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QUALITY OF CARE

The Good, the Bad and the Good

Family Focus

The Renal Community's Newspaper

VOLUME 10 NUMBER 1

WINTER 2001

WHAT DOES QUALITY
OF CARE MEAN TO YOU?



Government Takes New Interest in Quality of U.S. Dialysis Care

By Dolph Chianchiano, MPH, JD

The Medicare program that pays for dialysis and transplantation has received an unusual amount of attention lately. Medicare's regulation of dialysis clinics was questioned during a hearing in the United States Senate on June 26, 2000 and criticized in reports that were released at the same time from the General Accounting Office (GAO) and the Inspector General of the Department of Health and Human Services. These developments are remarkable for several reasons. First, there had not been a Congressional hearing concerning dialysis since April 3, 1995. Second, the Medicare agency had already instituted several programs in an effort to improve care



Good quality care means better treatment for patients.

for those on dialysis. The Core Indicator Project and the development of Clinical Performance Measures based upon the National Kidney Foundation's (NKF) Dialysis Outcomes Quality Initiative are notable examples of the agency's attempts to improve dialysis care. Another example is an initiative where Medicare will take data that relate to

quality of care at each individual dialysis center and make those data public on an Internet site that will be called "Dialysis Facility Compare." In addition, data will be presented that will show how each dialysis unit stacks up against all other dialysis clinics in the same state and nationwide. The most significant information that will be divulged by Medicare includes:

- Percent of a facility's patients who received adequate dialysis.
- Percent of a facility's patients whose anemia was adequately managed.
- Actual compared to expected patient survival at that facility.

"In 1999 only 11% of the dialysis units were actually inspected."

Medicare designed "Dialysis Facility Compare" to enable you to be informed consumers. The publication of data in "Dialysis Facility Compare" should assist you in evaluating whether the care you are receiving is similar to the care delivered in other clinics. The data being published by Medicare will allow you to compare your personal impressions and individual experiences with standardized measurements. Moreover, "Dialysis Facility Compare" should provide an additional tool for you if you wish to play a more active role in improving your health. For

example, it gives you a point of reference for discussions with your doctor and dialysis clinic staff concerning care goals. "Dialysis Facility Compare" should be



Discuss your concerns with your health care provider.

available at www.Medicare.gov by early 2001.

The Senate hearing and the related government reports lay the groundwork for new initiatives to benefit you and others with chronic kidney failure. For instance, Senator Grassley (R. Iowa) used the hearing to highlight the need to increase the number of site visits at dialysis clinics by government inspectors. (In 1999 only 11 percent of the dialysis units were actually inspected.) The NKF has advocated for more frequent site visits at dialysis clinics, and the Medicare agency had requested additional funding to make that possible. The interest raised by the hearing should increase the likelihood that the budget for these surveys will be increased. So, a new system for identifying dialysis clinics that should have a site visit is being developed, based on information from

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FROM THE EDITOR

On behalf of the Editorial Board, I am pleased to share with you that *Family Focus* will once again be coming to you four times a year. I hope that you will enjoy the issues as



Karren King

much as your Editorial Board enjoys putting them together for you.

This issue marks the tenure of a new Editorial Board. Some names will be familiar to you from our past issues and others will be new. As with all of our past Editorial Boards, the National Kidney Foundation has assembled an excellent group that represents the main members of the treatment team for those who have chronic kidney disease.

We have entitled this *Family Focus* issue on quality of care "The Good, the Bad, and the Good." What does this mean? As you can see from the cover story, there have been concerns raised recently about the overall care

that is being delivered in the dialysis community. We strongly believe that most dialysis providers are doing their best to give you adequate, even excellent, care. Yet, we also know that this is not universally true. The purpose of this issue is to further educate you about the type of care you have every right to expect and give you information on how to determine that you are indeed receiving that care. You deserve no less! Your dialysis facility and health care team also deserve no less from you than to have you participate as an equal partner in your care. You can help assure this will occur by learning about your treatment options, your diet and your medications. Your next step is to communicate questions, concerns and thoughts about any of these areas to your physician, nurse, technician, dietitian and/or social worker.

Working together as a team to enable you to receive the best care possible is the ultimate way to assure you will live a long, healthy and satisfying life on dialysis. Become empowered! It is your right and your obligation.

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

Government Takes New Interest ...

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the "Dialysis Facility Compare" project.

Another result of the Senate hearing is Medicare's decision to change the regulations that govern dialysis clinics. These regulations were originally issued in 1976 and have been amended rarely in the 24 years since. (An article in a future issue of *Family Focus* will be devoted to these regulations.)

Oversight of Kidney Dialysis Facilities Needs Improvement is the title of the GAO Report. It notes that ESRD Networks collect good information about the quality of care in dialysis clinics but it is not necessarily shared with the state survey agencies that perform inspections at the dialysis facilities. The GAO recommends that Congress consider strengthening Medicare's authority to impose financial penalties on dialysis facilities that



Your unit : A place for quality dialysis care

have the most severe or repeated serious problems. The report from the Office of the Inspector General is entitled External Quality Review of Dialysis Facilities: A Call for Greater Accountability. It concludes that individual dialysis facilities are often not compared to national standards of care. The NKF is studying these reports to determine what statutory and regulatory changes might be required.

People with kidney disease and members of their families who might want to join the National Kidney Foundation in its efforts to keep the government focused on the quality of dialysis care may phone (800) 889-9559 for more information about grass roots advocacy efforts or any of the matters discussed in this article.

Dolph Chianchiano is NKF's Director of Scientific and Public Policy. 



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Editor-in-Chief:
Karren King, MSW, ACSW, LCSW
Kansas City, MO

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Editorial Office:
National Kidney Foundation
30 E. 33rd Street, New York, NY 10016
(800) 622-9010 • (212) 889-2210
<http://www.kidney.org>

Executive Editor: Diane Goetz	Editorial Director: Gigi Politoski
Managing Editor: Sara Kosowsky	Editorial Manager: Sheila Weiner, MSW, CSW
Design Director: Oumaya Abi-Saab	Production Manager: Marilyn Lara

What is "Quality of Care"?

By Bobbie Knotek, RN, BSN, CNN

When you hear the phrase "quality of care," do you wonder what the words mean?

A simple explanation is that "quality of care" is getting the best possible care so you can be healthier and live longer. Many things affect the quality of your care. Here are three:

- Having a treatment plan that is based on standards of care and national goals.
- Being serious about following your treatment plan, including medications and diet.
- Being able to communicate with your treatment team about your needs and about any problems that come up.

To find out how well you and your clinic are doing with these three things, ask yourself the following questions:

Am I getting the type of care at my dialysis or transplant clinic that experts say I should be getting?

You owe it to yourself to find out as much as you can about federal government and state rules that tell clinics how they should operate; about standards of care for kidney patients and about national goals for dialysis and transplant patients.

Your End Stage Renal Disease (ESRD) Network can give you information about government and state rules. If you don't know how to contact your ESRD Network, you can ask your nurse or social worker or you can find the phone number on the Forum of ESRD Network Web site (www.esrdnetworks.org).

Several years ago, the National Kidney Foundation (NKF) published



NKF resources can help answer your questions about your care.

the DOQI (Dialysis Outcomes Quality Initiative) Guidelines. These guidelines for dialysis health care professionals and patients were written to help improve the care of people with kidney failure. They give expert opinions about hemodialysis and peritoneal dialysis adequacy, treatment of anemia, and vascular access. The NKF has patient education brochures called NKF-DOQI: Getting the Most From Your Treatment. These easy-to-read brochures explain the guidelines in non-medical language. To get a free copy of these brochures, contact your local NKF affiliate or call the national NKF office at (800) 622-9010.

There are other professional organizations that have written standards or guidelines to help improve the care of people with kidney failure. Ask your nurse or social worker about guidelines written by the organizations listed below:

- The Renal Physician's Association (RPA) has guidelines for hemodialysis adequacy and initiation and withdrawal of dialysis.
- The International Society for Peritoneal Dialysis (ISPD) has standards for peritoneal dialysis, including recommended treatment for peritonitis and exit site infections.
- The United Network for Organ Sharing (UNOS) has recommendations for transplantation.

The Health Care Financing Administration (HCFA), the agency that helps pay for most dialysis or transplant care, is very interested in the quality of care you are getting. HCFA collects data from dialysis clinics across the United States to measure how good a job they are doing. This data project, called the Clinical Performance Measures or CPM Project, helps them figure out national averages for these measures of care: hemodialysis adequacy (urea reduction ratio or URR and Kt/V), peritoneal dialysis adequacy (Kt/V and creatinine clearance, or CrCl) and anemia (hematocrit, or Hct, and hemoglobin, or Hgb). Many states

and ESRD Networks also collect this data from their dialysis clinics. This data, given back to the dialysis clinics as graphs and charts, helps them compare themselves to dialysis clinics nationwide. This helps you get better care because it means that clinics are trying to do as well as other facilities in the country.

To find the CPM data for your part of the country, log on to HCFA's Web site (www.hcfa.gov/quality/3m.htm).

Am I doing everything I can to take care of myself, so I can stay healthy and live longer?

Doing what you're supposed to do is easier said than done. There are many changes in your life – going without some foods you enjoy, limiting your fluids, taking medicines and showing up for every dialysis treatment or clinic visit. You do need to understand, however, that no matter how well your doctors and nurses follow current guidelines, if YOU don't take care of yourself, your quality of care will suffer. Try thinking of yourself and the clinic staff as a team working to keep you healthy. Everyone has a job to do – including you! Your job is to:

- Learn as much as you can about your disease and your treatment. When you have questions, ask your doctors, nurses, social workers or dietitians.
- Follow your diet and fluid orders (Ask for help – nobody says it's easy.) Sometimes it helps to start with one thing that you're having trouble with – like gaining too much weight between dialysis treatments – and work really hard to do a better job. You will miss being able to drink a lot, but you will be saving your heart. You may also have fewer problems with shortness of breath, blood pressure drops, and muscle cramps during dialysis, and being tired and "washed out" after dialysis.

Take your medicines – even those yucky phosphate binders (if you're on dialysis), or your daily handful of anti-rejection medicines (if you have a transplant). If you have a problem paying for medicines or taking

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What is "Quality of Care"?

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medicines, make sure you tell your doctor or social worker.

Keep track of your lab test results. Talk with your doctor, nurse, or dietitian when you have questions about your lab tests. Know what your dialysis or transplant numbers are. If you are on dialysis your numbers are your adequacy lab values, URR, Kt/V, or CrCl. If you have a transplant, your numbers are lab values like serum blood urea nitrogen or BUN and creatinine, transplant drug levels, and blood counts. NKF created the Dialysis Report Card, which helps patients track important laboratory data and analyze where they stand in relation to set goals. For copies, call the NKF at (800) 622-9010

Learn how to take care of your access (fistula, graft, catheter or peritoneal catheter).

Make sure you get all of your treatment every time (this is true whether you are on hemodialysis or peritoneal dialysis). When you don't get enough dialysis, you are putting your life and health in danger.

Go to all of your scheduled clinic



Keeping track of your labs is part of your overall care.

visits (this is true whether you have a transplant or are on home dialysis).

If you bring a problem or concern to the clinic's attention, are you and the clinic able to work together to try and solve the problem?

If a problem arises at a clinic, both the clinic and the patient need to be involved in trying to solve the problem. Both sides have something important to contribute, including what caused the problem, what roadblocks are in the way, and ideas for possible solutions. Unfortunately,

this doesn't always happen. People on both sides get angry, get their feelings hurt or feel they're being criticized.

Obviously, not every problem will affect your quality of care. However, if you and your clinic get in the habit of solving problems together, you will be better able to tackle problems that come up that could affect your quality of care. To work with your clinic in solving problems, try these suggestions:

- Find out which staff members in your clinic have the power to fix problems and then go to one of those people to discuss the problem in private (not in the middle of the clinic). That person may be your doctor, the director of nursing or the administrator. If you're not sure who to go to, ask your social worker.

- If the problem has to do with your care, ask to come to a care conference to discuss the problem. Bring a friend or relative with you to the care conference for support.

- If your clinic has a patient representative, talk to that person about your problem. Many clinics have meetings with their patient representatives to talk about problems other patients bring to them.

- Take care of problems when they are small. Small problems are usually easier to fix. Don't let a problem upset you for several weeks before you do something about it.

- "It's not what you say, it's how you say it." No one likes to be yelled or cursed at, or called names, so don't try to talk about the problem when you are angry or upset. Wait until you calm down. People are more likely to listen to what you are saying if you discuss your problem in a normal, calm voice. Also, even though you may be upset, try to be polite.

- Ask other patients if they notice the same problem(s) you do. If a problem affects a lot of other patients, ask them to help you talk about the problem with the person at the clinic who can change things.

It is always better to try to solve

problems at the clinic level. You and the clinic staff are the ones who are closest to the problem. Bring the problem to the clinic's attention in the following way:

a) first, talk one-on-one to the person who can change things

b) if that doesn't work, write a letter to the person you talked to restating the problem and keep a copy of the letter

c) if that doesn't work, send a letter describing your attempts to solve the problem to these people: the person you talked to, the other important people at the facility and the regional corporate representatives if your dialysis unit is part of a larger company, and keep a copy of the letter

d) finally, if nothing else has worked, call your ESRD Network, your state health department's ESRD survey department (Medicare works with an agency in every state that does its Medicare ESRD surveys, usually the state health department, or the Medicare Hotline at (800) 633-4227 for help. If the phone numbers for your ESRD Network and state health department's ESRD survey department aren't posted in your clinic lobby, ask your nurse or social worker for these phone numbers.

If you are afraid to talk to your clinic about a problem, you can call your End Stage Renal Disease Network or your state agency before you talk to your clinic.

Do more than just complain about the problem. Let the person know how the problem is affecting you personally. Share ideas on how the problem might be fixed. Be willing to be part of the solution.

Finally, remember that everyone at your clinic has a responsibility to make sure you and other patients receive the best quality of care. This includes your doctors, nurses, care technicians, social workers, dietitians and YOU. I encourage you to ask your clinic what you can do to help improve the quality of your care! 

Patient Rights And Responsibilities

By Barbara K. Campbell, MSW, ACSW

In 1976 the federal government made rules requiring dialysis and transplant facilities to inform patients of their rights and responsibilities. Those rules are still in force today and guarantee you these RIGHTS:

(1) To be informed about:

- Your rights and responsibilities
- The facility's rules and regulations
- What services the facility offers (treatment types, hours of operation)
- Locations where treatment is available
- How much the facility charges
- Who the care givers are
- Your medical condition
- Ways to treat kidney failure (hemodialysis, peritoneal dialysis, transplant, no treatment)
- Advantages and disadvantages of each treatment
- What happens if you refuse treatment
- What to do, where to go, whom to contact during a medical or other emergency
- Whether the facility reuses dialyzers, and the pros and cons of that practice.

(2) To participate in the planning of your care by:

- Getting answers to your questions in terms you can understand
- Knowing what types of treatment, including home dialysis or transplant, you are medically able to do, even if you must go somewhere else to get these treatments
- Understanding new procedures or treatments before you agree to them
- Providing input to your written care plans
- Choosing to participate or refusing to participate in experimental research
- Knowing that certain staff (medical director, head nurse, dietitian, social worker, transplant surgeon) must meet minimum qualifications. (Current federal law does not state qualifications for patient care technicians but your state can tell you about any statewide licensing requirements for technicians.)

- Knowing when a facility can transfer you to another facility or discharge you and getting advance notice of a transfer or discharge if:

- a) You need care that your current facility can't provide
- b) You endanger others by your actions; or
- c) Your facility is not paid for your care.

(3) To be treated with respect and dignity at all times by:

- Making facility allowances for your job schedule [Facilities are supposed to make every effort to schedule treatment so it does not interfere with your jobs]
- Offering help if you are blind, have a hearing loss, speak a different language, or have financial problems that might make it hard for you to carry out your medical treatment.

(4) To have your confidentiality assured by:

- Not sharing information about your life or treatment with other patients or those outside your facility and only sharing information with other staff if they need it to do their jobs
- Allowing your medical records to be sent to others outside of the facility only if approved by you or if it is required by law.

(5) To have a grievance mechanism for complaints that includes:

- Talking to facility staff about any problems with your care without fear of being "punished"
- Receiving a written grievance procedure that lists the steps to use to try to solve the problem
- Contacting your dialysis corporation or facility governing board, your ESRD Network, State Department of Health, or Health Care Financing Administration Regional Office if other steps fail.

Responsibilities go hand-in-hand with rights. Your RESPONSIBILITIES as a dialysis or transplant patient include:

- Learning as much as possible about your disease and treatment
- Asking questions about things

you do not understand

- Following your treatment plan as much as you can, or telling staff if you do not intend to follow your plan and explaining to them what you understand may happen if you don't
- Telling staff about any medical, psychological, social, dietary or financial problems that could cause you not to follow your treatment plan or for which you want help
- Asking for more information if you feel you have not received enough information from your care givers to make you feel comfortable agreeing to procedures
- Making your wishes about the type of medical care you would want in the future known in written documents (advance directives, such as a living will or health care proxy) and giving the documents to your health care providers and family (you have the right to expect to have your wishes followed)
- Treating staff and other patients with respect
- Arriving on time for your treatments and staying the full time
- Following facility rules about eating, smoking and visitors
- Obeying facility security rules and regulations
- Giving the facility correct insurance information
- Providing the facility with your current address and telephone number.

Understanding your rights and responsibilities can help you be an informed and active participant in your care. For more information about your rights and responsibilities contact your ESRD Network.

Ms. Campbell is the Director of Patient Services for the Intermountain End-Stage Renal Disease Network, Inc. in Denver, Colorado.



Get Quality Care Today for a Better Tomorrow

By Wendy Weinstock Brown, MD, MPH

DEFINITION OF QUALITY OF CARE

What is quality of care? In some ways, this is a very simple idea – are you getting care that makes sure you have the best possible health and daily life? In other ways, quality of care is complicated – health care should be planned for you as a person and related to your personal goals. Ideally, this means that there is ongoing conversation between you and your doctor and other members of the health care team.

If you are in your teens or twenties and have kidney disease, you probably believe that good medical care lets you return to school or work, have an active social life and participate in activities you enjoy. Young people usually do not think into the long-term future – over the age of 30 for example! It is important to realize, however, that the type and quality of medical care that you receive now may determine what happens to you in 10, 20, 30 years or more in the future. Whether or not you follow your diet, for example, may determine whether you develop heart disease or bone disease later. Whether or not your doctor recommends certain medicines or follows certain procedures may also affect your future health. Excellent quality of care determines not only your health today, but what happens to you in the future.

TEAM CONCEPT

Your health care team. You are part of the health care team. Dialysis or transplantation is not something that is done to you. You must actively participate in your care to achieve short- and long-term good health. The more you know about your body, your medicines, your treatment and your choices, the easier it will be for you to maintain good health and make wise choices. If you stay on your diet, take medicine as prescribed, and follow

your treatment plan, you are more likely to live a full and healthy life.

DOQI – K/DOQI

The National Kidney Foundation (NKF) developed NKF-DOQI – the National Kidney Foundation Dialysis Outcomes Quality Initiative in order to improve patient outcomes and quality of care. NKF-DOQI created clinical practice guidelines. Clinical practice guidelines are road maps for your health care providers for a particular treatment or condition. They are written by a panel of experts after a very careful review of the best available scientific information. Before these guidelines are published, they are also carefully reviewed by patients, health care workers and others, and are revised whenever newer, better information becomes available. Five guidelines have been published since 1997 (some of which have already been revised) and more are being developed. DOQI has now become K/DOQI – Kidney Disease Outcomes Quality Initiative – because the newest guidelines are also looking at quality of care before dialysis or transplant is necessary.

K/DOQI Guidelines



The following clinical practice guidelines have been published:

- Treatment of Anemia of Chronic Renal Failure (how to increase low blood count)
- Vascular Access (fistulas, grafts and catheters)
- Peritoneal Dialysis Adequacy (how to make sure you are receiving enough peritoneal dialysis)
- Hemodialysis Adequacy (how to make sure you are receiving enough hemodialysis)
- Nutrition in Chronic Renal Failure (how to make sure you are eating the right things to keep you healthy).

Four more are being written:

- ◆ Chronic Kidney Disease: Evaluation, Classification and Stratification (what are the causes of kidney disease and how should patients be evaluated)
- ◆ Bone Disease and Mineral Metabolism in Chronic Kidney Disease (healthy bones)
- ◆ Atherosclerotic Cardiovascular Disease – Dyslipidemias (hardening of the arteries and heart disease)
- ◆ Atherosclerotic Cardiovascular Disease – Blood Pressure (hardening of the arteries and blood pressure)

What your dialysis unit should be doing for you that is related to the clinical practice guidelines. Your doctor and the other members of the health care team should be familiar with the recommendations in the K/DOQI clinical practice guidelines. They should look at your medical condition and decide whether anything could be done in a different way to make you healthier. They should show you the results of your lab tests and explain whether the results are in the target (goal) range. They should share information about your blood pressure and weight gains with you and tell you why medicines or treatment plans need to change and how this will affect how you feel or how healthy you are in the future. They should ask you questions about how you feel, whether you are doing what you are being asked to do and how it affects you. They should listen to your problems and concerns about your medical care and work with you to make your treatment plan easier to follow.

What you should be doing for you that is related to the clinical practice guidelines. You should think about your personal goals. What do you want to accomplish with your medical treatment? What lifestyle is important to you? How can you combine your goals with the treatment plan so that you get the best possible care and stay healthy? Do your homework. Know your lab values, your blood pressure,

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Good Nutrition

Improve Your Health! Stay Within Your Fluid and Diet Limits!

By Rhonda Ann Knecht, RD, CD

Have you ever wondered why you are always asked what you have been eating? Does eating fast foods and pizza really matter? Does drinking a 32-ounce soft drink help you limit your fluid intake? How does what you have to eat and drink affect any of those "numbers" that show up on your lab reports each month? The answer is that what you do or do not eat and drink can make a huge difference in how you feel both during and between your dialysis treatments.

Healthy kidneys usually remove the waste products from what you eat and the fluid that you drink. When your kidneys are not working well, you can make your dialysis treatments easier by taking an active part in your own care. That includes:

- Coming regularly for your center hemodialysis treatments, not skipping home hemodialysis treatments, or doing all exchanges if you are on peritoneal dialysis
- Dialyzing your entire hemodialysis treatment time
- Following your diet and fluid guidelines
- Taking all of your medications as your doctor prescribes

Making changes in how you eat, and even many lifestyle changes, are not easy and are hard to make overnight. Working with your health care team to set realistic goals and to progress toward them will help your dialysis treatments or exchanges make more comfortable and better for your overall health.

Your dietitian can also help make sense of those numbers that appear on your monthly report cards and explain how high or low levels of certain nutrients can affect how you feel from day to day. A high potassium level in your blood can cause your heart to beat too fast and lead to a heart attack. On the other hand, your potassium value can become too low if you are not eating enough food, causing weak and cramping muscles or throwing up. (See the side bar for lists of high

potassium foods.) If you have diabetes in addition to kidney disease and your blood sugar runs high, it can also cause your potassium level to remain high.

Have you ever been told to cut down on high phosphorus foods? Have you been asked to take your phosphate binders with each meal? Those are common requests if your phosphorus level is high. If the amount of phosphorus in your blood becomes too high, you may experience bone pain, itchy skin, poor circulation, broken bones or calcium deposits all over your body. Although you may not feel the bone pain right now, the effects of high phosphorus are real. (See the sidebar on p. 14).

When your albumin, or the protein in your blood, is low, you may feel weak and tired. It also makes it harder to remove fluid during your dialysis treatments. Your albumin level can become low if you do not eat enough high-quality protein foods, such as meat and eggs, or just do not eat enough food. We know that low albumin levels can affect how long you may live. So eat adequate calories and your protein foods!

Your dietitian can help you with food selections that work in your lifestyle. Take that active step and ask for help. Your quality of life and well being are important.

By drinking even one cup of liquid over your daily fluid limit, your heart can become enlarged and overworked, your face and ankles can swell, and you can have trouble breathing or raise your blood pressure. Gaining too much fluid between dialysis treatments can cause cramping muscles. It can also cause your blood pressure to drop while you are on the dialysis machine, which can make you feel faint and sick to your stomach. Increased dialysis time to remove the extra fluid may be needed to get you

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HIGH POTASSIUM FOODS

- ▶ Avocados
- ▶ Bananas
- ▶ Apricots
- ▶ Cantaloupe
- ▶ Dried Fruit
- ▶ Artichokes
- ▶ Potatoes
- ▶ Sweet Potatoes
- ▶ Spinach
- ▶ Legumes/dried beans & peas
- ▶ Pumpkin
- ▶ Tomatoes
- ▶ Bran
- ▶ Salt Substitute
- ▶ Nuts
- ▶ Coffee
- ▶ Chocolate
- ▶ Milk
- ▶ Meat

Physical Fitness and Your Dialysis Unit

By Susan Carey, ACSM, MS

Every dialysis unit is concerned about the quality of care it offers its patients. This is a concern because your health care providers know that the quality of care you receive directly impacts your



Exercise can be a part of good quality of care.

quality of life. An important aspect of quality of life is your physical fitness. However, having a chronic disease such as kidney failure can affect your physical fitness, often making enjoyable and necessary activities difficult. It is important that your dialysis unit is actively involved in maintaining and/or improving your physical fitness level.

You may wonder what the dialysis staff could possibly do to help you stay physically active. Plenty! The dialysis staff should be encouraging you to either remain or become physically active, especially encouraging cardiovascular exercise such as walking, biking, swimming or dancing. This encouragement should occur frequently, since it is easier to stay on an exercise program when someone is expecting and encouraging you to do so. Wouldn't it be great to consider the dialysis staff as your coach and cheerleader, as

they look out for your best interest by encouraging you to exercise?

Dialysis staff may not be prepared to counsel you on how to get started with exercise, but they have access to educational material to help you. The National Kidney Foundation's brochure *Staying Fit with Kidney Disease*, a useful resource, is often readily available at dialysis units and can be obtained from the foundation by calling (800) 622-9010. Ask your social worker or dietitian about the video and booklet *Feeling Better with Exercise: A Guide for People on Dialysis*. These resources will provide you with information on getting started with exercise, as well as describing specific exercises for you to do to increase your strength and flexibility.

In some dialysis units, physical fitness is such a high priority that patients are given the opportunity to exercise during the dialysis treatment. Some units have exercise bicycles that can be placed against the dialysis chair to allow you to pedal during treatment. Many units have televisions and VCRs available for their patients. These units may offer their patients a seated aerobics video to participate in during their treatment. Patients should also be encouraged to do leg lifts and knee to chest exercise during treatment. These are excellent strengthening exercises and are easy to do from the dialysis chair. Doing stretching and strengthening exercises during the time you dialyze will make you more comfortable during your treatment and help you feel less stiff after dialysis.

There are two other routes that could be explored by the dialysis staff in the pursuit of improving your physical fitness. One is physical therapy. Physical therapists are licensed professionals who will assist you in the improvement of physical weaknesses or injury. Your health care team may refer you to physical therapy if you require general muscle strengthening, increased range of motion, walking assistance or training, or general conditioning.

Physical therapists generally work with people who are weak and not in good physical shape. They may be available to you at your unit. If they are not, you may need to visit a physical therapy department or the therapist may come to your home. If you or your loved one on dialysis lives in a nursing home, be sure to ask if physical therapy is available at the nursing home facility. In most states, physical therapy is covered by insurance for dialysis patients, although the number of sessions may be limited. The physical therapist can give you guidelines for improving your fitness and strength and you can do these exercises on your own at home.

The second route is a cardiac rehabilitation program. If you have suffered a heart attack in the past 12 months, have undergone bypass surgery, have had an angioplasty or stent placed, or if you have stable chest pain (chest-pain controlled by long-acting nitroglycerin or through pre-medication with sublingual nitroglycerin, as prescribed by your doctor), you will be eligible for Medicare coverage for cardiac rehabilitation. Cardiac rehabilitation is an outpatient program that is usually offered by hospitals to help people recover from cardiac problems and to help prevent them from recurring. The programs usually last for 12 weeks, with classes meeting one to three times per week, depending on the program. You will exercise on cardiovascular equipment such as treadmills and stationary bicycles. You will also receive education regarding risk factors associated with heart disease: smoking cessation, dietary consultation, stress management and cholesterol education. Participants leave the program with the knowledge necessary to continue independent exercise at home or at a community-based program.

Lastly, if your dialysis unit is unable to offer any of these programs, ask your health care team about programs available in your community. Gyms, senior centers,

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T R A N S P L A N T

R A N S P L A N T

Less Painful To Become A Hero

A Donor's Point of View

By Laurie S. Rosen, MSW

When my husband, Stan, needed a kidney transplant, I donated my right kidney to him by undergoing a laparoscopic nephrectomy.

When my husband's nephrologist told us that laparoscopic surgery was available for donor nephrectomy, my decision to be evaluated as a donor was immediate. Many transplant centers offer both procedures, but laparoscopic nephrectomy is the overwhelming choice over traditional surgery to remove a kidney. Why do donors prefer it?

Laparoscopic kidney removal involves using narrow instruments placed through tiny punctures that make it possible for the surgeon to free up the kidney and tie off the blood vessels. A short incision about two and a half inches long is made and the kidney is removed. This type of surgery causes reduced disturbance of the muscles, less pain, smaller scars and faster recovery when compared to conventional surgery to remove a kidney. Hospitalization of two to three days is normally needed.

Conventional open nephrectomy requires a long incision and may involve removing a rib to allow the surgeon access to the kidney, blood vessels and ureter. Hospitalization of about five days is necessary.

Living donors, although healthy, are patients, too, when we decide to donate a kidney. As patients, we have the same rights as patients who are ill. Donors have the right to informed consent and to be fully informed about the types of surgeries available, the statistics of the transplant center, and the number of surgeries of this type have been successfully

performed at the center. One donor mother with whom I became familiar had undergone an open nephrectomy. Although she interviewed several transplant centers, not one professional informed her that a less invasive surgery was available at competing hospitals. Another donor's transplant team told her that she was not a candidate for laparoscopic nephrectomy because her surgeon had selected her right kidney for donation. Ethically, the transplant team should have told her that this particular surgeon was not trained to remove a right kidney laparoscopically rather than

telling her that it could not be done.

While caring deeply about the person with chronic kidney disease, living donors must also take care of themselves. Donors need to be informed by impartial sources and become their own most assertive advocates. We have multiple concerns as donors, often dedicated to advocating for the recipient while at the same time attempting to ensure our own well-being. Anyone thinking about living organ donation should speak with donors who have already given the "gift of life" via laparoscopic surgery. Potential donors may be less frightened, and as a result, more motivated to donate a kidney when they learn of laparoscopic surgery. It has been over two years since I had the nephrectomy and my husband had the kidney transplant surgery, and we are both doing well. I would highly recommend you consider it!

Laurie Rosen is a psychoanalyst and clinical social worker in Commack, New York. 



Laurie & her husband Stan, enjoy life after transplant.

Get Quality Care Today...

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your dry weight and your medicines. Your dialysis unit may give you a list of your lab values each month and explain what the test results mean. The National Kidney Foundation publishes a Dialysis Report Card. Each month you or your dialysis care team can fill in the results of your lab tests, weight and blood pressure. You can look at your results and, with your dialysis team, figure out what changes need to be made to keep you healthy. Be responsible. Ask questions. No one cares more about you and your treatment than you. If you don't understand why something

needs to be done or why a change was made - ask. If your doctor asks you to take a new medicine, ask what it is for, whether there may be side effects and what would happen if you didn't take it at all or according to the directions you have been given. You also have the right to know about different treatment options. Ask about hemodialysis, peritoneal dialysis and kidney transplants. One of the other types of treatment may be a better choice for you.

To achieve the best quality of medical care **BE ACTIVE IN YOUR CARE!**

A last note - if you use the Internet you can read the K/DOQI guidelines at the following address: www.kidney.org/professional/doqi/index.cfm

You can also find information for kidney patients at: www.kidney.org/patients Both sites are part of the National Kidney Foundation Web page. 

Your Role in Advocating For Yourself

By Dale Ester

So, you are being asked to make decisions about different treatment options and diet, as well as to evaluate all of the restrictions each may impose. How will all of this affect your way of living and how might it change your family? You might even be wondering what will happen next. You might have an idea or thought that you would like to discuss with your health care professionals, but you are afraid to say anything because you don't know how people will react to you. After living the past 11 years with chronic kidney failure, I can tell you that you are not the only person in this situation who is having these same thoughts.

Your role as a person with chronic kidney failure means that you have the right to know about your care and to be involved in treatment decisions. Learning about dialysis and what the lab numbers mean is a good way to begin to gain an understanding of what is happening to you. It is very important to ask questions if you don't know exactly what certain laboratory results mean. The idea is to ask questions and learn more about how dialysis helps you feel better and what you can do to help dialysis work best for you.

If you think your questions have not been answered in a clear, understandable way, ask them again. Politely ask the person who is trying to help to explain using fewer medical, technical words. Once you really understand the answers, you will become a better, more knowledgeable patient and gain respect from other patients, as well as staff, because they will know you are becoming informed and empowered about your care. By asking questions, you will learn about your personal dialysis treatment. This will enable you to both suggest changes to staff and actually make changes yourself that will help you live a longer and happier life.

Those on your health care team who are available to answer your questions include the social worker, nurse, dietitian and doctor. In addition to talking with you about your questions, they may give you valuable information to read. If you are still not comfortable that your questions have been adequately answered, you may call the National Kidney Foundation (NKF) affiliate in your area or the National NKF office at 800/622-9010 to ask for educational brochures that could

help explain the answers to your questions. The public libraries and the Internet are also great places to find answers to questions. Remember, though, that not all of the information you find on the Internet is accurate, so always discuss any changes you would like to make with your health care team prior to making them. They know you best!

When speaking up for yourself it is important to remember that the health care professional may need time to research your question before providing an answer. Being courteous and interested will convey to your health care team members that you are genuinely committed to being an active participant in your care. Dialysis staff are generally trying to do a good job. Be patient and allow them to do that for you.

By participating actively in your care, asking for information and interacting with others in a respectful manner, you can help to effect change. You are to be congratulated for speaking up about questions you have. By doing this, you may become a role model for others who will see the benefits of discussing their concerns with the health care team. Don't ever forget that it is your care and your right to know about it. 

Physical Fitness and Your Dialysis Unit

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the Parks and Recreation Department and community colleges offer diverse fitness programs to fit the community's needs. Look into programs that offer strengthening, stretching and cardiovascular exercise. Cardiovascular exercises are those that involve the major muscle groups, are rhythmic in nature and can be sustained for a significant time, such as walking or biking. Begin with a low-level or beginning program that will be easy to start with, and progress from there. If the organized programs do not fit your schedule, adopt an exercise program of your own. Start walking regularly with a friend, look into the local mall-walking program, or buy a stationary bike or treadmill to use at home. Involve your dialysis unit by first getting permission from your doctor to start an exercise program and then by keeping the dialysis staff posted

on your progress. Remember, they can be terrific cheerleaders!

Staying physically active should be a personal goal of yours as well as an aspect of your dialysis unit's quality of care. Ask your dialysis staff what options are available to you from your unit. You may be pleasantly surprised, or your request may encourage to starting a program. If your dialysis unit is interested in improving quality of care in regard to patient fitness, they may contact Patricia Painter, Ph.D., an exercise physiologist at the University of California at San Francisco, at painter@itsa.ucsf.edu. Another readily available resource for staff is the article "Staff Responsibility to Exercise," which can be found in the journal, *Advances in Renal Replacement Therapy* (see Resource 1). Educational materials on exercise

are available to you and your dialysis staff free from the Life Options Rehabilitation Advisory Council at 800/468-7777 or via the Internet at www.lifeoptions.org.

Resources

Carlson, L., Carey, S.: Staff Responsibility to Exercise. *Adv Renal Replac Ther* 6: 172-180, 1999

Painter, P.: Renal Exercise Workshop Resource binder, 1998

National Kidney Foundation: Staying Fit with Kidney Disease

Painter, P.: Exercise: A Guide for People on Dialysis. The Life Options Rehabilitation Advisory Council.

I dedicate this article to the memory of my father, Joseph P. Carey, who recently passed away at the age of 82. My dad was an avid exerciser, both of body and mind, and enjoyed challenging himself each day of his life. May we all be inspired by life's challenges. 

The Parent Connection

Treatment Options for Children with ESRD and How They Differ From Adult Treatment

By Susan Furth, M.D., Ph.D. and Barbara Fivush, M.D.

Children progress to chronic kidney failure when their level of kidney function falls to less than 10 percent of normal for their age. Acidosis, growth failure, bone disease, high blood pressure and anemia are common at this level of kidney function. Fortunately, chronic kidney disease in children is much less common than in adults. The main causes of chronic kidney disease in children in the United States are glomerulonephritis and cystic, congenital and hereditary diseases⁽¹⁾. When their kidney function falls to less than five percent of normal for their age, children require dialysis or kidney transplantation to survive.

The first reports of successful hemodialysis in children and adolescents only date from the late 1960's and early 1970's⁽²⁾. Effective treatment options for kidney failure in children have only been available in the U.S. and Western Europe during the last two decades. These methods include hemodialysis, peritoneal dialysis, and kidney transplantation, the same options available for adults.

Hemodialysis is a procedure in which blood, passing through an artificial kidney, is bathed by a chemical solution or "dialysate." It is used to replace the main functions of the kidney. Hemodialysis requires a permanent vascular access so that blood can run from the patient, through the artificial kidney, and back to the patient. This procedure is usually performed in an outpatient dialysis treatment facility three times a week and requires several hours for each treatment, although parents can also be trained to do it at home.

Chronic hemodialysis therapy in children is harder to maintain than in adults due to problems placing and keeping a permanent access. The difficulty with the access is often related to the small size of children's blood vessels. Also, time away from school can be a problem for children on chronic center hemodialysis.

Continuous ambulatory peritoneal dialysis (CAPD) was first introduced for the care of patients with ESRD in 1976⁽³⁾. In 1978, a three-year-old Canadian girl was the first child to be treated with CAPD⁽⁴⁾. CAPD, which is usually done in the home, requires dialysis solution to be in the peritoneal cavity 24 hours a day, 7 days a week to bathe the blood vessels. Toxic wastes in the blood that would normally be removed by healthy kidneys can move from the blood into the dialysate and be drained four or five times a day. People on peritoneal dialysis must have a catheter in their abdomens to perform this treatment and need to be taught to do it. More recently, advances in peritoneal dialysis have led to continuous cycling peritoneal



dialysis (CCPD), where dialysate is cycled into and out of the abdominal cavity by a machine while the child is sleeping at night. This therapy is well tolerated by children, and they can attend school on a regular basis. Peritoneal dialysis is widely preferred as chronic dialysis therapy for young children.

Children's ages and the length of time they have had chronic kidney failure are important factors that affect their dialysis choice. As previously mentioned, maintaining vascular access is very hard in younger children, making hemodialysis a problem. On the other hand, frequent abdominal surgeries may prevent the option of

peritoneal dialysis as a treatment for chronic kidney failure. Repeated bouts of peritonitis, an infection, can cause peritoneal dialysis to fail, and children may have to transfer to hemodialysis.

Although the first recorded human kidney transplant occurred in 1906, there was no strong interest in transplantation as a good treatment option for kidney failure until the 1950's⁽⁵⁾. The first kidney transplants in children date from the late 1960's. At that time, transplant survival was poor in children, with only 25 percent of transplanted kidneys surviving more than two years. The introduction of cyclosporine as an immunosuppressive medication for pediatric transplant patients in 1982 dramatically improved transplantation⁽⁶⁾. As a result, patient and transplanted kidney survival have improved to the point that kidney transplantation is currently the most desirable treatment option for children with kidney failure. When compared to dialysis, children who have a transplant have improved survival, better quality of life, improved growth, and lower cost^(2, 7, 8, 9). For children who are too small for successful transplantation (less than 10 kilograms or 22 pounds) or do not have the option of a living donor, hemodialysis or peritoneal dialysis can be used until kidney transplantation is an option.

Kidney transplantation remains the treatment goal for children with kidney failure. Improvements in this treatment option hold the promise for long-term survival.

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Family Focus Spotlight

By Tonya Powell

This column features ways that kidney patients have made contributions to their communities and highlights significant individual accomplishments. The National Kidney Foundation's vision is Making Lives Better, and we're proud to see that others share this vision, too!



I want to share my experiences, accomplishments, hopes and dreams for my future as a patient living on dialysis. I hope my message will help you feel positive about your future as a dialysis patient.

I was diagnosed with glomerulosclerosis of the kidney at age 19. Eight years later, in December 1997, the day finally came when I was rushed to the hospital for emergency hemodialysis. I was terrified, thinking that I was on my deathbed. I remember praying constantly. Soon afterward I had surgery for placement of a catheter for peritoneal dialysis. This was my first and only experience in surgery.

Some of my initial concerns beginning dialysis were safely hooking up and performing dialysis, owning and interacting with pets, dating, selecting comfortable clothing, traveling and working. I own two dogs, and the only change I needed to make was to not allow them access to my bedroom. Though I was self-conscious about dating, I was able to begin and maintain a serious relationship while on dialysis. I have traveled to the beach and to the mountains while on dialysis. In preparation for working, I am attending school.

Many positive things have occurred since I began dialysis. Following 12 years of addiction to marijuana and cigarettes, I realized that I wasn't helping my health. I have been free from marijuana use for over two years, and I have been a non-smoker for two years. I appreciate life, family and friends more than I ever have. I am more organized, have better financial control and better time management. I have learned a lot about my body, and my experiences have given me a renewed sense of purpose. I am closer to my loved ones, who are my greatest support. Spiritually, I have taken a journey challenging me to trust

God and grow in faith despite my circumstances.

As a patient of peritoneal dialysis, I have also learned a respect and fear of peritonitis, which I have experienced to varying degrees three times. I am more limited in swimming and bathing. I often feel bloated, yet I cannot urinate. I cannot eat large portions. Yet in spite of these negatives, I am grateful for the personal growth my experiences have afforded me and would not change anything.

I am pleased with my accomplishments. I became involved with the fundraising efforts of the National Kidney Foundation, receiving certificates for being the Top Patient Salesperson from the Raleigh Dialysis Center in both 1998 and 1999. I also attended the Southeastern Kidney Council Workshop. With the support and guidance from my dialysis center social worker, I was introduced to vocational rehabilitation opportunities. I have completed three courses, and I am in the process of completing two others. My goal is to be a medical secretary in a private nephrology practice.

In times of need, I have found my social worker to be a good listener and during bad times a support. I wish to thank her for caring and being there when I needed her the most. I also wish to thank the home-training nurses for their patience and understanding as I learned to do dialysis.

My message to you, my fellow kidney patients, is this: persevere. Be positive in both good times and bad, and remember that the bad times don't last very long. Pray that your trials produce patience and strength of character. Reach out for encouragement, but also encourage others and be an inspiration to them.



Treatment options for children...

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Are we missing you?

We'd like to make sure that NKF Family Focus is making its way to every dialysis unit and transplant center in the country. If we're missing anyone, or if you would like to receive a copy at your home, please let us know by giving us a call at:

(800) 622-9010

Don't Live to Dialyze; Dialyze to Live!

Williard "Moody" Richardson

Until my 25th anniversary of being on home hemodialysis, I had never given much thought to my many years living on dialysis. They caught up with me recently and I was shocked when my nurse and technician told me that I was one of the longest-running home hemodialysis patients in America. I have become known as the "dialysis man" in the local West Tennessee area and many people who are facing dialysis frequently contact me. Now it is time to expand and share "Moody" with all of my 260,000 dialysis friends across America.

Dialysis wasn't easy in the beginning, and it is the same beginning for everyone. I was scared and felt I would have to change my whole life. After my wife and I trained for six to eight weeks to perform home hemodialysis, we returned home to begin dialysis in 1974. We were both scared to death of being "home alone." During the first two years I had given up on ever doing anything again, probably like some of you today. I had always loved to build things, yet I didn't want to start a building project because I thought I would not be around to finish the job. Finally, I had to face some cold, hard facts. I was living to dialyze, not dialyzing to live. After that revelation, I knew that I had to make changes in my life. Dialysis was working! I began to have a different outlook on life.

I found I could do anything I wanted to do, just at a slower pace. I went to college. I began going on vacation with my family. We hauled the old Drake-Willock hemodialysis machine and all of the supplies in the back of my truck from the Smoky Mountains to Florida and up and down the East Coast. I was dialyzing to live!

I was encouraged to run for mayor of Atwood, a town of 1,500, in 1981, and I won. Many days I worked 12 to 15 hours for my community. I barely had time for dialysis, but I never missed a treatment. I was able to juggle my dialysis days in order to attend meetings and other functions. A home patient always has this option. My wife and I also started local Cub Scout and Boy Scout troops, and I became Cub Master and later Chairman. Together we worked to see the completion of a veteran's monument and garden in our town. During the 90's I started building again and built

a 36' by 36' barn by myself. I also restored tractors and automobiles. Some said it would take six men to do what I could do.

My spouse and I have a routine that has been working all of these years. She goes to work each morning and I handle all of my extra projects, civic work, and some household chores. Three days a week, I set up the machine to dialyze, and five minutes after my wife walks in the door, we are all hooked up and dialyzing.

Now you may want to ask me why I have been bragging so much. The answer is simple. I am proud of what I have been able to accomplish while coping with and enduring dialysis for more than 25 years. Today I can still do whatever I set my mind to do. I can still accept challenges. Before dialysis I was just a country nobody. I was able to do something with my life because of dialysis. Even after 25 years on dialysis, I can say with pride that my life has been better, richer, and has more meaning. My story is for encouragement to all of my friends on dialysis - all 260,000 of you. Remember... do not live to dialyze but dialyze to live! There is a world of difference in that thought. Think about it! 

Donation is the best revenge

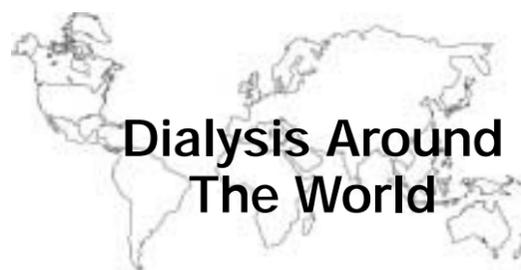
Dear Dolores:
You got the house.
You got the kids.
But you're not going
to get the Bentley.
I've decided to donate it to the
National Kidney Foundation

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.
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NKF National Kidney
Foundation

Upcoming Issues:



Complimentary and Alternative
Treatment



ESRD and the Life Cycle

*We invite you to submit contributions to the
Editorial Board.*

*Please send submissions to:
National Kidney Foundation,
30 East 33rd Street New York, NY 10016.*

Improve Your Health

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HIGH PHOSPHORUS FOODS

- ▶ Dairy products
- ▶ Yogurt
- ▶ Milk
- ▶ Cheese
- ▶ Ice cream
- ▶ Whole grains
- ▶ Quick breads, peas and lentils
- ▶ Green peas
- ▶ Mushrooms
- ▶ Organic meats
- ▶ Nuts
- ▶ Peanut butter
- ▶ Soy beans
- ▶ Beer
- ▶ Chocolate
- ▶ Cola drinks

back to your dry weight. Symptoms of excessive fluid weight gains between dialysis treatments can also lead to hospital visits for congestive heart failure and shortness of breath from fluid overload. Remember one kilogram, or 2.2 pounds of weight, is equal to drinking one quart of liquid.

You will not be getting adequate treatment if you skip dialysis treatments or shorten your prescribed time on dialysis. Adequacy is measured by urea reduction rate, or URR level, and Kt/V for hemodialysis. Kt/V and creatinine clearance are used to measure peritoneal dialysis adequacy. These values show how well your dialysis treatments have been at cleansing your blood of the toxins that build up in your body. When this value is too low, it can make you feel sick to your stomach and you may lose your appetite. If it is repeatedly low, it may also shorten your life. Your kidney doctor may increase the time that you are on hemodialysis or adjust your peritoneal dialysis exchanges to improve the quality of your dialysis.

Paying attention to your lab values and knowing what they mean and how they affect your health can help you make better food choices to maintain your good health. Your dietitian can provide information to assist you and other care givers in making well-informed decisions about what you eat and drink. They can assist you in creating meal plans designed to meet your individual food preferences and nutritional needs. Make the difference in your health and quality of life by working with your health care team. Remember your health is in your hands.

Rhonda Ann Knecht is a renal dietitian for Renal Care Group in Indianapolis, IN, and is vice president of the Indiana Council on Renal Nutrition. 

Family Focus Announces 2001 Themes

By Karren King, MSW, ACSW, LCSW,
Family Focus Editor

The Family Focus Editorial Board recently met and selected timely, thought provoking, and stimulating topics for this issue and the next three. I want to encourage you to submit an article, poem or photograph in keeping with the newspaper's themes for consideration for publication. Items should be sent to the Editor of Family Focus in care of the NKF. The themes of upcoming issues are Dialysis Around the World (which should be received by readers at the end of April), Complimentary and Alternative Treatment and ESRD and the Life Cycle.

Let us hear from you! 

*Reminder:
March is
Kidney Month*

Do You Know
Where Your Kidneys
Are?

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POETRY

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Ode to the HomeChoice Automated Peritoneal Dialysis System

By Perry Hayden

That first night I brought you home
now we were in bed together alone.
In my bedroom you required a place
of your own.
I waited until 9:00.
Getting you started went just fine.
I was nervous
but then we were united as one
to spend the night together.
Mmmh, mmmhh, mmmhh
You were restless all night long
with noises and movements that don't belong.

Is it love or just a passing fling?
This is no passing fling
for death do us part.
But do I love thee?
My emotions are mixed.
I depend on thee.
I hate and despise thee.
But I love to see
the dawn each day because of thee.

Thanks!

By Michael Lassiter

Age 13

The donation of life you gave to me
I am as thankful as can be
Words can not express the joy in my heart
Knowing you gave me one of your body parts

Now I have a chance to a normal life
After undergoing the skill of the
surgeon's knife

I may not ever know you 'til my dying day
But I know that God sent you this way!



C A R T O O N

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THE ULTIMATE LOVE/HATE RELATIONSHIP

Lee A. Dolezal

Editor's Note: The artist, Lee Dolezal, was a cartoonist for his local paper. A kidney patient from Yorkville, Illinois he passed away in November 2000



Family Focus Spotlight

There is Life After Dialysis



By John A. Reed, Sr.

I am writing this letter to encourage chronic kidney disease patients to become positive about their treatment. The following is an example of what you can do with a positive attitude.

It is almost 15 years since I was diagnosed with lupus. After I fought this disease for 12 years, it finally affected my kidneys and I wound up on dialysis. Shortly after this, I also came down with congestive heart failure. Then I had a heart attack resulting in a quadruple bypass. All of this time I was going for dialysis three times a week. After using wheelchairs and stretchers to get to and from dialysis, things started to get better for me. I was just going through the usual problems of starting on dialysis and not knowing what to expect. After

asking many questions of the nurses and technicians, I began to feel better about my treatment. I have not missed a single treatment in almost three years.

I have learned to travel now. My wife and I spent two weeks in Maine two years ago. Last summer we spent a month in New Hampshire, and this summer we plan to return for two more months. I just celebrated my 75th birthday and went tandem (connected to a professional diver) skydiving from 13,500 feet! My wife and I work in our church thrift shop to keep busy, and I also usher in our church. What time is left, I spend working on stained glass.



*Living' La Vida Loca!
John Reed celebrates his 75th birthday flying high!*

This all happened because for the past three years I have had a very positive attitude. I have also found out the power of helping others. 



At the 6th Annual "Kidney Fest" near Kingsport, TN, families gathered to display quilt squares to raise awareness about the need for organ donation.



(From left) Jama Keefer, 29, of Elizabethton, TN, and her mother, Charlotte McBride, 57, of Kingsport. Jama donated her kidney to her mother.

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