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## SPECIAL 10<sup>th</sup> ANNIVERSARY ISSUE

# Family Focus

The Renal Community's Newspaper

VOLUME 9, NUMBERS 2 & 3

FALL 1999/WINTER 2000

*Our heartfelt  
thanks to  
Amgen Inc.  
for its support  
of this special  
Anniversary  
Issue.*



*Happy Birthday,  
Family Focus!  
Family Focus  
celebrates 10 years  
as the Renal  
Community's  
Newspaper. See  
inside for stories  
on rehabilitation  
and the best of the  
last ten years.*



## Rehabilitation for ESRD Patients: Live Well and Prosper

by Beth Witten, MSW, ACSW, LCSW

**W**hether you just found out you have kidney disease or have been receiving treatment for some time, you need to know how kidney disease will affect different aspects of your life.

Rehabilitation is often thought of as helping people with kidney disease keep or find jobs. Although vocational rehabilitation is an important goal, it is only one part of the total picture of rehabilitation. Rehabilitation also means promoting stable health, a positive attitude and enjoyable activities. These factors make up what most people call "quality of life."

Each individual's rehabilitation goals are different and personal. As you think about what you need to help you live long and well with kidney disease, make a list. This list can help you come up with rehabilitation goals.

Living with a chronic illness isn't easy. Learning how to cope with your illness is **emotional rehabilitation**. To cope successfully, figure out what has helped you feel better when you've been sad or frustrated in the past. Talk with others who have lived with kidney disease and learn what helped them cope. Research has shown that faith and strong social support can help you live longer. Consider which family members, friends and renal caregivers you can ask to support and encourage you when you're having a rough day or feeling down.

It's easy to feel out of control when others are telling you what to do, as often happens when you have a chronic illness like kidney disease. People who take an active role in their care do better. Learn what you need to know to help you take control of what may seem to be an uncontrollable situation. Members of your health care team are the consultants in your education. Keep a running list of questions as you think of them for

your health care team. Ask the most knowledgeable sources you can find for answers. Order free or low-cost materials from organizations such as the National Kidney Foundation. The Foundation has an entire series of brochures on rehabilitation and other topics related to kidney disease, which you can order by calling (800) 622-9010. Use the library and Internet to read more about your illness and treatment choices.

**Physical rehabilitation** is also a key part of your treatment. When you feel

tired and weak, it's hard to find the energy to do things you have to do, much less things you'd like to do. Make sure you are getting enough dialysis and eating the right foods to keep you strong. Most people with kidney failure are anemic, which causes them to feel tired and weak. If you are anemic, find out how well your anemia is being controlled.



*Rehabilitation includes resuming physical activities, as well as reaching emotional and vocational goals.*

(photo by Jay LaPrete)

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*This publication is a Family Focus Program of the National Kidney Foundation and is made possible through an educational grant from Amgen.*

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## FROM THE EDITOR



**Karren King**

**F**or years, the renal community did not readily discuss the topic of rehabilitation, which was typically thought of in very narrow

terms relating to patients re-entering the workforce. When attempts were made to convince Congress to expand Medicare coverage to those with renal disease, testimony was provided that 60 percent of those on dialysis would return to work following retraining and 40 percent would be able to remain vocationally active without further training.<sup>1</sup> However, although a 100 percent employment rate was predicted, it did not actually happen.

As a result, the renal community began to believe it had failed in the area of rehabilitation. However, the testimony to Congress had not taken into account factors such as the increased age of those on dialysis, with many not being of typical working age, and barriers that programs like Social Security Disability would place on returning to work.

There has been a resurgence of interest in renal rehabilitation over the past several years, as the concept of rehabilitation has come to be thought of

more broadly in terms of enhanced quality of life. This most certainly includes returning to or maintaining employment, but also includes such things as volunteer work and education. Our definition of rehabilitation has also come to include physical functioning and emotional and social well-being. Lastly, there has been recognition that in order to achieve a satisfactory level of rehabilitation, a person on dialysis must have certain positive medical outcomes. Dialysis adequacy, nutritional status and hematocrit level all must be optimal so an individual can reach the desired level of rehabilitation.

This issue of *Family Focus* showcases this new, enlightened definition of rehabilitation; each article deals with rehabilitation from a different perspective. As you read the articles, I urge you to consider the various areas of rehabilitation as they relate to you. What can you do to take charge and assure that the goals you set for your personal rehabilitation, whatever they might be, are met?

This issue also marks a milestone for *Family Focus* — its 10th

anniversary! The NKF has always been dedicated to providing education and assistance to those with chronic renal failure and their families. Thus, it was a logical step to develop this newspaper to further that mission. These past 10 years represent the hard work and dedication of many individuals, including past and present editorial board members and NKF staff. This issue, in addition to the rehabilitation focus, includes the "best" of *Family Focus*' past articles. I hope you enjoy reading them as much as the editorial board did when given the difficult task of making the selections from so many excellent articles. On behalf of the editorial board, I want to thank the dialysis community for extending their congratulations. Also, I would like to acknowledge AMGEN for their generous support of *Family Focus* over the years.

Happy 10th anniversary *Family Focus*, and here's to the next 10 years!

*Karren King*  
For the Editorial Board

1. Gutman RA, Amara AH: Outcome of therapy for end-stage uremia. *Postgrad Med* 64: 183-194, 1978.

**Turn to page 25 for a special memorial to *Family Focus* Patient Editor, Wayne Nix.**



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1/4 PAGE

**COVER STORY****Rehabilitation for ESRD Patients...**

*continued from page 1*

Ask for a copy of your lab report. If your hematocrit is less than 33 percent, EPO and iron may help. Consult with your health care team if you have any questions about the treatment of anemia.

Exercise plays a major role in physical rehabilitation. Studies have shown that exercise can help build strength and endurance, reduce depression, help control blood pressure, strengthen bones and raise hematocrit. A standard exercise program requires that you start slowly and increase your physical activity to 30 to 45 minutes three times a week. Your health care team members can help you start an exercise program that is geared toward your individual abilities and goals. (For more tips, see the fitness article on page 7).

It's important to keep working or stay in school if possible. Resuming these activities is part of **vocational rehabilitation**. These activities provide opportunities for financial, social and personal well-being. If you

think you might have to stop working or going to school, ask your health care team for help. If you're being treated in a hemodialysis center, ask about scheduling dialysis around your work or school hours, or consider home dialysis, which allows more flexibility. Research has shown that people who have a higher level of physical and vocational functioning have a lower risk of hospitalization and death.

If you had to quit school or stop working when you became ill, consider other activities that will help you feel worthwhile and make you happy. If you're considering returning to work but don't know what type of work you can do now, there are many employment agencies and community colleges that offer vocational testing. Your state vocational rehabilitation office may be able to help finance your education or retraining. You might also consider becoming a volunteer, which will help test or build your skills while helping others.

It is essential to review your rehabilitation goals regularly to see

which you've met and which are still in progress. Keeping motivated is the key to successful rehabilitation. You may not notice gradual changes right away. Tracking progress on a wall chart or writing in a diary can help you stay motivated. Reading past notes in your diary may help you put your current situation in perspective so setbacks don't become roadblocks that stop you from moving ahead.

Your choices determine both how long you live and how well you live. Although it's never easy to ask for help, others are willing and able to help you if you reach out and take their hand. You can be your biggest foe or your strongest ally in achieving full rehabilitation. The choice is up to you. **FF**

*Beth Witten, MSW, ACSW, LSCSW, has 20 years' experience as a nephrology social worker and is a renal rehabilitation consultant. Beth staffs the Life Options Rehabilitation Resource Center and serves as patient education coordinator for the Missouri Kidney Program Center for Renal Education.*

1/2 page ad



# The Doctor's Role in Renal Rehabilitation

by George A. Porter, MD, FACP

**H**elping people with kidney failure lead active, productive lives is a team effort.

Successful rehabilitation requires the cooperation of family members, physicians and dialysis unit staff, as well as your active participation as the patient. Rehabilitation means enabling patients to achieve the best quality of life, but it may not mean exactly the same thing for every person. For a student, rehabilitation may involve returning to school and after-school activities. For a wage earner, it may mean having the ability to return to work, and for a homemaker, being able to run the household and care for family. The entire health care team, including you, sets realistic goals. As leader of the team, the doctor sets expectations and attitudes, prescribes appropriate medical treatment and manages the rehabilitation process.

## SETTING EXPECTATIONS

For most patients, information about kidney failure and their own diagnosis first comes from a doctor. At this point, even before dialysis begins, the physician can set the stage for successful rehabilitation. How? First, the doctor can reassure patients that a long life and a good quality of life are possible even with End Stage Renal Disease (ESRD). Second, the physician can share information about how to live with kidney failure. Doctors who listen, reassure, encourage questions and take time to answer them can help patients feel that their lives are not over because they have ESRD—they are just going to be different. One patient explained, "We have to know right from the onset that we're not going to die, there are options, that it's okay to be healthy, it's okay to be functional, and that we can do it."<sup>1</sup>

Doctors can—and should—create positive expectations and attitudes among other dialysis professionals. Establishing unit policies that encourage self-care, patient education and other rehabilitation-friendly activities make it clear that the priority of the facility is to help patients live full lives.

## PRESCRIBING APPROPRIATE TREATMENT

You need to feel well to take advantage of rehabilitation opportunities. Helping dialysis patients stay physically healthy is the most important responsibility of the doctor. It is complex to prescribe and deliver appropriate medical treatment for kidney failure and its many symptoms and related conditions. The National Kidney Foundation Dialysis Outcomes Quality Initiative (NKF-DOQI) was developed to provide guidelines for health professionals who care for kidney patients. The medical experts who worked on the guidelines agreed that appropriate treatment must include the following:



*Getting the right amount of dialysis is important to your health.*

**Vascular access.** A reliable, comfortable access is, literally, a lifeline for patients. The arteriovenous (AV) fistula is the preferred form of access. Access problems, like infections or clotting, can lead to hospitalizations and interfere with rehabilitation. Prevention, whenever possible, and aggressive management of access problems are an important part of the doctor's role.

**Adequate dialysis.** Getting adequate dialysis is key to long-term survival, physical health and rehabilitation. How much dialysis is enough? Kidney doctors use formulas, Kt/V or Urea Reduction Rate (URR), to help calculate how much dialysis a patient should get in each treatment. NKF-DOQI recommends minimum values for Kt/V and URR for dialysis patients and pays special attention to the different needs of hemodialysis and

peritoneal dialysis patients, and adults and children. The "target" values are prescribed by your doctor and are the minimum amount of dialysis required for each patient. It is important to remember that if you come late to dialysis treatments or stop early, or skip peritoneal dialysis exchanges, you may not be receiving the proper amount of treatment.

**Anemia management.** Left untreated, anemia (the shortage of oxygen-carrying red blood cells) makes patients too tired, weak and confused to participate in rehabilitation programs. The kidneys make a hormone called erythropoietin that stimulates the bone marrow to make red blood cells. When your kidneys don't work, they stop making this hormone. Doctors prescribe a man-made form of the hormone erythropoietin (EPO) and iron supplements to help correct the anemia. This hormone is given either by vein or as injections under the skin.

An NKF-DOQI guideline on nutrition for both adult and pediatric patients will soon be available. Doctors and renal dietitians must ensure that patients get enough dietary protein to meet their energy needs and preserve muscle. The renal diet also helps reduce the buildup of wastes and fluid that can only be removed by dialysis. Proper nutrition helps patients maintain their strength and avoid illness that can interfere with participation in a rehabilitation program.

## MANAGING THE REHABILITATION PROCESS

Good medical treatment based on NKF-DOQI guidelines forms a solid foundation for rehabilitation, but success also requires planned programs and activities. The patient, nurse, dietitian, social worker, nephrologist and family members all develop a patient's rehabilitation plan. As a starting point, many doctors use the "5 E's" of rehabilitation as defined by the Life Options Rehabilitation Advisory Council (LORAC): Encouragement, Education, Exercise, Employment and Evaluation. A comprehensive rehabilitation program will include

*continued on page 8*

# Self Care—Being Independent

by Betty Murray, RN

In this age of computers and advanced technology, we have all realized and enjoyed a new level of independence. We no longer have to wait for the mail to be delivered because information can be faxed or e-mailed in an instant. We no longer have to wait in long lines at the bank because we now have direct deposit and ATMs. Such choices and conveniences are also available to the renal community. Individuals with End Stage Renal Disease now have choices that allow them independence as part of their rehabilitation.

To encourage independence, in-center self-care hemodialysis programs are increasingly being considered as a treatment option. The decision was made to establish a self-care program in my unit with the realization that individuals who dialyze in a home setting have better expected outcomes, including fewer hospitalizations. Our self-care program was established nine years ago with great success and has maintained between 10 and 12 active participants.

## SETTING IT UP

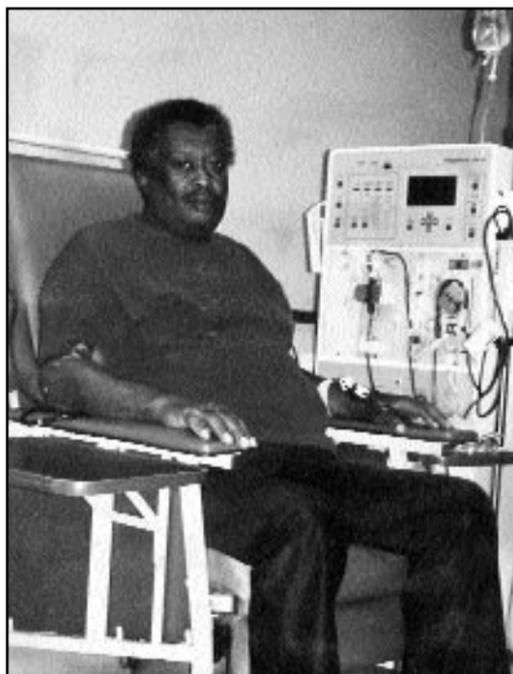
We realized from the onset that for the program to have a greater chance of success and survival, a separate area would be needed to provide the necessary training and treatment. A room was designated with six stations and patients were given the option of either a morning or afternoon shift. One primary nurse partner was assigned to each patient in order to provide continuity of care and to simulate a home-care setting with a one-on-one relationship.

To meet this program's expectations, the following steps were taken:

1. Policies and procedures were adopted that allowed individual patients to provide their own care.
2. A care plan was developed that set the goals of the unit, the nurses' responsibilities, and patient acceptance criteria and responsibilities.
3. A contract or agreement was developed to be signed by the nurses and patients. The signing of the agreement sets the stage for a joint effort.

## THE AGREEMENT

In the self-care setting, all tasks to be performed by the participants are listed in the agreement to ensure that jobs are defined and all aspects of care are completed. Some of these responsibilities include gathering supplies, monitoring weights and vital signs, initiating, overseeing and terminating the dialysis treatment, completing all charting and fluid removal. Self-venipuncture has remained optional, since it is dependent upon the access type and location. Some patients do not feel comfortable with this task, but they always have the option to learn how.



*Teaching in-center patients how to perform their own treatments increases confidence and understanding.*

## SELLING THE IDEA

So why do self-care? To understand why, we simply asked patients who currently perform their own care. The newest member to our unit previously had been on peritoneal dialysis. When PD was no longer an option and the need for hemodialysis became evident, self-care seemed like the most logical choice to him. He could still function independently. Several others in the unit stated they had toured other in-center units, but the atmosphere in the self-care unit was what sold them on trying this treatment option. Another reason was recommendations from doctors. Whatever the initial reason for undertaking this challenge, everyone was in total agreement on the advantages of self-care hemodialysis.

## ADVANTAGES

Most patients agreed that independence was the primary advantage of self-care. Being able to perform the treatment tasks and make decisions about their own care meant a lot to them. One self-care participant of more than three years said, "It makes me feel better about myself that I'm able to do this on my own."

Another advantage to performing self-care dialysis is the educational aspect. In self-care, patients learn the how and why things are done, which helps to promote a positive learning atmosphere. This knowledge has in turn increased self-esteem and self-satisfaction, and has also decreased the fear of the unknown. "I not only learned how to perform dialysis, but it helped me to learn how to take care of myself at home," said another self-care patient.

The social setting is what has kept some patients in self-care for years. Reminding, helping and encouraging each other in a relaxed atmosphere has been a positive experience for all participants in the self-care unit.

## ACCENT THE POSITIVE

So what about the negative aspects or disadvantages of self-care? One patient noted that the only drawback is "having to clean up after myself." The positive aspects for patients and nurses definitely outweigh the negative. For nurses, the ultimate reward is seeing patients progress to independence and take a leadership role. 

*Betty Murray is a registered nurse at DCI in Nashville, Tennessee.*

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**Correction:** the correct author of "Your Dialysis Nurse and Technician," Volume 8, Number 3, is Kimberly Ward, BSN, RN, Corporate Clinical Surveyor for Dialysis Clinic, Inc., Nashville, Tennessee.

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## Living to the Fullest

by Roxanne Poole, RD

**A**udrey Williams became depressed when she was diagnosed with polycystic kidney disease in 1989. Her previous experiences with family members on dialysis led her to believe that life would soon be over. Audrey's mother had polycystic kidney disease and was on dialysis from 1971 to 1976. Her mother was the second patient in South Carolina to be on home dialysis, and when Audrey was in high school, she had helped her father set up the machine for her mother's treatments. Her aunt had also been on dialysis, and her grandmother had nephritis. They had all died by the time of Audrey's diagnosis.

Audrey was working as a senior associate county agent/home economist at the time she required dialysis. She had not been employed long enough to be eligible for retirement and disability. She had to work. So, Audrey commuted 60 miles each way to her job. Her supervisor worked with her so that she could dialyze at the clinic near her home on Tuesdays, Thursdays and Saturdays



**Audrey Williams and Roxanne Poole at "Dining on Dialysis."**

and work in the local office after her treatments. She commuted to her regular office on non-dialysis days. After one year of commuting, she was able to transfer to the local office, which allowed her to spend more time with her husband, Marshall, and their three young children, Philip, Wes and Jessica.

Audrey's work involves developing, planning, conducting and evaluating new community programs in foods and nutrition, home furnishing, clothing and textiles. She advises the Family Community Leaders Association and teaches financial resource management. She works in the evenings and on the weekends to

present these programs. The people where she works have been very supportive, and because she works extended hours, she does not have to use sick leave for her dialysis treatments.

In addition to her work, Audrey finds time to sing in the church choir and work with the Wednesday night supper committee that prepares food for 150 people. She has also collaborated with her dietitian to present a program called "Dining on Dialysis" to professionals and fellow patients. Additionally, she has written an article on food safety and preparation, which was featured in the National Kidney Foundation of South Carolina's newsletter, *Kidney Connection*.

Audrey looks forward to each day. Rather than dialysis being the end, working and dialysis have given her the opportunity to stay involved and make a difference in people's lives. **F**

*Roxanne Poole, RD, is a dietitian at Gambro Healthcare in Orangeburg, South Carolina.*

1/2 page ad

# Exercise: Helping You Get Back to Your Life

by David Miller, MS, and Susan Carey, MS

The goals of rehabilitation are to improve your health and make it easier to participate in pleasurable and meaningful activities—or to improve your quality of life. The renal community recognizes that maintaining a good quality of life is just as important as treatment for kidney patients. Physical fitness is an important part of your quality of life.



You may even be able to exercise while undergoing treatment, which may prevent you from cramping or getting tired. Find out if your facility offers this option.

Light-to-moderate physical activity done on a regular basis can bring positive results: greater strength, endurance and flexibility; better control of blood pressure; decreased risk of heart disease; and, possibly, decreased levels of depression or anxiety. For these reasons alone, increasing your physical activity is a good idea. You can achieve desired fitness levels by gradually increasing activities such as walking, stretching and strengthening exercises.

There are also more subtle benefits that come from increased fitness levels. Your life is not based upon how far you can walk or how much weight you can lift. It is based upon family, friends, and personal goals or ambitions. Increasing your levels of fitness allows you the energy to participate in social activities. It also allows you to pursue personal interests such as hobbies, returning to work or starting a new career.

Exercise truly helps to achieve the goals of rehabilitation—empowering you to feel well enough to return to doing the things you enjoy most. Participating in regular exercise can build your confidence in your physical ability and generally boost your self-esteem. It gives you a sense of control. Since only you can actually do the exercise for

yourself, you have complete control over this aspect of your health care.

Here are some recommendations about how to stay physically fit while on dialysis:

## Developing cardiovascular endurance

1. Type: Choose activities, such as walking or biking, that use the large muscle groups for a prolonged period of time.
2. How often: Exercise at least three times per week. If you are only able to exercise for a few minutes at a time, consider exercising several times during the day.
3. How hard: The exercise intensity should range from light to moderate; exercise does not need to be exhausting to be beneficial.
4. How long: Start with an exercise duration that you are comfortable with and gradually progress to 30 minutes or longer.

## Developing muscle strength

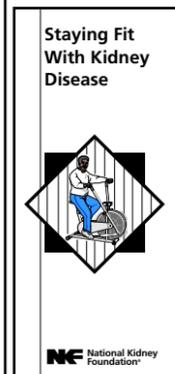
1. Type: Use light hand weights, resistance bands, weight machines and household items, such as soup cans and detergent bottles.
2. How often: Select at least one exercise for each major muscle group; do the exercises at least three times per week.
3. How hard: Choose a weight or resistance that you can do at least one set of 12-15 repetitions of each exercise. Increase the resistance gradually as you get stronger.

Becoming physically fit is especially important if you are considering a kidney transplant. Increased physical fitness may allow you to tolerate the transplant surgery more easily. Recovery from your transplant surgery also requires making a commitment to getting fit. Many of the same types of physical activities that you do while on dialysis, such as walking, stretching and muscle strengthening exercises, will still be appropriate. If you don't exercise while you are on dialysis, take the time to celebrate your new life with your transplant by starting a regular physical activity program. Exercising after transplantation may help prevent

muscle weakness and excessive weight gain, as well as improve the quality of your life. Talk to your physician or a physical therapist if you are unsure about what types of activities you can do safely.

Rehabilitation is achieved when your level of physical fitness allows you to feel well enough to pursue social activities and personal goals. If you are interested in learning more about getting started with an exercise program to increase your fitness level, ask your health care providers for more information.

Susan Carey, MS, is a clinical exercise physiologist at the University of California San Francisco Medical Center.

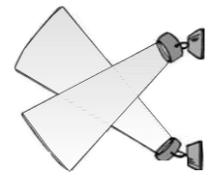


Editor's Note: The National Kidney Foundation's brochure "Staying Fit With Kidney Disease" can give more information on the benefits of exercise. To order a copy, call (800) 622-9010.

ADA ad



## Family Focus Spotlight



*This new addition to Family Focus will feature ways that renal patients have made contributions to their communities as well as highlight 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!*

In recognition of National Kidney Month, over 200 patients, staff, family and friends of South Queens Dialysis Center in Jamaica, New York, gathered for a Celebration of Life Luncheon. Gloria C. Generette, patient coordinator of the event, was honored with a proclamation from Councilman Archie Spigner and Assemblyman William Scarborough for her hard work in organizing this luncheon. She was also acknowledged for her desire to live life to its fullest despite kidney disease. The mission of this celebration was to encourage our patients not to let the changes they have to make in their lifestyles prevent them from leading full and productive lives. Also, the goal was to educate family and friends about kidney disease.

*Doris Francis, MS, RD, Jamaica, New York*



*Staff members at the South Queens Dialysis Center celebrate life.*

This letter is to let you know that I recently received Worcester's "key to the city" from the city's mayor. This key is awarded to people for community service. I believe that my volunteerism and pride in my neighborhood contributed to my receiving this award. My tremendous pride in the rich history of my neighborhood compelled me to try to keep it as clean as possible, even as the area changed greatly over the years. I worked with the city government to plan a revitalization project, which included tennis courts. When the park was revitalized and the tennis courts installed, I volunteered to give group lessons to children who lived in the neighborhood.

*Mollie Yeaton, Worcester, Massachusetts*

People usually do not look forward to Mondays. People look forward to coming to dialysis even less. But since January 1997, Evelyn Pearlman has given patients at Beverly Hills Dialysis Center in Los Angeles something to look forward to. Every Monday she has had "Evie's Theater Party" for the patients on her husband's shift. She shows a movie and serves dietitian-approved refreshments. This gives the place an upbeat atmosphere, and the movies help time on dialysis pass much more quickly.

*Ruth Sugerman, LCSW, ACSW, Los Angeles*

### The Doctor's Role...

*continued from page 4*

components from each of these five areas.<sup>2</sup>

The National Kidney Foundation's RISE Program (Rehabilitation, Information, Support and Empowerment) is designed to motivate patients to return to meaningful activity, whether this is employment, education, volunteering or other daily tasks. Participants in RISE will gain knowledge and self-esteem and learn their rights and responsibilities as they relate to accessing treatment and other services. (See article on page 25 for more information.)

Dialysis center rehabilitation programs can be very effective, but the rehabilitation-oriented doctor will take advantage of additional resources, including referrals to physical or occupational therapists, vocational rehabilitation counselors, and exercise physiologists or trainers.

Today, kidney patients, dialysis centers and caregivers are recognizing that rehabilitation is very important. The role of the doctor in rehabilitation is changing. Providing quality medical care will always be a top priority, of course, but other responsibilities—such as managing effective rehabilitation

activities—contribute significantly to improving patients' quality of life. 

#### References:

1. Rettig RA, Levinsky NG, eds. *Kidney Failure and the Federal Government*. Washington, DC: National Academy Press, 1991.
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*Dr. Porter is a professor of medicine in the Division of Nephrology and Hypertension, Department of Medicine, at Oregon Health Sciences University in Portland, Oregon.*



Volume 4, Number 2

## Adequate Dialysis: Your Rights and Responsibilities

by Wendy Brown, MD

**A**s a person with chronic kidney disease, you require regular dialysis (either hemodialysis or peritoneal dialysis), a special diet, certain medicines and a positive, cooperative attitude to stay healthy. You have a right to excellent care from your doctor and nurses, and you have the responsibility to take part in your care in a reliable manner. This does not mean that you cannot ask why certain medicines have or have not been prescribed or why your treatments last a certain amount of time. What is happening to your body is your business and you have a right to have your questions answered. As a matter of fact, the more you know about your treatments, your medicines and your diet, the better off you will be as a patient.

### **Q. Who is the health care team?**

**A.** As a dialysis patient, you are part of a team that works together to make sure that you stay healthy and active. In addition to yourself, the team includes your nephrologist (kidney doctor), your dialysis nurse and technician, the renal dietitian, the renal social worker, and your family and other loved ones. Dialysis is not something that is done to you; it is a treatment in which you take part. In order to receive the best care, you need to take some responsibility.

### **Q. What is adequate dialysis?**

**A.** Adequate means enough. In your case enough dialysis is the amount needed so that you don't get sick from the waste products that have built up in your blood stream, or from fluid (water) that has collected in your body. Waste products and water normally end up in the urine when your kidneys are working. If you are not receiving enough dialysis, you may feel tired or short of breath. Your health care team can tell if you are getting enough dialysis by looking at a number of things. These include examining you and

listening to how you feel, and looking at lab tests and X-rays. Your doctor will also use some of these things to figure out how much dialysis you need (this is called Urea Kinetic Modeling) and whether you are well-nourished and eating the right kinds and amounts of food. He or she will then order a "dialysis prescription." Your dialysis prescription consists of such things as the amount of time you need to be on dialysis, the type of dialyzer, the type of dialysate or dialyzing fluid that is best for you and so on. The amount and kind of dialysis that your doctor prescribes is exactly what you need and will probably not be the same as what another patient needs.

### **Q. Why can't I stop dialysis a few minutes early (or skip a CAPD exchange)?**

**A.** Cheating, even a little bit, will add up and show up! Many patients insist on stopping dialysis early or skipping treatments, not following their diet or not taking their medicines regularly. You may seem to get away with these things for a while, but eventually you will get in trouble. The trouble may be problems with your heart because potassium is high in your blood, or problems with your bones because you eat food high in phosphorus or don't take your calcium. You might have bad itching, cramps in your legs at night or shortness of breath. You might get very sick and need to come into the hospital or your heart could stop. You might even die, without any warning.

### **Q. What are my rights as a patient?**

**A.** You have a right to good health care. You have a right to be listened to and evaluated when you have a problem. You have the right to know why certain medicines have been ordered or why you need to follow a certain diet. You have a right to know why your dialysis time has been changed. You have the right to

know what will happen to you if you don't have enough dialysis or take your medicine regularly or follow your diet. You have the right to know what all your choices are: whether hemodialysis or CAPD is better for you, or whether you can have a transplant. You have the right to have as much information as you need to understand what is happening to you.

### **Q. What are my responsibilities as a patient?**

**A.** You have the responsibility to cooperate with your caregivers. You have the responsibility to take your medicines the way they are ordered and to follow your diet. You have the responsibility to report any unusual symptoms to your doctor and to let him or her know if your medicine looks different (it could be the wrong pill!) or if you are feeling different. You have the responsibility to ask questions if you don't understand something. You have the responsibility to come to dialysis on time and to stay on dialysis for your full treatment. You have the responsibility to do as much as you can for yourself.

Dialysis has come a long way. It is a life-saving treatment for more than 250,000 people in the United States and for more than a million people in the world. Good dialysis, adequate dialysis, that allows you to function at your best with the fewest problems, requires a partnership between you and your health care team. Be involved in your care. Be a part of the team! **FF**

### **NKF Family Focus**

### **Will Spotlight Parenting**

*Editor's Note: Upcoming issues will spotlight Parenting and Putting a Face on Kidney Disease. We invite readers and health care providers to submit their contributions to the editorial board in c/o the National Kidney Foundation, 30 East 33rd Street, New York, NY, 10016.*

# Your Dialysis Nurse and Technician

by Deborah Brouwer, RN

**T**he roles of the dialysis nurses and patient care technicians are diverse and evolve as the world of health care changes. As the patient caregivers in the dialysis facility, the nurses and technicians have many different roles. They are supervisors, teachers, listeners, lab technicians, schedulers, machine technicians, performers of patient care, and anything else that they may need to be throughout the day.

There are three types of nursing/ technician personnel who will perform direct patient care for you while you are on dialysis. The registered nurse (RN) is an individual who has had formal training from an accredited school of nursing. RNs must complete the dialysis facility's training program if they have had no previous dialysis experience. The licensed practical nurse (LPN) is an individual who has been certified from an accredited licensed practical nursing program and has also completed the dialysis facility's training program. In some states, the LPN works as a senior dialysis technician (SDT). The patient care technician (PCT) is an individual who has a high school diploma or general education degree and may have six months related experience in the health care field. The PCT must also complete the dialysis facility's training program. Reuse or machine technicians (also called renal technologists or technicians) work with the machine hardware or hemodialyzers and may be trained to provide direct patient care as PCTs.

The role of each of these caregivers is different. The RN is responsible for the day-to-day operation of the dialysis unit and supervises the other employees in the unit. RNs also work closely with the physician to schedule procedures, exams and treatments, etc. They are licensed to administer medications and blood if you need them while you are on dialysis, and generally are also responsible for administering IV medications, or medications that go directly into the bloodstream. RNs assess your

physical condition to determine if there are any problems prior to your dialysis treatment.

RNs initiate the long-term care plan, which is used to review the methods of dialysis that are available to you. Your RN should review all treatments, including hemodialysis, peritoneal dialysis, home hemo-dialysis and renal transplantation, with you. Your input should be taken into consideration when choosing a method of treatment. RNs are considered a "jack of all trades" when it comes to the dialysis patient. They are key players in the education of your disease, access care, emergency drills, diet and fluid balance.



LPNs function in a role where they work very closely with the PCTs and any other unlicensed personnel. LPNs prepare, set up and monitor the patient, hemodialyzer and dialysis machine. They collect pre-, intra- and post- dialysis data, and monitor you during your dialysis treatment. They draw any required blood samples needed for laboratory tests, perform blood glucose checks, and do any additional necessary lab tests that can be performed in the dialysis unit. In some states, with specialized training, the LPN may administer specified IV medications. These are generally the routine medications you receive while on dialysis, such as heparin, mannitol, calcitriol and EPO.

The LPN/SDT or RN can serve as your primary nurse. The primary nurse is responsible for reviewing your home medications on a

regular basis, and teaching you about your medications and their purpose. He or she implements the short-term care plan, which identifies any specific problems you may be experiencing and includes ways to correct these problems. For example, if you are having a problem with high phosphorus, the primary nurse will set a goal for you to reach by the next month. This nurse will ask the dietitian to review your diet with you and tell you which foods to avoid that are high in phosphorus. The LPN or SDT primary nurse also assists the RN with the long-term care plan in reviewing the methods of dialysis. LPNs are also essential in teaching you about dialysis and the things that are associated with your dialysis treatments. They have an array of duties to perform with you and the dialysis machines. These caregivers are essential to quality dialysis treatments.

The patient care technician (PCT) is considered more of a "hands-on" caregiver. PCTs set up the dialysis machine, initiate, monitor and terminate your dialysis treatment. They will put in your dialysis needles, take your vital signs while you are on dialysis, terminate your treatment when it is over and set the machine up for the next patient. In addition, PCTs will aid the RN, LPN or SDT with the short-term care plan, assessments, education, collecting blood specimens and performing in-house laboratory tests such as glucose monitoring. They may complete monthly assessments under the guidance of the RN, LPN or SDT.

The RN, LPN, SDT, PCT and other health care team members all have specific duties to perform, but they also work together as a team. They will meet to review your progress on a regular basis and will evaluate how well you are adjusting to your current treatment. We, the caregivers, would not be here if it were not for you, the patients. Your input is always welcome. You are a vital element to us, just as we are to you. **FF**

**The Best of Family Focus: Health Care Team**

## Dining for Special Occasions

by Julia Spitzfaden, MEd, RD, LD

**F**or many of us, holidays and other special occasions mean a time for family, friends, love, laughter, gifts, parties, food, drink, and more food. These are times when people often reach out to others, providing the most precious gift of all—love. Many times people express their love with the gift of nourishment. To a person receiving dialysis, this can be a blessing or it can turn out to be harmful.

Special occasions can be very intimidating for someone on a renal diet, but it does NOT have to be that way! With careful consideration by the host and careful choices by the dialysis patient, it is certainly possible for the host to prepare one meal for all, enabling the dialysis patient to stay within the dietary plan, feel well, and enjoy all of the festivities.

How a meal is presented can be just as important as what a dialysis patient eats. So many things affect how we feel about the food we eat. For instance, many

believe that we taste food only with our mouths. This is not true...our desire to eat is affected by what we see, smell, taste and feel. Dialysis patients and their loved ones may want to try to make meal times special and pleasing in appearance not only for special occasions but all throughout the year.



The following are some of the ways to make meals more appealing.

- ✓ Serve a meal on a beautifully decorated, candle-lit table and create an inviting ambiance!
- ✓ The colors of foods artistically arranged on a plate can enhance one's desire to eat. A colorless meal may give the impression of being bland, but a full plate of vibrant-looking foods will be much more attractive
- ✓ The smell of foods is certainly enough to get our mouths watering. However, keep in mind that if someone feels nauseated or

queasy, the smell of food can make it worse. If this is your situation, it may be a good idea to prepare cold sandwiches and cold dishes—in fact, throw a blanket on the floor or in the yard and have a picnic.

- ✓ As anyone on a sodium-restricted diet will tell you, taste is very important! So, remember that spice rack in your kitchen? Use it and experiment with the herbs and spices; ask your dietitian for a list of which spices complement which foods and which are acceptable.

As you can see, there are many ways to spice up the renal diet! You can also contact the NKF to order a copy of the NKF publication "Spice Up Your Cooking" for further suggestions on how to enhance the renal diet with spices and herbs. If you are on dialysis, or know someone who is, please remember that good nutrition every day, as well as during special occasions, will allow that person to have a better quality of life. May you be able to celebrate the gift of love with your loved ones through the pleasurable experience of eating together. Happy feasting!

*Julia Spitzfaden, RD, LD, MEd, is a renal dietitian for Total Renal Care in Cincinnati, Ohio.*

### Special Occasion Menu Tips

*The following are special occasion menu suggestions that can be enjoyed by a person on a renal diet as well as the entire family:*

- **Entrees:** roasted pork, beef, lamb, cornish hens, turkey, chicken
- **Breads/Starches:** buttered noodles and pasta, rice, dinner rolls, homemade bread stuffing
- **Vegetables:** green beans, wax beans, cauliflower, asparagus, beets, carrots, cabbage, eggplant, lettuce salad
- **Condiments/Relish plate:** celery, green pepper, carrots, radishes, cucumber, cranberry relish
- **Beverages:** (within the fluid allowance) tea, water, coffee, \*7-Up, \*Sprite, ginger ale, cranberry juice drinks, lemonade, limeade
- **Desserts:** pie (apple, peach, cherry, blueberry, strawberry or lemon), cookies (sugar, butter, spritz, shortbread), sherbet, fruit ice, angelfood cake

*\*Diabetics: use caution with sweets, limit the serving sizes, use sugar substitutes and diet beverages. Angelfood cake can fit beautifully into a holiday theme as well as a diabetic diet.*

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*Family Focus* on this 10<sup>th</sup> Milestone

# Preparing for a Transplant

by Jenny Bell, BSN, RN, CNN, CCTC

**T**ransplantation is only one of the treatment options for kidney failure. Everyone who chooses transplant would like it to be successful for them. Here are some simple ways to prepare yourself that will help ensure success.

## Medical Preparation

- ☞ Keep your doctor's appointments. Come with a list of any questions you may have. Don't be afraid to ask "why."

- ☞ Run the entire prescribed time on hemodialysis, or if on PD, do all your exchanges. Being underdialyzed will give you less energy, more nausea, more nerve and heart damage. It will also affect how well you heal after transplant.

- ☞ Take all your medications as prescribed. Do not take any folk remedies, extra vitamins or minerals, or over the counter drugs before consulting with your nephrologist. These drugs could interfere with the absorption of your prescription drugs or cause dangerous side effects. These drugs may also interfere with the efficiency of the anti-rejection drugs after a transplant.

***If you cut corners and self prescribe now, you get into a mindset of not following directions. This can cost you your kidney.***

- ☞ Blood pressure should be kept below 140/90. This may be an important factor in maintaining the life of the transplanted kidney. Good blood pressure control is also necessary to preserve the health of your heart and blood vessels.

- ☞ Diabetics need to get into the habit of controlling their blood sugar levels. Blood sugars that are too high or too low can harm your health and also may shorten the life of the transplanted kidney.

- ☞ Maintain the health of your bones and tissue by keeping your calcium and phosphate balance. Prednisone that is usually given after a transplant can weaken your bones.

- ☞ Hematocrits should be maintained between 33 and 36 by taking EPO and iron as prescribed. Diet and exercise will also help build hematocrits. Blood transfusions can build antibodies, which may make it difficult to find a kidney match. There is also the possibility of a transfusion reaction that can be very serious.

- ☞ Eliminate the focus of infection. It is generally suggested that if you have infected kidneys, they be removed before transplant. The same is true if you have kidney stones or gallstones. Any infection after a transplant may threaten your life or the life of the kidney as the anti-rejection medication makes it more difficult to fight off infections.

## Mental Preparation

- ☞ Read about transplants, talk to patients who have had successful transplants and to those whose transplants have failed.

- ☞ Contact your local National Kidney Foundation affiliate for help. Go to the transplant support groups. Become a member of your local AAKP (American Association of Kidney Patients) and attend the meetings. Get involved with your renal community. Most dialysis centers have a patients' bulletin board where these items are posted. Ask your

social worker about these activities if you cannot locate them yourself.

- ☞ Find out what's involved in having a kidney transplant, including your financial responsibility.

- ☞ Develop a positive attitude. Concentrate on what you can still do, not what you can't do.

There are no guarantees in having a successful transplant, but if you follow these tips, you can help ensure that you have done your part of the process.

## Nutritional Preparation

- ☞ Following your dietary restrictions is extremely important in maintaining your general health. Keeping up adequate protein values will make a difference in how well you heal and fight off infections. Keeping your fluid gain less than 2 kg between dialysis sessions will help control your blood pressure and keep your heart muscle from stretching out. Too high a fluid gain can cause pneumonia or pulmonary edema. Potassium should be kept within a normal range. Levels that are too high or too low are life threatening.

- ☞ Maintain a healthy weight. Overweight patients take on added risks with a transplant. There may be poor wound healing, pneumonia, blood clots, and delayed kidney function. Obesity also increases the likelihood of getting steroid-induced diabetes after the transplant. Anti-rejection medication will make it very difficult to lose any weight after the transplant.

- ☞ Cholesterol levels should be kept below 200. Fifty percent of transplant patients develop high cholesterol levels within three months after a transplant. (*Handbook of Kidney Transplantation*, ed. G. Danovich, pg. 183). High cholesterol levels cause strokes, heart attacks and clogged blood vessels. This can result in the loss of your kidney or your life. Get into the habit of eating low-fat and high-fiber foods before the transplant. Read labels to find out fat contents. There are renal low-fat cookbooks available from the National Kidney Foundation. Ask your renal dietitian for help.

*Jenny Bell has been in nephrology a total of 18 years, as a renal transplant coordinator for the past 10 years. Excerpts of this document are reprinted with permission from an article Jenny wrote for Nephrology News and Issues (Nov. 1994).*

# What You Can Do To Cope With Stress

**M**r. Allan Kennedy has worked in a variety of clinical settings as a physiotherapist. He is also a licensed professional counselor. Mr. Kennedy offers several views on stress and how it can be managed:

■ The most basic point is the strength of the body we are born with. The key is, the stronger the body, the more stress it can handle. That is why exercise is so important.

■ Coping with stress also depends on how many major insults the body has to deal with, such as depression, divorce, drug or alcohol abuse. The greater the history, the less stress a person is able to cope with.

■ Next comes control. We have no control over people or over certain situations. People starting dialysis or getting ready for a transplant have little control, and that is scary and causes stress.

■ Perhaps the biggest factor that can determine how people deal with stress is their perception of an

event. Perception can change. For example, imagine you are on a crowded bus and someone keeps jabbing you. How do you feel? Angry. Stressed. You want to jab him back. You turn around to get him and you see an elderly blind woman with a bag of groceries. How do you feel now? You feel sorry for her. The stress is gone. What happened did not change, but the way you see the event did.



■ Stress happens quickly. We have to realize that if we are going to handle stress better, we have to think about what happens. We have to ask ourselves why we are getting so angry, and what we can do differently not to feel so stressed. It isn't easy, but if we are honest with ourselves it can be done.

■ We have to realize that whatever we do affects other family members. Although family members have not gone through the physical challenges, they also experience the emotional stress of your condition.



■ Talk about your feelings and establish your core value. A core value is the four things you most value in life listed in the order of importance. A powerful way to handle stress is to think of it in relation to your core value. For example, let me share mine with you: 1-my wife, 2-my boys, 3-my faith and 4-my job. Lets say I lost my job and I let the stress from that take over my life. I should remind myself that if I lost my job, my wife will still love me, my boys will love me, God won't look down on me, and I can always get another job. Now I can stay on an even keel and not feel so stressed.

■ Exercise is also important in helping to deal with stress. That is because exercise helps to improve moods and feelings. Follow an exercise program your physician has approved.

■ Keep a diary. When people write down their feelings, whether they are happy or sad, angry or content, they feel better after they are finished. Do this each day.

■ Keep your sense of humor. Humor is important in everyone's life. Try to find something funny in everything that happens.

These are ideas that will help you to lower your stress to a manageable level.

*This article was adapted from presentations at the 1994 U.S. Transplant Games Family Focus Symposia on Managing Stress and How to Live with It.*

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