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CHRONIC KIDNEY DISEASE

Family Focus

The Renal Community's Newspaper

VOLUME 11 NUMBER 2

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WHAT DOES CHRONIC KIDNEY
DISEASE MEAN TO YOU?



What You Should Know and Do About Chronic Kidney Disease

By Theodore Steinman, MD

About 260,000 people in the U.S. are receiving dialysis treatment for kidney failure. Probably at least 10 times this number have kidney disease that will need dialysis during their lifetime. In addition, about 13-15 million Americans have some decrease in kidney function.

Early treatment can prevent or slow the progress of kidney disease and its complications. Learn how kidney disease is diagnosed and treated so that you can work with your doctor to stay as healthy as possible.

DIAGNOSIS OF KIDNEY DISEASE

About 10 to 14 percent of family members of people with chronic kidney disease are at risk for kidney disease. This number is based on results from screening a large population for abnormal kidney function, high blood pressure and protein in the urine. The people most likely to have abnormal findings were those in whom a family member had known chronic kidney disease. If there is no family history of kidney disease, then the likelihood of finding one of the above problems falls to one to two percent when screening a large "healthy" group. Therefore, if your family members are at risk, they should know their:

1) Blood creatinine level –a routine test of kidney function that is done using a blood sample. Creatinine is a chemical in the blood that comes from the normal functioning of muscle in the body. The kidney is the only organ that gets rid of this chemical. As kidney function gets worse, the amount of creatinine excreted in the urine goes down and the levels in the blood go up. Ask your doctor what yours is and what percent of normal kidney function you have

2) Urine protein –normal is negative, meaning that there is no protein in the urine. A positive test is abnormal and further testing (such as additional blood studies, collection of a 24 hour urine and maybe a kidney biopsy) is needed because this can be a sign of chronic kidney disease.

3) Blood pressure – "normal" is about 120/80. High blood pressure (hypertension) is a level higher than 140/90. People with kidney disease and even those with normal kidney function should have blood pressure as close to normal as possible because high blood pressure makes kidney function worse.

TREATMENT OF EARLY KIDNEY DISEASE

Early treatment is better. Studies have shown that lowering high blood pressure, decreasing the amount of protein in the urine and lowering high cholesterol levels in the blood can slow the decrease in kidney function in those people who have abnormal

kidney function. People who are treated early do better than those who are treated late in the course of their disease. You also have to take part in your care to do well. Below are some things that you can do to improve your overall health and, hopefully, your quality of life.



- 1) **Change how you do things:**
 - **Weight loss:** Consider speaking with a dietitian about a plan to lose weight if you weigh more than you should for your sex, age and height. Your doctor can tell you what your ideal weight should be.
 - **Regular exercise:** Plan to do an exercise program at least four times per week for 20 to 30 minutes per session. Your exercise regimen can range from such things as walking, using a treadmill or working out with weights to playing basketball.
 - **Diet:** Your blood pressure can fall just by eating a diet that doesn't contain a lot of salt. Some people have blood pressure that increases more than others due to

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FROM THE EDITOR



Karren King

Chronic kidney disease..... what do these words really mean? For years you may have heard other words used to describe various stages of kidney disease. Many of us often used End Stage Renal Disease, or ESRD, to describe the point at which a person required either dialysis or a kidney transplant to remain alive. While the use of the words "end stage" simply referred to the fact that the kidney had reached a stage where it no longer functioned well enough to sustain life, the words used sounded much more ominous. When attempting to describe the population of individuals who had kidney disease, eventually requiring dialysis or transplantation, the terms pre-ESRD or pre-dialysis were typically

used. However, when someone used these words, what exactly did it mean? Was the individual in question at the very early stages of impairment or was the person close to requiring dialysis? As you know, that is a very wide range. Historically, less attention was paid to the segment of the population who had early signs of kidney disease. Greater attention was paid to treating and educating those who would soon experience kidney failure and need to make a treatment choice.

The National Kidney Foundation (NKF) set about attempting to simplify the terminology used and to make it more universal. Thus, the words chronic kidney disease have been clarified to encompass all stages of kidney disease, ranging from those who do not yet have problems with their kidney's function to those who do have some level of kidney impairment (to those who require dialysis or a kidney transplant). The words kidney failure are being suggested to replace the use of the term ESRD. The first new set of clinical practice guidelines under the NKF's Kidney Disease Outcomes Quality Initiative

(K/DOQI), Chronic Kidney Disease: Education, Classification and Stratification, not only aids us in clarifying the terminology used, it goes a step further by establishing important medical criteria to aid in differentiating the five stages of chronic kidney disease.

While this issue is devoted to chronic kidney disease (CKD), from beginning diagnosis to requiring dialysis or transplantation, much of the content focuses on the new K/DOQI guidelines. I have great confidence that these guidelines will aid tremendously in not only assuring that we all "are on the same page" with the language we use, but more importantly, as with the NKF guidelines that came before them, that the care provided to all individuals who have CKD will be greatly enhanced because of them.

For you, the reader, the information provided in this, and every issue of *Family Focus*, does no good if you simply read it and file it away. Don't be passive readers or recipients of care! Take this information and use it. Ask questions of your doctors and other health care providers, make a lifestyle change that will improve your health, encourage your family members to be evaluated for signs of kidney disease. Make *Family Focus* make a difference in your life! 

Karren King, MSW, ACSW, LCSW
For the Editorial Board



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What You Should Know and Do About Kidney Disease

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high salt foods. Work with a dietitian to plan a low salt diet.

- **Alcohol:** Drinking alcoholic beverages can make your blood pressure high. Men should have no more than two small drinks a day and women one drink daily.
- **Smoking:** Cutting down is not okay. You must stop completely. Smoking causes a narrowing of your blood vessels that will cause a higher blood pressure and less blood flow to your kidneys. People who smoke have a much greater chance of developing heart and lung disease, and these diseases make treating kidney disease much more difficult.



2) **Medications:** Discuss blood pressure medicines with your doctor and find out what works best for you. If you develop side effects such as dizziness, nausea, leg swelling, headaches or fatigue from your specific high blood pressure medicine, it is important that you don't simply stop taking it. Discuss the problem with your doctor, who can suggest alternative treatment.

3) **Check your blood pressure regularly:** Ask your doctor or nurse to teach you how to take your blood pressure. Then take it at home, write it down and discuss it with your doctor. Many blood pressure readings over time, including some taken outside of the doctor's office, will tell your doctor what medicines you need in what dose to control your blood pressure.

4) **Protein in the urine cannot only be a sign of chronic kidney disease;** it can cause kidney disease to get worse. Ask your doctor to check your urine for protein. Some medicines, angiotensin converting enzyme inhibitors (ACEI) and angiotensin receptor blockers (ARB), have been shown to decrease protein in the urine and can slow progress of kidney disease in some people.

5) **Blood cholesterol and other lipids (fats) in the blood may make kidney disease worse and cause heart disease.** This should be treated with a low fat diet and medication for cholesterol. The goal should be under 200 and for triglycerides it should be under 150. You should know your numbers for "good" cholesterol (HDL cholesterol, which should be greater than 60) and "bad" cholesterol (LDL cholesterol, which should be less than 120), and what they mean.

6) **Blood sugar** – If you have diabetes (also known as sugar diabetes), it is important for your blood sugar to be as close to normal as possible. This usually means sticking to a strict diet, controlling your weight and taking pills or using insulin. You need to work closely with your health care team to help make sure your blood sugar is not too low or too high. Diabetes is the most common cause of kidney failure and early treatment can slow down the progress of kidney disease and help avoid eye disease and nerve complications, which can result from diabetes.

Your kidney disease might get worse even with good care and the right medicines. Although the treatment can not always stop kidney failure, it is important to know that treatment may slow the kidney disease and delay the need for dialysis or transplantation.

COMPLICATIONS OF POOR KIDNEY FUNCTION

1) **Bone disease** – Calcium and phosphorous are minerals found in the body. The kidney helps keep levels normal and bones strong. The right diet and medicine can keep the levels in normal range and decrease the bone disease that can happen with kidney failure.

2) **Acid** - As kidneys fail, acid made by the body and that comes from food is not passed in the urine. The increase in acid levels, called metabolic acidosis, can affect your heart and appetite and make bone disease worse. Treatment with bicarbonate can make acid levels normal.

3) **Nutrition** – Malnutrition or undernourishment typically occurs when kidney function falls below 25 percent of normal. Eating the right foods can help stop major problems

associated with not keeping body protein at normal levels. Your dietitian can help you select these foods.

4) **Anemia** – Anemia occurs when your red blood cells are in short supply. Red blood cells carry oxygen from your lungs to all your organs and tissues, providing energy for your daily activities. When diseased kidneys no longer make enough of a hormone that tells your bone marrow to make more red blood cells, anemia can result. Treatment may include a special diet, supplements and medication.

WHEN KIDNEYS FAIL

Making an access (fistula) to your blood vessels should be done at least six months before you need dialysis so that it is ready when you need it. A fistula is the preferred access because it is associated with fewer complications from clotting and infection. If you do not have an access in your arm when it is time to start dialysis, you may need to be in the hospital and have a line for dialysis placed in a blood vessel in your neck. Patients who have to start dialysis as an emergency usually have more difficulty at least in the beginning than those who have been able to plan ahead for access placement. If at all possible, it is important for you to discuss the placement of your dialysis access with your doctor before you actually need dialysis. Sometimes an AV fistula does not "mature." That is, the blood vessels do not get large enough or strong enough to use. Or the surgeon may examine the blood vessels and decide that an AV fistula doesn't work. The surgeon may place a "graft" made of man-made material, a hollow artificial blood vessel, that can be used for dialysis.

In summary, treatment of chronic kidney disease may stop or slow the speed at which kidneys get worse. You should know what treatment is possible and talk with your doctor. A kidney doctor can help your regular doctor take care of your special needs. 📌

Dr. Steinman is a professor of medicine at Harvard Medical School and the director of the dialysis unit at Beth Israel Deaconess Medical Center in Boston. He is also a member of the Kidney Disease Outcomes Quality Initiative (K/DOQI) Medical Advisory Board.



Good Nutrition

The Importance of Healthy Eating in Chronic Kidney Disease

By Kathy Schiro Harvey, MS, RD, CSR

According to the recent National Kidney Foundation (NKF) Kidney Disease Outcomes Quality Initiative (K/DOQI) Chronic Kidney Disease (CKD) Workgroup, over 13-15 million Americans have reduced kidney function and over eight million of these have CKD. The most important health risk for those with CKD is the development of kidney failure and likely progression to the need for dialysis. This is despite the fact that CKD itself is much more common than kidney failure and has a much greater impact on the health and well being of more Americans. To address this problem, the K/DOQI CKD Workgroup has written guidelines identifying the risks associated with the loss of kidney function, which include the risks of poor nutrition.

PROTEIN ENERGY MALNUTRITION

Protein Energy Malnutrition develops in children and adults whose intake of protein and calories is not adequate for the body's needs, and those who have trouble absorbing vital nutrients or converting them to energy needed for healthy tissue growth and organ function. In fact one of the hallmarks of kidney failure is anorexia, or loss of appetite and low food intake. Research shows that when your glomerular filtration rate, or GFR, (a measurement of kidney function which can be calculated from a blood test)—drops below 60 ml/min, you may begin to eat less food. Why this occurs is unclear—perhaps it is your body's way of limiting the buildup of toxic waste products that come from food. Or maybe you eat less because you have other medical problems that make you feel ill, such as diabetes, heart disease or infections. Whatever the reason, the outcome of eating fewer calories and less protein is a higher risk of developing protein energy malnutrition.

As food intake declines, you may show signs of malnutrition. These may include less body fat and muscle, usually seen as a drop in your weight or less tissue around your eyes, shoulders, hands and arms. Blood tests can show that your albumin,

prealbumin and transferrin levels are lower than normal. These are protein substances in the blood, which build healthy tissues, carry iron and also measure nutrition health. Food records can show that you are eating less protein and fewer calories than you need and that your intake of fats, carbohydrates, minerals and vitamins is out of balance.

When you have protein energy malnutrition you have a greater chance of getting ill, being hospitalized and having health complications, such as fatigue, anemia and infections. Studies also show that when you have protein energy malnutrition you may also have more inflammation (your body tissue's response to injury) than when you are well nourished. This may be related to heart disease.



NUTRITION ASSESSMENT

The K/DOQI CKD Workgroup recommends that people with CKD receive a nutrition assessment after their GFR falls below 60 ml/min. This assessment may include a referral to a dietitian who has special training in nutrition in kidney diseases. Part of the nutrition assessment should include measuring your weight and comparing it to standard healthy weight tables. Your blood tests should include a measurement of albumin, which is a marker of nutrition and protein health. The nutrition assessment should also include a review of your usual food intake or a dietary interview, to measure the amount of calories and protein

you eat and compare it to your recommended level.

The renal dietitian will make diet recommendations based on your nutrition assessment. It is most important for people with CKD to eat enough calories to stay at a healthy weight. This may mean you need to add extra foods to your meal plan or adjust the type of foods you eat, depending on your weight goals. In addition, the dietitian will determine your protein needs, based on your level of kidney function and overall health. It is important that you eat just the right amount of protein to prevent malnutrition but also to limit toxic wastes, which can affect your appetite. Besides calories and protein, the renal dietitian can address other areas of your diet that may need adjustment to maintain good health, such as the type and amount of fats, minerals and vitamins you eat. If you have diabetes, the dietitian will recommend the best meal plan for you to maintain healthy blood sugar levels and may refer you to a diabetes educator for follow-up.

If you have CKD you are at risk for progression to kidney failure, but there are still steps you can take to regain and maintain your health. It is important that you learn as much as you can about your kidney disease, stay in close contact with your health care team and take an active role in your care. Learning about the nutrition risks of CKD and working with a renal dietitian to plan healthy meals can be your first step in preventing protein energy malnutrition. 

REFERENCE

National Kidney Foundation *K/DOQI Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification*. Am J Kid Dis. 39(2):S17-S31, 2002 Suppl 1

Kathy Schiro Harvey has been a practicing renal dietitian for over 22 years and is a member of the NKF K/DOQI Chronic Kidney Disease Workgroup. Kathy is chief renal dietitian at Puget Sound Kidney Centers in Mountlake Terrace, Washington.



Exercise to Help You Manage Your Health

By Tiffany Shubert, MS, PT

Remember to check with your physician before embarking on a new exercise regimen.

Starting dialysis changes your life. Suddenly, everything you do has some effect on how you feel. There are many new restrictions in your life, what you eat, where you go, what time you have to do things. Many people stop doing activities they enjoy when they start dialysis, and often, even when they feel better, they forget to start doing the things that they like to do. Once your health is stable on dialysis, it is important to remember that your life can begin again, and there are things you can do physically and emotionally to feel better. Exercise is an activity that you can return to when you are stable on dialysis. Many folks on dialysis know that they want to start exercising, but they are not sure how to begin. Just like the diet you follow on dialysis, there are some do's and don'ts with exercising. This article will tell you what is known so far about exercise and dialysis and will give you some guidelines for starting your own exercise program.



Doctors and health care providers often now ask questions about how much or how little people on dialysis exercise. There are many tests that have been developed to determine how well your heart and lungs work and to assess the strength in your arms and legs. When people with chronic kidney disease are tested, their fitness scores are lower than those who do not have kidney disease. Low fitness scores also suggest that people with kidney disease may have a much harder time doing basic activities such as cooking, cleaning and other things that we all

do every day. They might find it harder to get out for social and recreational activities. What is even worse is that low fitness performance scores have been related to greater chances of death. People with chronic kidney disease become inactive and weak for many reasons: anemia, sickness and getting overloaded with fluid. There are many challenges for dialysis patients to starting an exercise program, but it is known that people who become inactive experience even more problems with other parts of their bodies, including muscles, heart, lungs, digestion and nervous system.

We do know that people of all ages benefit from regular exercise, and even a very small increase in activity can result in better health and quality of life. Researchers are learning about people on dialysis and discovering that they can exercise their heart (aerobic) and their muscles (strength training) to improve their physical performance, to help manage depression and to make daily activities easier to accomplish. Common sense leads one to think that people with chronic kidney disease who exercise will have a better chance of living longer, healthier lives.

The first step is usually the hardest. People are afraid of starting a new activity. You don't know how it may feel: it might be too hard, it might not feel good and you might sweat! The checklist below will give you information so that starting an exercise program may not be so scary. Fill it out. Remember you are doing this for your health, and go for it!

Decide what you would like to do: walk, cycle, dance or go up your stairs. Maybe your unit offers a program like stationary cycling or strength training either before or during dialysis.

I would like to _____

Talk to your doctor. The biggest risk for those with chronic kidney disease is a problem with your heart. Heart disease often accompanies kidney failure. Most problems that affect your heart, such as high blood pressure, blood sugar management and high cholesterol, improve with exercise. But your doctor will have

guidelines for how much you can safely do.

My doctor has told me I can safely (fill in the activity) _____ for _____ minutes.

Choose which days and how long you would like to exercise – and be consistent.

I want to exercise 3 days a week:
_____, _____,
_____.

I want to exercise for _____ minutes/session.

Ask for your doctor to arrange for you to talk with a physical therapist or an exercise physiologist about a program that will be safe for your muscles. If you start out slowly, you should have only minor muscle soreness. Another risk if you are on dialysis is injury to bones or joints. You should be able to protect your body from injury by starting out slow.

I am meeting with a physical therapist/exercise physiologist on _____ to talk about a program.

All exercise programs should have a long warm-up and cool-down period, which will also protect you from injury.

A modest increase in daily activity and a minimum of 30 minutes of aerobic exercise three times a week will result in better health. However, try not to push yourself, know your own limits.

The goal is to have fun! It is also to prevent muscle weakness and get stronger.

I will smile and laugh while exercising!!!!

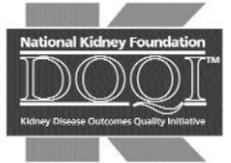
If you have pain or discomfort during or after exercise, stop and talk to your doctor. Do not start again until you feel okay – remember, you are in control!

1. *Warm Up:* Time for your heart and muscles to wake up for exercise!

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K/DOQI: What Is It and Why Do We Need It?

By L. G. Hunsicker, MD



Because there are differences in the way that kidney doctors take care of those on dialysis around the United States, in 1997 the National Kidney Foundation (NKF) began a program, the Dialysis Outcomes Quality Initiative, or DOQI, to recommend to kidney doctors the ways of taking care of people on dialysis that had the best results for the patients. This has been very successful over the past five years. For example, the chance that a person on dialysis will die became much lower as kidney doctors started to follow these "best practice" or "best ways of doing things" guidelines. Now the NKF has started another major new program, the Kidney Disease Outcomes Quality Initiative, or K/DOQI. What is this all about? Why do we need a new program like this?

“Studies have shown that one in every nine Americans has kidney disease. In addition, another one in five Americans are at risk for kidney disease because of high blood pressure, diabetes, older age or their race or ethnic background.”

Since 1997, we have learned that kidney disease is very common. Studies have shown that one in every nine Americans has kidney disease. In addition, another one in five Americans is at risk for kidney disease because of high blood pressure, diabetes, older age or their race or ethnic background. Most of the people with kidney disease or those at risk for developing kidney disease don't even know it. People with kidney disease not only have a greater chance of kidney failure requiring dialysis or a kidney transplant; they are also at a much higher risk for heart attacks, heart failure and strokes. Over the past 10 years we have learned of several ways to diagnose and treat

people to decrease the chance of developing kidney disease or to slow its progress, and we have learned how to lower the risks of heart disease and strokes, but all health care providers are not yet using these methods. Clearly, it is important for people to know about kidney disease and that there are ways to prevent it or slow its progress and to treat it properly at its earliest stages.

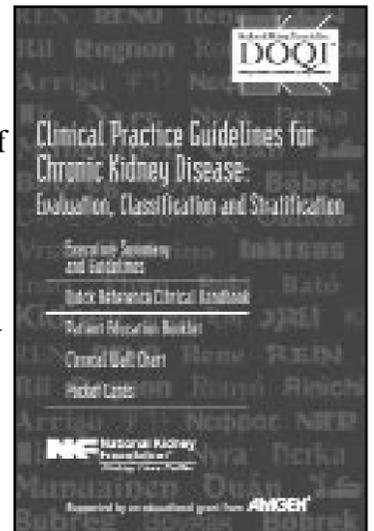
The large numbers of Americans at risk make it impossible for all of them to see a kidney doctor about it. Therefore, the first new clinical practice guidelines developed under K/DOQI, Chronic Kidney Disease: Evaluation, Classification, and Stratification—a program designed to help all health care providers recognize and diagnose kidney disease early and to provide the best care for people as early as possible when treatment has the most benefit—is now available. These K/DOQI guidelines say that two simple tests should be done on people, along with a medical history and measurement of blood pressure. The first of these tests requires only a sample of urine to look for proteinuria, the second requires only a single simple blood test to check your serum creatine level.

With this information, the doctor can determine if a person has kidney disease, and if so, identify which of five categories of seriousness the individual fits into: kidney disease present but kidney function normal; kidney disease present and kidney function decreased slightly, moderately, or severely; or kidney failure requiring dialysis or transplantation. In addition, these K/DOQI guidelines suggest, for each level of kidney disease, a series of other tests and treatments that doctors and patients should consider to slow the progress of kidney disease, to prevent some of the complications of kidney disease that begin to appear very early and to lower the risks of heart disease and stroke.

These guidelines were published in February 2002 in the *American Journal of Kidney Diseases*, presented

at medical meetings and made available over the Internet so that all health care workers can become familiar with them and use them as needed to take care of their patients. The NKF wants all health care professionals to give appropriate care to those people with chronic kidney disease, to start their patients' treatments early and to know when to send someone to a kidney disease doctor.

These K/DOQI guidelines are the first part of a four-part NKF plan to attack the problem of chronic kidney disease. The other parts of the plan are 2) a public relations



campaign to reach Americans at increased risk of kidney disease to encourage them to be tested routinely, 3) the Kidney Early Evaluation Program (KEEP) aimed at identifying directly those with chronic kidney disease or at high risk of developing it and referring them to their doctors and 4) an expanded education program to tell health care professionals about these K/DOQI guidelines. We believe that the K/DOQI guidelines, together with the other parts of this four part plan, will result in improvements in the care for those individuals with chronic kidney disease that are as great as those that resulted from the DOQI program that came before K/DOQI. And that is good news for all people with kidney disease! **FF**

Dr. Hunsicker is a professor of internal medicine at the University of Iowa College of Medicine where he is also the medical director of organ transplantation.



PATIENT AND FAMILY CORNER

Chronic Kidney Disease—Is It a Death Sentence?

By Dale Ester

I authored the Patient and Family Council article this issue because the topic of chronic kidney disease (CKD) really hits close to home for me. The type of support I find myself providing to others to learn to live with enthusiasm, even though their lives may be changing, is pertinent for those with kidney disease regardless of the degree of severity. Sharing ideas and feelings helps individuals to fully realize that their lives are still meaningful even after being diagnosed with CKD. Daily schedules may have to change and priorities will most likely have to be revised differently than before since CKD can be demanding, but life and the spirit to live it well are still worthy of your best personal effort.

“It seems primitive today. How times have changed in a mere three decades! But history lessons should never be forgotten.”

You may be surprised to learn that in the 1960's the treatment of dialysis for kidney failure was not funded by any government programs. There was no easy access to dialysis machines so everyone who needed dialysis could not be dialyzed. To deal with the problem of having too many people who needed dialysis to live and too few machines and staff to dialyze them, selection committees were formed to decide who would be "suitable" to dialyze. Most committees used a person's age, intelligence, potential to be employed, finances, tax paying status, ability to cooperate with the treatment, a psychiatric evaluation and a person's medical condition to help them determine who to accept. Typically excluded were those who had other major illnesses such as diabetes, which is now the most common cause of kidney failure.

You should realize that the committee that made this decision of who would live and die did so based partly upon their perception of the patients' value and worth to society. Typically those people selected for dialysis were under age 45, thought to be stable physically and mentally and employed.¹ Rather than shout when the committee chose to grant dialysis treatment to the patient with kidney disease failure, the tears that were seen were often from the joy of realizing that death due to a lack of dialysis was not forthcoming.

It seems primitive today. How times have changed in a mere three decades! But history lessons should never be forgotten.

Now compare the selection committee process to the current situation and try to imagine: Why do some today view dialysis as a death sentence when patients who need dialysis treatment are provided the opportunity to live well? These thoughts, while understandable, are sometimes uninformed and misguided. CKD is not a death sentence. Nor should dialysis treatment with any modality be considered anything less than the best and most effective way to adapt and compromise to changing conditions of simply growing older and living longer.

CKD may create despair, but if you seek to discover the good in the diagnosis, the despair could be replaced with gratitude by understanding just how far dialysis and support treatment for kidney failure have come in such a short time. Here's to another 30 years of positive changes in this medical field. We've come a long way!

Life can still be good. Attitude plays an important role in how you judge your current condition, your physical well-being and yes, even how you interact in daily events. To be successful and enjoy the opportunities dialysis has to offer you by giving you life, remember to be eager

to manage your CKD as carefully as possible, control your diet and fluid restrictions (when needed), and listen closely to the health care team. Success is all about you!

“How you react with CKD and its treatment options is up to you. Life is what you dream of it—make it great!”

Dialysis keeps you alive. If you consider CKD and dialysis as a death sentence diagnosis, then any lack of control will diminish the personal improvement you could achieve. No longer must a committee render a decision based upon your value to society and family because almost everyone now is treated as worthy and entitled to treatment as part of being a legal resident of the United States. Be proud of your heritage!

How you react with CKD and its treatment options is up to you. Life is what you dream of it—make it great!

¹ Price C: Is It Time Again for Patient Selection Criteria? *Nephrology News & Issues*, February 2002, pp. 18-20. 

Are you a patient, family member or a friend of someone affected by kidney disease or transplantation?

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Living Long and Well with Chronic Kidney Disease: Guideline 12: Functioning and Well-Being

By Beth Witten, MSW, ACSW, LSCW

The National Kidney Foundation (NKF) recently finished a two-year project that resulted in published guidelines for chronic kidney disease (CKD) for doctors and other health professionals. These guidelines are now available to help doctors identify those who are at increased risk of developing kidney disease, and treat those with CKD sooner.

The guidelines answer these questions:

- What are the stages of kidney disease?
- How many people fit in each stage of kidney disease?
- How does aging affect kidney function?
- What makes people at higher risk for developing kidney disease?
- What is the best way to find out if the kidneys are damaged?
- How can doctors identify and treat those who have CKD sooner?
- How can doctors treat such complications of CKD in adults as high blood pressure, anemia, poor nutrition, bone disease, nerve damage and problems with physical, emotional, social or vocational functioning?
- How can we educate patients, professionals and the public about CKD to prevent more people from developing it or to keep those with CKD from getting worse?

Doctors and staff want to know what causes CKD, how to diagnose it, what stage of kidney disease a person is in and what problems develop because of it. However, someone with kidney disease may have different questions. How will kidney disease affect my quality of life over time? What symptoms might I look for and when? As I have more symptoms, how will I feel about my health and life? Will I be able to work, keep house, enjoy leisure activities and visit with my friends and family? How will kidney disease affect my mood? The NKF wanted to answer all of these questions in its new guidelines. Guideline 12—Association of Level of GFR with Indices of Functioning and

Well-Being—focuses on changes in patients' quality of life over the course of kidney disease.

Many researchers have studied how kidney failure affects functioning and well-being. Only a few researchers have studied how earlier stages of kidney disease affect functioning and well-being. In the past, researchers asked health care professionals how they believed patients functioned and coped with kidney disease. When researchers found that patients rated themselves differently from how these professionals rated them, researchers began to put more weight on what patients reported.

The goal of this guideline is to help doctors and other care givers identify problems earlier, treat them more effectively and help patients live happier, healthier, more active and more productive lives.

This guideline is based on what researchers learned from patients with CKD about how worsening kidney function affects functioning and well-being. It focuses on:

- Symptoms and what the person thinks about his or her health
- Physical functioning
- Depression and mental health
- Work, home management and recreation
- Social functioning.

In study after study, as kidney function worsened, patients reported more problems in all of these areas. Patients reported changes long before they had kidney failure.

Other factors besides worsening kidney disease can affect functioning and well-being. Income, education and

health conditions, such as diabetes, hypertension, anemia, bone disease and neuropathy (nerve damage), can also harm functioning and well-being. Doctors need to know who is at risk, treat other health conditions early and help those who experience problems with functioning and well-being sooner. By knowing that these problems happen earlier than they might have expected in the course of kidney disease, they can find and correct problems sooner.

This guideline suggests that doctors ask each patient to complete one of the recommended surveys to find out from the patient's perspective how kidney disease is affecting his or her functioning and well-being. Using this information, health care professionals will learn what problems develop, when they develop and what treatments help and which do not. The goal of this guideline is to help doctors and other care givers identify problems earlier, treat them more effectively and help patients live happier, healthier, more active and more productive lives. If nephrologists and other physicians use these guidelines, it will aid the National Kidney Foundation in achieving its vision of *Making Lives Better*. 

REFERENCE

National Kidney Foundation. *K/DOQI Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification*. *Am J Kidney Dis* 39:S1-S266, 2002 (suppl 1).

Beth Witten, a clinical social worker, served on the K/DOQI Chronic Kidney Disease Evaluation, Classification and Stratification work group and wrote the guideline on functioning and well-being. With over 20 years of nephrology experience, she established Witten and Associates, LLC, and provides educational and rehabilitation consulting to clients including the Missouri Kidney Program and the Life Options Rehabilitation Program.

The More YOU KNOW

What's New at NKF...?

Serving the needs of patients and families affected by kidney disease has always come first for the National Kidney Foundation (NKF). Through our many educational and supportive materials and programs—like KEEP (Kidney Early Evaluation Program, a screening program to test those at greater risk for kidney disease), People Like Us, Live! (an interactive patient and family education program about kidney disease) and RISE (Rehabilitation, Information, Support and Empowerment, a rehabilitation program to help those with kidney disease return to meaningful activity)—we have been able to accomplish this successfully. As we grow in our knowledge, we continue to learn about the best ways to offer programs and services to ensure that the needs of people affected by kidney disease are being met.

With the development of NKF's K/DOQI (Kidney Disease Outcomes Quality Initiative) and the creation of the *Clinical Practice Guidelines for Chronic Kidney Disease (CKD)*, we now have more information about all aspects of kidney disease. We know that CKD is a worldwide public health problem. We also know that the rate of kidney failure is rising and that there is an even higher rate of CKD than earlier reports have shown. We have

learned that early kidney disease can be detected through special tests and that treatment in the earlier stages can slow the progression toward kidney failure. And, we now know that there are five stages of kidney disease.

What does all of this information about kidney disease mean for you and your family? It means that everyone—including patients and professionals—is better able than ever before to tackle the challenge of identifying and treating CKD, and the NKF is better prepared to educate and support both patients and professionals. To help us meet the challenge of educating even greater numbers of people, including those who are at increased risk for kidney disease as well as those who have CKD, the NKF has created the K/DOQI Learning System or KLS™.

KLS means that the NKF will have information on chronic kidney disease to support and educate you no matter how mild or severe your kidney disease is. For example, you might be in the very early stages of chronic kidney disease and having problems with high blood pressure or anemia. Learning about how you can best manage these problems to help slow the progression of your disease would be of interest to you. The NKF will

have information and programs to help educate you and your family and answer your questions about the many issues you face. Suppose you have an increased risk for developing kidney disease because your close relative has kidney failure or you have diabetes. Or, suppose you are worried about a loved one who has been diagnosed with chronic kidney disease. KLS programs and materials are aimed at helping all individuals at any stage of kidney disease and those who are at increased risk for developing kidney disease (these may be your family members). It is the NKF's goal to have materials targeted at the specific stages of kidney disease so that a patient can easily locate information specific to his or her stage. Most important of all, understanding your disease and knowing how to manage it will help you stay healthy and get the proper care through early detection and treatment. Even if your kidney disease does progress, you will have the information you need to make the best treatment choices for you and your family.

Other K/DOQI clinical practice guidelines are currently under development. For more information about K/DOQI and KLS, contact the NKF at 1-800-622-9010 or visit our Web sites at www.kidney.org or www.kdoqi.org 

What is your stage of kidney disease?		
Stage	Description	Glomerular Filtration Rate (GFR)
At increased risk	Risk factors for kidney disease (e.g., diabetes, high blood pressure, family history, older age, etc.)	More than 90
1	Kidney damage (protein in the urine) and normal filtration rate	More than 90
2	Kidney damage and mild decrease in filtration rate	60 to 89
3	Moderate decrease in filtration rate	30 to 59
4	Severe decrease in filtration rate	15 to 29
5	Kidney failure (dialysis or kidney transplant needed)	Less than 15

The Journal

By Olive Goodman

I read an article by Stacy Colona in the *Ladies Home Journal* that keeping a journal and writing about a difficult or painful event in your life accelerates the coping process and can improve your mental and physical health.

I've found this to be true. Just last June I had to go on kidney dialysis. This was a shocker to my system! I never dreamed I had this trouble. My dialysis is a three-hour treatment regime, three days a week. Now how much traveling can I do? None. It is so confining. It leaves me tired and needing a nap. That's something I never did—nap in the daytime. On the machine I'd have cramps, get sick and my blood pressure went way down and I'd have to lay flat, which was frustrating.

So after I started writing in the journal about how difficult it is, I find it is easier. I've had six treatments with no trouble. I've been warmer and not asking the nurse, "How much longer?" I now watch TV, listen to music, knit and sometimes nap. I have found that if I want I can vacation and have treatments there. My center will make appointments for me. Isn't that grand? I plan to go to Branson, Missouri next summer.

There are 16 other people on dialysis with me and I am now involved with them. They are a special part of my days. This gives me a positive attitude instead of frustration over my own feelings. I sometimes ride senior transportation with two others, and we visit as we travel back and forth. That is a bonus.

I am springing back. I look forward to each day again. I sew at home on off days. I'm glad to be adjusted and cheerful again. My nurses are wonderful. Also, my kidney doctor, my social worker and my family and friends are so helpful. So again, life is good. The treatments keep me alive. I follow the rules and keep a journal. I recommend it. I think it will be a help. 

Olive Goodman was a dialysis patient from Illinois. She passed away on September 4, 2001 at age 82.

MAILBOX



Dear Editor:

In your summer 2001 issue of *Family Focus*, the Renal Community's Newspaper, Volume 10, Number 3, page 4, there is a big headline, "Kidney Disease Caused by Chinese Herbs" above the article written by Marc E. DeBroe, MD, PhD. Would you please ask whoever writes these headlines to read the article first? On page 3 it says "..... chemical used.....20 years....not caused kidney disease in any of these patients." On page 4 it reads ".....patients who developed kidney diseases also took.....fenfluramine and diethylpropion....."

Of course you need to be careful what you take! False and misleading headlines/articles from an organization like you cause unnecessary confusion. Can we really trust what you tell us?

Sincerely,
Robert Johns

Dear Mr. Johns:

Thank you for your letter. We apologize if you found this particular title misleading. We do our best to assure that the information provided in *Family Focus* is always accurate. We definitely believe that the readership can trust what is printed.

Sincerely,
Karren King
Editor

There are lots of reasons to donate a vehicle. Funding kidney research and patient care are only a few. Make your car a Kidney Car. Cars that save lives. For more information, call 1-800-488-CARS.



NKF National Kidney Foundation®

*Consult your tax advisor for details.

The Parent Connection



K/DOQI Chronic Kidney Disease Clinical Practice Guidelines for Children

By Katherine Barth and Susan Furth, MD, PhD

The National Kidney Foundation (NKF) initially developed a set of clinical practice guidelines for taking care of kidney dialysis patients in 1997. This was called the Dialysis Outcomes Quality Initiative (DOQI). It was hoped that these guidelines would standardize dialysis procedures for people on dialysis. DOQI became extremely successful, and the guidelines became widely known.

A little over two years ago, the NKF reexamined DOQI and its widespread success and decided there was a need to expand the guidelines to include all people with chronic kidney disease (CKD), not just those on dialysis. The plan was to make sure that the guidelines existed for individuals with chronic kidney disease even before dialysis needed to be started. As a result, the Kidney Disease Outcomes Quality Initiative (K/DOQI) was created. A group of professionals from all parts of the country joined together to complete the first new guidelines under K/DOQI. Pediatricians were included in the workgroup to assure that the new guidelines were appropriate for children.

The result of this effort was to create a new set of guidelines for patients with CKD called the *Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification and Stratification*. These new guidelines help care givers evaluate and manage adult and pediatric patients with CKD. All of these new K/DOQI guidelines do not apply to children. However, the ones that do (guidelines 1, 4, 5 and 6) should help care givers take care of pediatric patients with chronic kidney disease.

K/DOQI Chronic Kidney Disease for Pediatric Patients:

Guideline 1: Stages of Chronic Kidney Disease

This guideline separates the degree of CKD in children into five stages (stage one being the most mild stage and stage five being the most severe),

based on kidney function. This is measured using a test called the Glomerular Filtration Rate (GFR—a measure of your kidney function). As kidney function worsens, the GFR decreases, and a very low GFR means a very severe CKD. The new guidelines separate the stages of chronic kidney disease for pediatric and adult patients.

Guideline 4: Estimation of GFR

The new guidelines say that, "Estimates of GFR are the best overall indices of the level of kidney function." Therefore, it is very important that the GFR is correctly calculated. The guidelines stress the importance of using a formula, which takes into account body size. In children, the formula recommended to calculate GFR is the Schwartz or Counahan-Barrett formula. The Schwartz formula is the most widely used in the United States. This formula is based on the child's age, height and creatinine level in the blood. Creatinine is a waste product that is normally excreted in urine, but gets elevated in the blood when kidney function is low. Different formulas are used to calculate kidney function for adults. It is important that pediatricians use the right formula to calculate kidney function in children, so they can know the actual level of kidney function.

Guideline 5: Assessment of Proteinuria

People have proteinuria when they have increased levels of protein in their urine. Proteinuria can be a sign of early kidney damage or of decreased kidney function. Guideline 5 provides instructions for obtaining good samples of urine in children so that the protein level can be measured correctly. It states that the best urine sample to look for protein is the first one of the morning (just after the child has woken up).

Guideline 6: Additional Markers of Chronic Kidney Disease

This guideline lists other tests that help to evaluate CKD in children.

Guideline 6 recommends checking the urine of pediatric patients with CKD, as well as performing special imaging studies such as ultrasound and CT scan. This guideline also states that children who have a higher chance of having kidney disease should be checked using these urine and imaging studies. Children who have a higher risk of having kidney disease include those with hypertension, diabetes or a family history of urologic or kidney disease.

The K/DOQI *Clinical Practice Guidelines for Chronic Kidney Disease*, in addition to the previously published DOQI guidelines, were created by the NKF to help make sure that each patient receives the best and most appropriate care. The NKF also hopes these guidelines improve the quality of care for both pediatric and adult patients with CKD long before they require dialysis or transplantation. In addition, the new guidelines look differently at children and adults and will help doctors assess and manage pediatric patients with CKD.

In summary, there are four areas in the new guidelines that specifically apply to children with CKD. They are listed below:

- 1) The five stages of CKD are defined for pediatric patients.
- 2) The way to correctly calculate kidney function in a child is described.
- 3) The correct method of evaluating proteinuria in a child is detailed.
- 4) How to evaluate a child with CKD is explained. 

Katherine Barth is an undergraduate student at Johns Hopkins University studying behavioral biology with plans for medical school. Dr. Susan Furth is a pediatric nephrologist at Johns Hopkins University School of Medicine and served on the pediatric work group for the NKF K/DOQI Clinical Practice Guidelines on Chronic Kidney Disease.

Two Years and Pressing On

By Mariann Burkett

I am just completing my second year on dialysis and what a change it has been. My first year was like a rocky road, getting attuned to the new venture in my life, numerous hospital visits and reading how awesome dialysis was. Many days I was in "limbo," not knowing what the next day held.

But my second year changed for the better. At the unit I developed strong friendships with staff and patients which were refreshing and many a day encouraging. At the end of my first year I was fortunate enough to attend a patient education seminar. What an eye-opener that was! I learned so much about improving my life on dialysis that it was phenomenal. I learned about my diet, the foods that were important to eat and those that I should stay away from. Finally, with the help of a better diet and medication, my anemia improved and I could maintain a hemoglobin level that made me feel alive.

When I had renewed strength, I began to feel very bored. I realized I needed to get busy. After much thought I decided to volunteer at a senior center. They welcomed me with open arms, and being able to help to cheer other people was a blessing. What is this all about? Dialysis is not sitting in a chair three times a week. It entails much more.

Here are some tips that made my second year a success. I hope they help you, too!

1. Read and inform yourself about every aspect of dialysis. It is an everyday pursuit. Look for the posters and pamphlets in your unit. They are always

there to inform you of new literature and seminars that will make you feel more comfortable on dialysis.

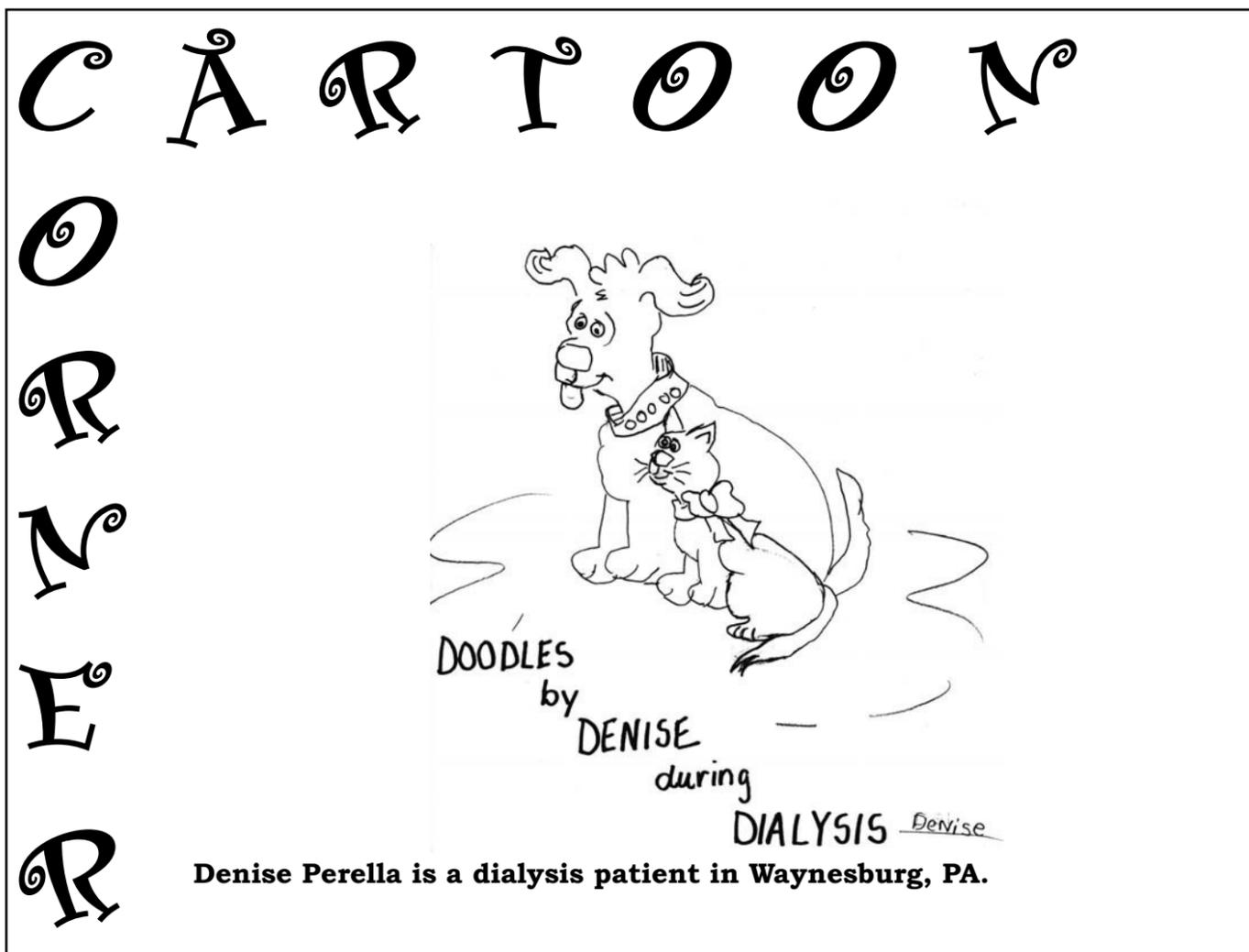
2. Watch your diet, watch your liquid intake and take your medication.
3. Be aware of your blood levels. Know the meaning of BUN, Creatinine and KT/V.
4. If at anytime you need help, the staff at the unit are there for you. Also, get acquainted with your End Stage Renal Disease Networks.
5. Look at dialysis as the rising sun. It brings the sunshine into your life.

Last but not least, my faith that my health would improve and my family and friends made life so meaningful and beautiful.

Happy Dialysis. 



Mariann Burkett



T R A N S P L A N T

R A N S P L A N T

The Timing of Transplantation

By Linda Harte, RN, BSN, MA, CNN, CCTC

If you develop kidney failure very suddenly, having no previous knowledge of kidney problems, you may not have a choice of what type of treatment to have. The most important concern is to get you out of danger and preserve your health as soon as possible with some form of dialysis. After dialysis begins, then you can be presented with the options for treating kidney failure: hemodialysis, either at home or in a center, peritoneal dialysis and transplantation. As a member of your health care team, you need to find out as much as possible about each option to help make the decision that is the best for you.

If you have been followed by a nephrologist (kidney specialist doctor) before you need to begin dialysis you have hopefully had time to learn about medications and a diet to help delay the progression of kidney disease and the need for these treatments. You should also be able to talk with a nurse educator, a nutritionist and/or a social worker for more information about the treatment options. Talking with other people who have been treated by one of the treatment options can be one of the best ways to learn about it first-hand. If your doctor thinks that transplantation is an option for you, talk with someone who has had a transplant. The doctor, transplant nurse or social worker can arrange this.

If you decide that transplantation is the treatment of choice for you, do you have to wait until you have started dialysis before pursuing the option of transplantation? In the past, this was usually the case, unless you had a family member who was willing to be tested to be a donor. Now it is certainly possible to be transplanted without starting dialysis.

When your doctor discusses the need to take over your kidney function with dialysis or transplantation, and if you have decided to pursue transplantation, ask about the possibility of considering it first. Receiving a

transplant before starting dialysis is called preemptive transplantation, and it is done frequently. Your doctor will refer you to a transplant center to talk with the transplant team to find out more about it. If you have a relative or friend who has expressed an interest in being a donor, encourage that person to go with you when you meet with the team. Most transplant teams consist of a transplant surgeon, nephrologist who cares for transplant patients, social worker, financial specialist and a transplant nurse.



All transplant centers must comply with regulations to assure that transplantation is safe, fair and accessible to all candidates. UNOS, the United Network for Organ Sharing, is the contracted agency that oversees transplantation in this country and has developed the criteria for placing patients on the waiting list for a non-living donor kidney. Your education about transplantation and evaluation for a transplant can start at any time you desire, but you cannot be placed on the waiting list for a non-living donor kidney until your kidney function meets UNOS criteria. UNOS states that the creatinine clearance (a test that measures how much kidney function you have left) and is done on a 24-hour urine collection, must be 20ml/min or

less for a patient to be on the wait list. Your doctor will discuss the results of this test which is performed regularly on patients with kidney failure.

As soon as you have finished your evaluation by the team, are found to be a good transplant candidate and meet the UNOS criteria, you can be placed on the (cadaveric/non-living donor) waiting list. Your place on the list is determined by points. One way you accumulate these points is by being placed on the list as soon as possible because points are added to your "score" for every day you have been waiting. You also get points by how close your match is with the non-living donor. Ask your transplant coordinator for more details on the point system. Again, the sooner you start your testing to be a transplant candidate, usually the quicker you can be transplanted, even before starting dialysis.

If you have a living donor, you may not ever need to go on the waiting list. You do not have to follow the same UNOS criteria. In other words, you can be transplanted with a creatinine clearance a little above 20 ml/min. It also depends on when your doctor feels is the best time for you. It is possible for you and your donor to start testing at the same time. If you desire, your transplant can certainly take place before needing dialysis because everything can be timed; that is, when you have reached the point that you need to start some type of treatment, your donor is ready.

It is to your advantage to participate in deciding on your treatment options, including kidney transplantation, with your health care team. Talk with your kidney doctor and transplant team if this option sounds right for you. **FF**



Family Focus is available on the Web. To find this issue or back issues of the newspaper, go to www.kidney.org/patients/backissues.cfm

Knowledge is Power

By Dolph Chianchiano, JD, MPA

The National Kidney Foundation (NKF) is convinced that individuals approaching kidney failure need more information about treatments for kidney disease and deserve to have that information early in the course of their illness. Patients have the right to make informed decisions about their health care, but often are not given the tools to make such decisions. Therefore, the NKF has been working with Congressman Philip Crane (R. IL) to create a new Medicare benefit that would pay for pre-dialysis education. This coverage would be in addition to the nutrition counseling benefit that the Medicare, Medicaid and SCHIP* Benefits Improvement and Protection Act (BIPA) provided for pre-dialysis patients in December 2000.

“It is important to understand that this legislative proposal would not directly benefit every pre-dialysis patient.”

Representative Crane introduced the Kidney Disease Educational Benefits Act of 2002, H. R. 3770, on February 14, 2002, and is currently calling upon other members of Congress to join him as co-sponsors of this bill. When enacted, this legislation would direct Medicare to pay for six education sessions, provided by a qualified social worker, nurse or other member of the kidney health care team. These can be either group sessions or one-on-one appointments. The legislation does not specify where the education should be conducted. The sessions could take place in a doctor's office, a private social work or nursing practice office, a dialysis clinic or at an NKF Affiliate office. It is important to understand that this legislative proposal would not directly benefit every pre-dialysis patient. In order to qualify for this coverage, the patient would have to be entitled to Medicare by either being over 65 or receiving Social Security Disability Income payments for 24 months. On the other hand, there is reason to believe that other insurers will follow the lead of Medicare in providing this benefit after it is enacted.

Using the NKF's comprehensive People Like Us, Live!TM (PLUL!) program as a guide for quality education about kidney disease, this instruction should include the following:

1. Overview of kidney function, including an explanation of the complications associated with a decline in kidney function (such as high blood pressure, anemia and bone disease) and available treatments for those complications, both before and after starting dialysis or receiving a transplant.

2. Description of treatment alternatives for kidney failure, detailing the advantages and disadvantages of each and the role of the patient and family in connection with each type of therapy:

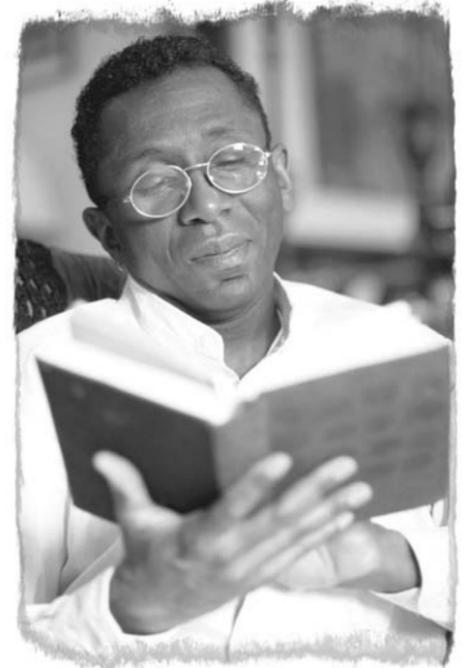
- A) Hemodialysis (in-center, in-center selfcare, daily dialysis and home hemodialysis)
- B) Peritoneal Dialysis (inclusive of continuous cycling peritoneal dialysis)
- C) Transplantation (especially the option of living organ donation).

3. Pros and cons of vascular access options and the value of early planning for and placement of vascular access.

4. Review of financial topics, such as the role of employer-based health insurance that covers the patient or his or her spouse, Medicare, Medicaid, Medigap insurance and state kidney programs.

5. Psychosocial issues associated with chronic kidney disease, including understanding the emotional impact of the disease on the patient and family members and how to access support networks.

Research indicates that people who have participated in a comprehensive pre-dialysis education program are less likely to be hospitalized, are more likely to take an active role in their health care, have decreased anxiety and a greater sense of control than those who have not had the opportunity for such instruction. Therefore pre-dialysis education should improve quality of life and result in cost savings for patients and their families, as well as reduce costs



for the health care system. In addition, many People Like Us, Live! participants have told us that their treatment preferences changed as a result of what they learned during that educational program.

“The content of pre-dialysis education programs must be extensive, well-rounded and unbiased and the instructors must be qualified to provide this service.”

The content of pre-dialysis education programs must be extensive, well-rounded and unbiased and the instructors must be qualified to provide this service. For that reason, H.R. 3770 would require that minimum standards for these programs be established through a federal regulatory process.

If you would like to join Representative Crane and the National Kidney Foundation Office of Scientific and Public Policy in recruiting co-sponsors for H. R. 3770, please call (800) 889-9559, to sign up as a legislative advocate. Since Senator Blanche Lincoln (D. AR) is planning to introduce the Kidney Disease Educational Benefits Act of 2002 in the U. S. Senate, we will also need your help in getting your Senators to endorse this legislation. **F**

Dolph Chianchiano, JD, MPA, is the National Kidney Foundation's director of scientific and public policy.

* State Children's Health Insurance Program



POETRY

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Dialysis Thoughts

By Marcia Vandervort

Here I sit in my favorite chair,
Nothing on my mind, with an empty stare.
Enjoying the activity around me,
Lots going on for all to see.

Another chance to see a beautiful day,
Praises and wishes for me to say.
Spirit and joy within me,
Keeping strong thoughts is the key.

I could complain about things to you,
Complaining is not what I want to do.
After all things could be worse,
It does no good to scream or curse.

Counting my blessings is a good way,
To make success of a long day.
Maturing gracefully in thought and mind,
Trying not to leave good friends behind. 

Energy

By John Taylor

People –
Just want to be happy
Even while on dialysis
Sharing special moments
Together –
Making plans for distant
Journeys –
Where rainbows are found.
Precious times –
With loving Grandchildren;
Fabulous meals with wife/
Husband at your "Favorite
Café."
Some days –
There are no words,
And you are my friend who feels
Alone –
Praying –
To the voice within; to know
Oneness –
The Greatness of Love... 

Heroes

By Paula Snow

*Dedicated to the patients of the Three Affiliated Tribes Kidney
Dialysis Unit on the Fort Berthold Indian Reservation in North Dakota.*

Since I came to work as a new social worker
In a little dialysis unit on the prairie

My heroes have always been dialysis patients.
And yes, some are cowboys.

They travel for hours every other day to treatment
To be hooked to the machine for a couple more
Then ride home for another few.

Exhaustion, fatigue and a bumpy ride on the
reservation roads
Cannot wipe away the dignity and bravery in the
face of ESRD.

Humor is their secret weapon.
Laughter is the best medicine in our unit.

Our patients are the first to tell the newest joke
And laugh heartily
Out loud.

The best of times and the worst of times
All find their way to our dialysis unit.

And when the staff feels tired and burnt out,
It just takes the gratitude of a patient or family
member
To rev' up our engines again.

Some people work and pray for money and power.
I pray for kidneys
And work for wellness. 

Exercise to Help You ...

continued from page 5

Plan on 10-15 minutes of deep breathing, gently moving your arms and legs, stretching your muscles.

2. Exercise: Pick something that you like to do – if it is walking, choose a distance that you think you can do, and do half of that distance. For example, if you know you can walk two blocks, plan on walking one block, and taking a rest. If you feel out of breath or you can't talk, you need to take a rest until your breathing goes back to normal and you can talk. If you can talk after one block, keep going for the second block. If you want to dance, put on some music and dance for one short song. Check yourself. If you can easily carry on a conversation, you are exercising within your limits. If you are out of breath, slow down.

3. Strength training: After exercising your heart you can do a few exercises to start increasing the strength in your arms and legs. Try standing up and sitting down from a chair five-10 times. If it is easy, try not to use your arms to help.

4. Cool Down: Give yourself 10-15 minutes again of deep breathing and getting your breathing back to normal. Also, during your cool down, focus on stretching your muscles and gently moving your arms and legs.

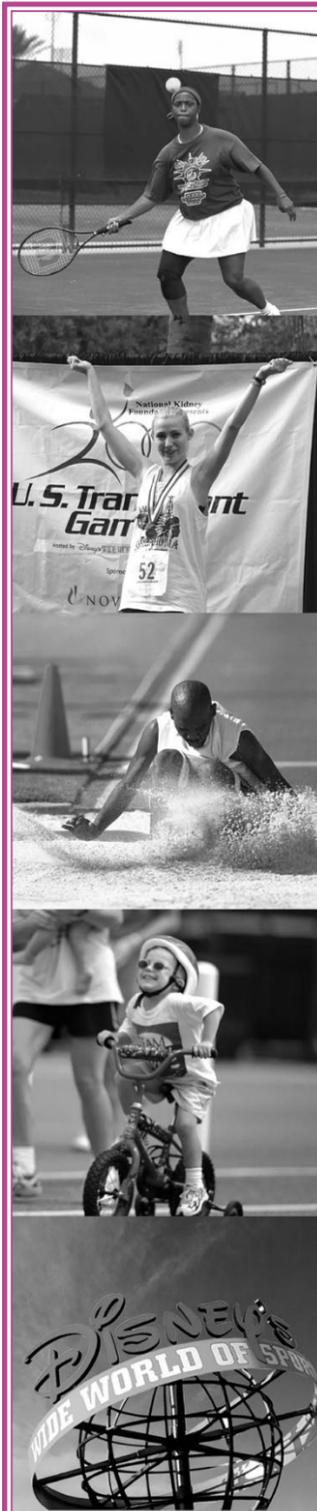
Try doing this program for the next few months. If you feel strong, gradually increase your exercise time by two minutes per week. Remember to go slowly and carefully.

GO FOR IT!

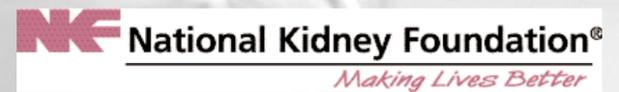
Resources:

A great resource for exercise training is the National Institute on Aging's free Exercise Guide. Call (800) 222-2225 for a copy.

See the NKF's brochure *Staying Fit with Kidney Disease*. To order call (800) 622-9010 or e-mail info@kidney.org 



June 25th - June 29th, 2002



The U.S. Transplant Games are a four-day athletic competition taking place at *Disney's Wide World of Sports™* Complex, Lake Buena Vista, Florida. They consist of 12 sports and 41 events for recipients of organ transplants—heart, liver, kidney, lung, and pancreas. Allogeneic bone marrow recipients are also eligible to participate.

For more information go to
www.transplantgames.org
 or call the National Kidney Foundation at
(800) 622-9010.

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