when you're telling someone special for the first time about your kidney failure. Once you open the lines of communication you'll feel more comfortable talking about it. Those open lines of communication will also make it easier for your partner to share his or her feelings. ●

– FINANCIAL ISSUES –



Another long-term health issue related to ESRD is finding payment for your medications. If you're on dialysis, most of your prescriptions are not covered by Medicare. If you have a transplant, your immunosuppressive coverage ends after a certain period of time. Your transplant social worker will probably be aware of financial programs and can help you find the programs that are best for you.

There are many programs available. High-risk health insurance is available in 28 states. There are also government-funded state programs such as Medicaid, state renal programs and specialized state assistance programs. There are also pharmacy patient assistance programs and associations or foundations that may provide a one-time emergency grant to help you through a transition period. In addition to these resources, medication assistance programs are available from drug manufacturers. Your social worker can help you to find these programs. You also have the AAKP available to provide you with a list of commonly used assistance programs. Please see the Appendix for assistance programs. ●

– CONCLUSION –

Just the Beginning . . .

A Friendly Note: This is the conclusion of the AAKP Patient Plan[®], but it's not the conclusion of your journey. ESRD is something we'll always have. We'll always deal with the diets, medications and treatments. However, I don't look down on that picture. It's a part of me, yes, but it doesn't define me. I'm still the person I was before I was diagnosed with kidney failure – there are just a few extra things I have to do for my health, that's all.



The following article was written by a remarkable woman who had both ESRD and diabetes. She became diabetic after her pregnancy with her third child. She later lost kidney function as a result of the diabetes. She knew the importance of learning all you can about your disease. She spent the majority of her life volunteering her time and spirit to help and educate other people with ESRD and diabetes. Mildred “Barry” Friedman passed away a few years ago, but her strength and determination continues to live in the articles she wrote for AAKP. This article sums up who we are. We're survivors and we have the power to continue moving forward. I hope you'll read this article and walk away with the message that Barry had intended, or maybe you'll find your own message.

I've seen a wheelchair dancing. Dancing magnificently. Dancing as part of Ben Vereen. As I watched the performance, he won my respect and admiration. I honor and acclaim survivors and this man fits the bill. A while ago he was severely injured in an accident. Nobody expected him to walk again. He walked. He walked earlier than anyone thought he would. He danced.

Bodies, as we know, don't always do what we want them to and Ben Vereen's knees gave way. The reason could be dancing on them too soon, or the old accident or just a life-time of cavorting. I don't think it matters because the result was two knee replacements. New joints require their owner to allow them to heal. So patients have to stay off them and use them gradually. Mr. Vereen, therefore, was in a wheelchair.

Now, I'm not a dancer or even an athlete but I know that certain people have total control of their body motions. For them, every little muscle movement is managed, not always consciously, but in an ordered way. Actions that work are natural and flow. Things that are contrived look that way. They look labored which can be either good or bad, but Mr. Vereen's gestures came across to me as, simply, right. The wheelchair had become an extension of his body, an inherent part of his person. It never occurred to me that a wheelchair could dance, but it can.

At the end of the show, the dancer disappeared backstage. A few minutes later he reappeared and walked slowly to center stage using two canes. He won't be kept down. He manages. He copes. He's a survivor.

And you too, are survivors. Whether you're the patient who has lived through end-stage renal disease (ESRD) or the loved one who lives next to it, you are survivors. Because you're reading this, I know you're intelligently involved with your disease, that you want to learn about it, that you want to go on.

ESRD is not a simple thing with which to live. Good days and bad days happen. Medications have to be managed. You have to keep an eye on your supply and take them when you should. Appointments have to be made and kept. Diabetics must keep records and do unpleasant things to themselves like sticking fingers to do blood sugars and injecting themselves if they take insulin. Dialysis patients must know where their next treatment will be or, for peritoneal dialysis patients, that the supplies they require are at hand. That's the physical part.

The emotional part is more subtle. We have complaints and problems but we deal with them. We may squeak a bit, but then it's the squeaky wheel that gets the grease, and sometimes we need grease. Look around you. Find out how many years that patient and this one have been on treatment. Called "chronic diseases," our illnesses don't get cured; don't go away. We learn to live with them and around them. What I mean is that other aspects of our lives get much of our energy and concentration. We live.

Other survivors are probably better known than we are. I think of Franklin D. Roosevelt who overcame the crippling effects of polio and rose to fill the highest position in the land. You may or may not be an FDR fan, but admiration for his successful efforts should be part of his image. During his presidency the world was a madhouse. War was declared. He traveled to meet other world leaders. His medical problems (and they were more than just paralysis) were not in the news reports. He just went on.

Julio Iglesias was a professional soccer player. There was a car accident. "You'll never walk again," the doctors said. Well, Mr. Iglesias crawled on the floor and learned to walk again, but he needed another career. Good decision. Now as a rich singer, he is also a survivor. He didn't give up.

Without sight and without hearing, the child Hellen Keller didn't give up either. Both senses were lost early in her life due to an illness, but with the aid of a great companion, she entered the world and conquered it. She learned to speak, to listen with her hands, to physically write. She was grumpy at times. We're all allowed a grump or two. Books were written. Trips were taken. Friends were made. She coped. She survived.

While in Denver for an AAKP convention, I went to the museum to see an exhibit on the Buffalo soldiers. Buffalo soldiers were black men who joined the army after the Civil War. They weren't allowed into white units. Not allowed to command themselves. They were governed by white officers. The record these soldiers achieved was excellent. I was impressed and couldn't get them out of my mind. Later, at the AAKP reception, I chose to sit at a table with a man who was alone. I told him of my afternoon. He looked at me with a quizzical expression on his face and said, "I am a Buffalo Soldier." We spoke and he told me of the black regiment he had been part of during World War II. Again, these men were not deemed worthy to command themselves and their officers were white. Their record was extraordinary. Now, this man had kidney disease. He had lived with the prejudices of his time and now was dealing with his illness. He is a survivor and I was honored to have had a conversation with him.

People go on. Ben Vereen used a wheelchair and so do competitors in the Transplant Olympics. What a zest for life they have. I think we have all known others who've just given up and wait around to die. Some aid the process. But then there's Christopher Reeve. Almost totally paralyzed from the neck down, he's resumed his career. Yes, I think he's still Superman and this time for real.

You are for real too. Life is lived. Sure medical problems take a lot of energy. I've attended many AAKP conventions and talked to a lot of people. There was usually a laugh, a smile, a joke and a reaching out for the solution to a problem, but seldom a complaint. It may be there. I've never heard it – the "Why me?" question.

As I meet you, or just know that you are out there, I'm happy to be one of you, part of the group. However, my mind is busy telling me that we should have a theme song. How about "I'm Still There" or maybe "My Way?" 🌍

"I am only one; but still I am one. I cannot do everything, but still I can do something; I will not refuse to do something I can do."

-Helen Keller



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

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Acute Rejection: A reaction that occurs in some patients after transplantation, generally occurring within the first several weeks or months and is usually reversible.

Amyloidosis: A long-term complication of dialysis caused by the buildup of a protein in the body known as B₂M.

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.

Cholesterol: An important lipid (fat-like substance) that is an essential nutrient necessary for repairing cell membranes, manufacturing vitamin D on the skin's surface, and creating hormones, such as estrogen and testosterone. High levels can be dangerous.

Chronic Rejection: A reaction that occurs in some patients after transplantation, generally over several years and is usually not reversible.

Creatinine: A waste product from meat protein in the diet and from the muscles of the body. The kidneys remove creatinine from the blood. *See also Creatinine Clearance.*

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

Electrolytes: Chemicals in the body fluids that result from the breakdown of salts, including sodium, potassium, magnesium and chloride. The kidneys control the amount of electrolytes in the body.

Emphysema: A disease, usually caused by smoking, in which the very small airways (bronchioles) of the lungs that join the microscopic sacs in the lungs (alveoli) are damaged and the walls lose elasticity. Pockets of dead air form in the injured areas impeding the ability to exhale and reducing normal respiratory function.

Epogen® (Epoetin Alfa): A medication that stimulates your bone marrow to produce red blood cells. The medication acts the same way as the natural human hormone erythropoietin. When someone experiences kidney failure, less erythropoietin than normal can be made.

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

GLOSSARY

Gout: A type of arthritis caused by chronic hyperuricemia — a long-lasting, abnormally high concentration of uric acid in the blood.

Hematocrit: The amount of red blood cells in the blood stream. The target range for ESRD patients is 33-36 percent.

Hypertonic Saline: A concentrated saline used to increase blood flow to the muscles by pulling fluids into the blood vessels and other tissues. Helps to stop muscle cramps during dialysis.

Hypoglycemia: A condition of abnormally low blood sugar (glucose). Insulin shock is a term for extensive hypoglycemia that results in unconsciousness.

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

Intravenous (IV): The process of receiving medication through an IV line.

Nonsteroidal Anti-Inflammatory Drugs (NAIDs): Medications which decrease inflammation by inhibiting an enzyme that is required to form chemicals that cause an inflammatory response to an injury.

Parathyroid Glands: Most commonly exist as four glands near (under) the thyroid gland in the front of the neck. The important product of the parathyroid glands is parathyroid hormone (PTH).

Parathyroid Hormone (PTH): A hormone made by the parathyroid glands that keeps blood calcium and phosphate at levels necessary for proper function.

Renal Osteodystrophy: Bone disease common to kidney patients.

APPENDIX

– JOURNALING MY JOURNEY –

It can be rewarding to keep a journal on your thoughts and experiences over the years. When you reread it, your written words can be powerful motivation for future experiences. You may be surprised by how far your journey has taken you. These questions may help you in writing your thoughts.

1. What skills have I learned while on dialysis that have helped me, my family, other patients?
2. Write about a positive word of encouragement I shared with a fellow patient, my family, myself.
3. Because I have been on dialysis _____ # of years, I have been able to _____.
 (List the new births, weddings, anniversaries, graduations, confirmations, communions, New Year & Christmas celebrations, hankie celebrations, Thanksgiving, world series, super bowls, Olympics, etc.)
4. Many say dialysis is a second chance at life. What am I doing different now than when I was diagnosed with ESRD?
5. Before dialysis, my dream was to be/do _____. Now that I am on dialysis I have/am doing _____.
6. Did I go one step further today than yesterday? Will I do it again tomorrow? Why?
7. Who did I bring a smile to today? Why did I do it?
8. Have I said thank you to those who have loved me and continue to love me?
9. Have I taken the time to teach someone why I feel the way I do, so he or she can learn that life is worth living
10. Did I use my diagnosis to offend someone today? Why did I do this? Was I angry or sad? Did I apologize?
11. How can I use my anger over my diagnosis to help me find hope?
12. What new hobby can I learn that I can do while on dialysis?
13. How was I kind to myself today?
14. List five things I'm grateful for today.

– AAKP RESOURCES –

As a member of AAKP, there are several AAKP resources available to you. Below is a description of AAKP programs. Members are updated when new programs are created.

aakpRENALIFE

This is the official magazine of AAKP. The contents address concerns of the patient which include medical procedures, real life experiences, pediatric issues and legislative results. It is published six times a year.

AAKP Renal Flash

The second Wednesday of each month, AAKP transmits an electronic newsletter using the technology of the Internet. It provides valuable information to patients, family members and professionals about living with kidney disease, legislative information and AAKP activities. More information about the *AAKP Renal Flash* is posted on the AAKP web site at www.aakp.org.

The American With Disabilities Act

This brochure discusses the Americans with Disabilities Act of 1990 and how it applies to end-stage renal disease (ESRD) patients who are employed. It provides phone numbers for additional assistance.

Na-K-Phos Counter

The first in the dietary series, this 14-page pocket-size brochure provides sodium, potassium and phosphorus counts for various types of food. It is available in both English and Spanish.

Protein and Calories Counter

The second in the dietary series, this pocket-size brochure provides the protein and calorie values for various types of food. It is available in both English and Spanish.

AAKP Hemodialysis Advisory

This brochure discusses the importance of enough dialysis, how to calculate URR and Kt/V, the importance of proper nutrition, how blood should be drawn and questions patients should ask their doctor about their dialysis.

AAKP Peritoneal Dialysis Advisory

This brochure, similar to the Hemodialysis Advisory, discusses the importance of enough dialysis, the significance of proper nutrition, how often the residual function and peritoneal membrane functions should be measured, the benefits of a well-functioning catheter and questions patients should ask their doctor about their dialysis.

– AAKP RESOURCES –

The Iron Story

This brochure discusses the importance of IV iron usage in addition to Epoetin to keep your blood count high and prevent anemia. It is available in both English and Spanish.

Why Kidneys Fail

This book discusses the different treatment options available to ESRD patients.

Peritoneal Dialysis...Is it the best choice for me?

This book discusses the peritoneal dialysis process, required training and any lifestyle changes. It also has a glossary of medical terms for easy reference.

New Life, New Hope:**A Book for Families and Friends of Renal Patients**

This resource book was written to address the concerns and interests of the family members and friends of the renal patient.

www.aakp.org

AAKP's web site displays several materials and brochures. The site is also linked to numerous sites, allowing for easy access to topics of interest for renal patients. The AAKP web site address is www.aakp.org.

AAKP Patient Plan®

An educational program developed to provide kidney patients with a guide to their care as they progress in their treatment of kidney disease. The Plan is developed into four distinct phases and includes information on treatment options, diet, traveling, medications and many other important topics.

AAKP Annual Convention

AAKP's Annual Convention is a four-day event featuring seminars addressing treatment options, health care, psychological and social concerns and all aspects of living with kidney disease for patients and their families.

AAKP has numerous back articles of aakpRENALIFE available. They address such topics as dialysis, transplantation, social issues and family matters. Please call the national office at (800) 749-2257 or e-mail AAKPnat@aol.com to request a complimentary copy of any of our brochures and articles or to inquire about a specific topic of interest. AAKP's web site also displays useful information for the renal patient.

– FINANCIAL RESOURCES –

There are various programs available for kidney patients. Some programs focus on emergency aid, while others are ongoing. Your social worker can provide you with local programs available in our city or state.

American Kidney Fund

800-638-8299

www.akfinc.org

Health Insurance Portability Act

www.hcfa.gov/regs/hipaacer

Listing of Federal Programs

www.health.gov

Medicaid Information

www.hcfa.gov/medicaid/mcaicnsm

National Transplant Assistance Program

800-642-8399

www.transplantfund.org

Novartis Patient Assistance

888-455-6655

PROGRAF/Fujisawa Patients

Assistant Program

800-477-6472

Reimbursement Hotline for EPOGEN®

800-272-9376

State Childrens Health Insurance Programs

www.hcfa.gov/init/children

U.S. State and Local Gateway Family & Children Funding

www.hhs.gov/families/funding

KNOWING WHAT TO KNOW

A CHECKLIST FOR A LONG & HEALTHY LIFE

I participate in some form of exercise at least three times per week.

If my center re-uses dialyzers, I check the dialyzer before each treatment to ensure my name is on it.

I stay for my entire prescribed treatment if I'm on hemodialysis or I do all of my exchanges if I'm on peritoneal dialysis.

I know the names of all my medicines, what they're for and when to take them.

I take my blood pressure at home regularly and work to keep it below 140/90.

I see a dermatologist regularly and always use a sunscreen.

Before taking any over-the-counter medicines, including herbs and vitamins, I check with my nephrologist.

My family knows who to contact in an emergency.

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

- ✓ How do I know if I have bone disease?
- ✓ I am interested in changing my treatment options. What options are available to me?
- ✓ As a woman, I am interested in starting a family. What must I consider with regard to my healthcare?
- ✓ What is my cholesterol level?
- ✓ What over-the-counter medicines are safe for me?
- ✓ Should I share my living will with my healthcare team?
- ✓ Has my dry weight changed and if so how is it affecting my dialysis?
- ✓ Will being on dialysis for many years cause other medical problems?
- ✓ How do I help my family prevent burnout in their assistance with my healthcare?
- ✓ If my disease is hereditary, how can I help my family members seek and receive the proper information?

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