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HEALTH CARE TEAM

Family Focus

The Renal Community's Newspaper

VOLUME 8

NUMBER 3

WHAT IS YOUR ROLE ON
THE HEALTH CARE TEAM?



The Health Care Team: Playing To Win

by Paul E. Teschan, MD

The “health care team” in part refers to a group of trained professionals, including a doctor, nurse, dietitian, social worker, technician, and maybe a receptionist or secretary, too. These professionals provide you with your diagnosis and instructions or necessary procedures for your treatment. More recently, what they do for you may be influenced (and sometimes controlled) by the managed care managers, who often have no medical training. Occasionally “risk-managers” and “quality-control managers” may also get involved in the health care team.

The most important person on the health care team is you! Staying healthy can be thought of as a kind of game in which you are the main player on the health care team. And members of your

family, perhaps even your closest friends, are also players whose job is to learn with you and to help you win in every way they can.

While the professionals work as a team, they're really not the players — they're your coaches. They don't have your disease, they don't follow the instructions or have the treatment done to them — you do. As your coaches, they want you to succeed, to do well, to win, but they can't play the game for you! You are the player who does whatever winning or losing there is to be done! But health care professionals are trained in the habit of giving directions and may prescribe for you rather than coach you. So you should let them know, gently and firmly, what is the best way you think they can help you learn about your treatment.

As a coach of some winning players with kidney disease, I can tell you how you can win. This program works!

① Make up your mind that you (and your health) are worth the effort. You are a unique and precious person, and your health, fitness and wellness are worth working for!

② Let your health care team know that you intend to be the “lead player” and that you want them to stick with you and coach you on how to take charge of your health; manage your blood pressure, diet and medicines; know what dangers to avoid; and help you understand the reasons for what you need to do.

③ Bring the supporting players, your family or friends, into the picture so they can learn enough to understand

WHO IS THE HEALTH CARE TEAM?

Here are descriptions of some of the members of the health care team and how they help contribute to your care:

▶ **Nephrologists** are the “kidney doctors.” Nephrologists are doctors who have advanced training in treating kidney disease. They are responsible for medical care during dialysis treatments, and may also be responsible for care before and after a kidney transplant.

▶ **Nephrology Nurses** are licensed, registered nurses who have specialized experience in the care of patients with chronic kidney failure. They coordinate patient care with other team members. Nurses may train patients to do home hemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and continuous cycling peritoneal dialysis (CCPD).

▶ **Renal Nutritionists** are registered dietitians who have specialized degrees in dietetics. They know what foods kidney patients should eat and help patients plan their meals. They help individual patients deal with nutrition problems based on their unique needs. Their overall goal is to promote the best nutritional intake to ensure the patient's optimal health.

▶ **Nephrology Social Workers** are licensed or certified in clinical social work and provide counseling to help patients and their families cope with kidney disease and changes in the family, home, workplace and community. They identify sources of emotional support, as well as services within federal, state and community agencies that patients can access to improve their quality of life.

▶ **Patient Care Technicians** are directly involved with the patients' dialysis treatments. They may be responsible for starting and ending each treatment, and for monitoring patients before, during and after treatments.

▶ **Renal Technologists or Technicians** are responsible for maintaining dialysis machines and water quality in the dialysis facilities. They order dialysis supplies and perform reprocessing of dialyzers.

▶ **Secretaries or Unit Clerks** may be the first people patients meet at the unit. They may help answer patients' questions or direct them to the health care team member who can help them.

▶ **Financial Counselors or Billing Personnel** can answer questions about insurance coverage, payment or billing.

▶ **You** are the most important team member and must work with all of the above professionals to stay healthy!



The patient is the most important member of the health care team.

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FROM THE EDITOR



Karren King

The area of chronic renal failure is unique for many reasons. For example, this is the only diagnosis, combined with the need for dialysis or transplantation, that entitles a qualified individual to receive Medicare coverage without being at least 65 years of age or receiving Social Security Disability for a minimum of two years. As part of this extension of Medicare coverage, the federal government mandated that those who provide care to ESRD patients meet certain requirements. One such requirement was that care should be delivered by a multidisciplinary team, including a physician, nurse, social worker and dietitian. The Federal Register goes even further to specify the education and credentials team members should have, as well as the types of services they should provide to you. The requirements for this team are, once again, unique.

Of course I can only speculate on the reasons for including all of these individuals on your care team. I do, however, have to credit the government with being farsighted enough to realize that when someone is diagnosed with a chronic illness, it will impact many aspects of his or her life. Thus,

individuals with very different but complementary roles, who possess the skills necessary to assist with your physical, social, emotional and nutritional needs, are required to be available to you. This issue of *Family Focus* is devoted to the health care team, with several of the articles focusing on its various members in an effort to clarify their roles in your care.

The federal government also recognized that you are a major "player" on your team. It mandated that you should be involved in planning your care because, after all, it is YOUR care! Several articles highlight your importance and role as the main team member. Lastly, keep in mind that it is up to you to use the professionals on your team to assist you in leading a quality life. Communicate with them and learn from each other. Together you can really make a difference. **FF**

Karren King
for the Editorial Board

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 dropping us a note or by giving us a call at (800) 622-9010.

Next Issue NKF Family Focus Spotlights NKF-Dialysis Outcomes Quality Initiative

Editor's Note: Our next two issues will spotlight NKF-DOOI and Rehabilitation. 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.



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In Memoriam Irv Wolper

I would like to dedicate this issue of *Family Focus* to a very special person. Although I realize that doing this is somewhat unique, so was the person, the late Irv Wolper, to whom I am dedicating this issue. Irv had been on hemodialysis for many years, yet he did not allow his treatments to interfere with his goals. Luckily for the National Kidney Foundation, Irv's goals encompassed the NKF's vision statement, "Making Lives Better." He set out to do this for those on dialysis in many ways. He began by dedicating countless hours to the NKF of Florida's Patient Services programs, going to their office daily as a volunteer. He was also a member of their Executive Committee and Board of Directors. I got to know Irv when he began attending the National Kidney Foundation's national quarterly meetings, where he served on the Patient Services Committee and the Patient and Family Council Executive Committee. Irv's dedication to the NKF and what it stands for was exceptional. Although the NKF has lost a true friend, our lives have been enriched by having had the opportunity to know and work with him. He will be greatly missed.

Karren King

The Role of the Renal Dietitian

by Sharaine Fisher, MS, RD, LD

Most people have very little idea about the role of the dietitian on the health care team or the specialized training required to be a renal dietitian. Your dietitian is a highly trained nutrition professional who understands the interaction of food and nutrients in the body in health and disease. The renal dietitians' unique training allows them to know what foods and amounts are best for kidney patients. It is this knowledge that makes the dietitian such an important part of your health care team.

One of the most important roles performed by your dietitian is education. Imagine that your doctor asks you to cut down on foods with potassium, but doesn't tell you anything to avoid except bananas. Since bananas are not the only source of potassium, you may not be able to solve your problem without some additional information. A dietitian will teach you which foods to avoid or limit. In other words, your dietitian helps you learn the "how to" of your diet.

Diet education is an essential part of learning to successfully manage kidney disease before dialysis, at the onset of dialysis, during treatment and even after transplantation. Every new dialysis patient spends some time with a dietitian learning that the renal diet is one of the most important parts of treatment. In fact, following your diet is just as important to your health as taking the medications prescribed by your doctor. A skilled dietitian can help you understand what foods are allowed on the renal diet and help you fit the guidelines into your lifestyle. Renal dietitians can often provide recipes and hints to make food choices easier and tastier.

Research has shown that dialysis patients who are well nourished and have good levels of protein in the blood do much better on dialysis, get

fewer infections and spend less time in the hospital. Malnutrition has been identified as one of the biggest problems faced by patients on dialysis. Despite the best medical care, many patients still battle malnutrition. Dietitians understand why people on dialysis have problems eating and can help them meet their nutritional needs. Your dietitian can help cross the bridge from malnutrition to health.

As you adjust to dialysis, you may want to get back to work or start an exercise program. Again, nutrition will be one of your main focuses. If you are diabetic, your renal dietitian can help teach you how to manage glucose levels during exercise and can recommend some strategies to improve your workouts just by making the right food choices and following some simple guidelines. Most patients find that they call on their dietitian regularly as they work to regain their previous health and activity levels.

Your renal dietitian is knowledgeable about laboratory values and the effects your diet can have on those values. Each month when you have your labs drawn, your dietitian spends time reviewing your lab report with you to be sure you understand it. If you have a nutrition lab value that is high or low, the dietitian helps you find the cause and recommends dietary changes to help correct the imbalance. Although making the changes is always your responsibility, you can count on your dietitian to be supportive and resourceful in helping you find solutions.

Some dietitians are also involved in calculating your Kt/V, which is a measurement of how well you are being dialyzed. Since getting enough dialysis can affect the quality and length of your life, this measurement is extremely important. If dietitians discover that your Kt/V is low, they

often recommend options to the other members of the dialysis health care team for increasing your dialysis adequacy. For hemodialysis, this may involve changes in your dialyzer, length of treatment, and blood and dialysis flow rates. With peritoneal dialysis, this may include dialysis volumes and frequency. Be sure to ask your dietitian about your Kt/V; it is important for patients to know their own values.




In addition to patient education, dietitians are often responsible for dialysis education. The dietitian is an

expert in such topics as vitamin/mineral metabolism, malnutrition, food composition, drug/nutrient interaction and nutrition management of chronic diseases. Education often takes place during a normal day's activity, as nurses and technicians seek expert information on nutrition-related subjects. Some education also takes place in the form of regular staff in-services led by the dietitian. Your dietitian believes that the more educated your dialysis staff can become, the better treatment you will receive.

Nephrologists consult with dietitians regularly about several aspects of dialysis care. For example, if a patient needs to have all nutrition given through a tube, or an IV, it is important that the patient gets just the right amount of protein, calories and fat, as well as the right balance of vitamins and minerals. The dietitians' background allows them to calculate the best option for each patient on an individual basis.

The renal dietitian is definitely a valuable member of the dialysis health care team and performs a wide variety of important tasks. If you have questions, ask to talk with your dietitian. The dietitian is there to assist you in making healthy diet choices so you can feel your best.

Sharaine Fisher, MS, RD, LD, is a renal dietitian at Pacific Northwest Renal Services in Portland, Oregon. 



Laughter is Good Medicine

by Connie Forrister, Cleveland, TN

I will not spend time discussing all the ins and outs that dialysis patients go through. We know them all too well — all the sad, happy, exciting, boring, fearful and fascinating things we are challenged by. There is a great deal we have to contend with on a regular basis. And if it were not for the compassionate nurses at the dialysis unit, the adjustments would be more difficult.

Every dialysis patient finds his or her own personal trick for coping with dialysis. Some elements for keeping a level head and making life as normal as possible are family involvement, hobbies and a sense of humor. You may wonder, what hobbies can you do with the rigors of dialysis? Whatever you were accustomed to before dialysis, you can continue with a few modifications. Maybe now is the time to write that book you have thought of writing about your journey through dialysis. Whatever you do, keep your family involved. Keep a journal. This vents frustration and

will keep your family informed about your feelings and needs. Keep your hands busy — it settles the nerves. Lastly, ah, have a sense of humor. Here's a sample of the things I find humor in:

I Lost as Housekeeper of the Year


I found an Easter egg behind the couch last week. I guess it reflects on my housekeeping skills. Immaculate isn't a word used to describe my housekeeping abilities. Although I don't enjoy cluttered countertops and cabinets, I'm not one of those dear women who does a spring cleaning every few months. Sometimes there are glasses in the sink and a few cluttered magazines here and there. I want those who visit to feel free to rest their feet on my coffee table. I want children to feel free to pick up and examine whatever I have sitting around.



Much of the stress in our lives is caused by our possessions. We



spend too much time cleaning, repairing, storing and caring for them. My husband, Tony, found out a few years ago that when I work, I don't do much housework. In fact, he remarked to my sister one day that I didn't do housework on Sunday, and it looked like every day of the week was Sunday. What of it?! Some things you've just got to be in the mood for, like ironing. Housework will always be there when you get through doing what you want to do.

I would rather see a glow on my child's cheek than on the silver, play board games than mop, and have laughter echoing through the house along with piling laundry. So what if you can write in the dust on my piano — make it a love note! I'm not worried that my plants talk to me, begging for water, or that there's something fuzzy growing in the dish in the back of my refrigerator. Maybe I've discovered a new strain of penicillin! Housework can wait — life can't. 



Poetry

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Long Road

by Joann Mallett

When I looked down this
long road I was to travel
Much pain and trouble
was to unravel.
My burdens were many and
oft times tears would flow.
I was neither brave nor bold
and soon it was taking its toll.
I was so consumed by anxious
fears of mine

It seemed the light
would never shine.
The lord put his arms around
me and said child you are mine.
Don't look ahead or behind.
Just walk it one mile at a time
Just trust me for each day
and each mile of the way.

Parent Connection

Children and Their Families: Valuable Members of an Important Team

by Fred Kouri, LMSW

Children who have end stage renal disease (ESRD) and need dialysis or a kidney transplant have many medical, social and educational needs that are best met through teamwork. The goals of dialysis or kidney transplantation services are to treat the effects of kidney disease, prevent the disease and its treatment from interfering with your child's development, and offer education and referral services to lessen the disease's impact on your family.¹ Together with doctors, nurses, technicians, dietitians and social workers, you and your child play critical roles on the health care team that works to meet these goals.

Impact on You

As caregivers, you realize how your child's need for dialysis or a kidney transplant impacts many aspects of your life, including your career, financial and insurance matters, and other family members. Without a doubt, the family is the most important constant in the life of a child with kidney disease. Therefore, the health and well-being of your entire family is important to the medical team. Please talk with the medical team any time you have a concern so that they can help you find a solution.



“A chronic illness does not change the basics of child rearing; whether ill or healthy, children need to grow up safely and with the support of family in order to develop self-esteem, self-reliance and autonomy.”



Impact on Your Child

From birth through adulthood, your child will have to face medications, doctor appointments and medical tests. However, focus on the individual needs of your child and not just his or her medical requirements. Although it is difficult at times, it is more helpful to emphasize health and not illness. How children experience the impact of a chronic illness may depend upon the age they started dialysis or needed a

transplant. As caregivers, you must be aware of your child's educational, emotional, social and vocational needs, and how they compare to the needs of children without kidney disease. This information will help you to choose services and goals that are most appropriate for your child. The entire team needs to be sure that they are always effectively communicating with the child and that the team's expectations match the child's abilities.

Here are some ideas on how to work with children to ensure that they always feel like an important part of the team:

Infancy: Schedule developmental screens and early intervention studies to help your child gain important learning skills. Offer reassurance, stability and love.

Toddlers: Give toddlers choices, clear limits and as much supervised control as possible. Allow them to explore their world in a safe manner.

Pre-Schoolers: Help them understand health matters and explore their ideas about what is happening in their lives. Reinforce communication and cooperation at home and in the hospital. Teach them to help with simple tasks related to their care at home. Medical play is an excellent way for children to become comfortable with their health care needs.

School-Age Children: Explain things at their developmental level through the use of art, play and activities that explore feelings and ideas.



Discuss their ideas of “normal.” Give them an opportunity to take control of some aspects of their health care.

Adolescents: Promote normal growth and development, peer interaction and open communication with family and medical staff. Discuss issues of vocational development, social skills, personal strengths and sexuality. To avoid the normal adolescent struggles with independence, focus on the strengths and abilities of the teen rather than limitations.

A chronic illness does not change the basics of child rearing; whether ill or healthy, children need to grow up safely and with the support of family in order to develop self-esteem, self-reliance and autonomy.¹ Your child has the opportunity to be autonomous by participating in his or her own treatment. Questions or concerns about how to increase your child's involvement in treatment need to be directed to your physician, nurse, social worker, dietitian or child-life specialist. They can help you and your child develop a plan that meets your needs.

How would you respond if someone asked you, “What has dialysis kept you from doing?” In a recent →

Changing Health Care Environment



government agencies that pay for health care and dialysis want reports from the doctor and other members of the health care team that show you are receiving quality health care. So much complicated information is produced and required that it is becoming impossible to manage without using computers and computer networks. Some dialysis centers now use electronic charting. Information is transferred electronically from the dialysis machine directly into the patient's chart. Dialysis nurses and technicians type information directly into a computer instead of writing it in the chart. Computer programs have been developed that can organize information in such a way that it is easier to understand, helping to improve your care. All members of your health care team will eventually have to learn how to use these new technologies.


An interesting development in your care is the push to evaluate your dialysis "life line" — your dialysis access — more carefully. Some kidney doctors have become very specialized in the care of vascular access. There is a new kind of kidney specialist called an "interventional nephrologist." This is a kidney doctor who has learned how to evaluate dialysis grafts with special X-ray procedures such as angiography and ultrasound. During an angiography, dye is injected into the graft and X-rays are taken. This procedure is used to find out why a

graft is not working properly or has clotted. These specialized doctors also use innovative techniques to remove clots from a dialysis graft using catheters or tiny balloons. Problems with vascular access have become the "Achilles heel" of dialysis and are a major cause of under-dialysis and resulting complications. These problems with vascular access account for 25 percent of the hospital admissions and costs associated with end stage renal disease.

It is becoming more apparent that prevention of complications and better quality of care before a patient requires dialysis may not only delay the need for dialysis, but may also affect how patients do when they are on dialysis. This new knowledge is causing a change in the types of research studies being performed and in the education and care of kidney patients. It is hoped that education of family physicians and internal medicine specialists will result in earlier referral of kidney patients to kidney specialists. The sooner a kidney doctor sees a kidney patient, the more likely that the patient will receive the kind of care and education that will result in better health.

Everything that I described above has the potential to provide better care and health for kidney patients, but there are also some risks. Managed care and capitation provide a fixed amount of dollars for patient care. If the renal health care team spends more money

on patients than has been allowed for their care, more dollars are not paid. The money paid for each patient is an average of what the managed care company thinks the care should cost. Capitation relies on the fact that some patients cost more, but others cost less. There is also a risk, however, that expensive medications or treatments may not be ordered because they are too costly. The health care team has to be very careful to manage the available money so that patients receive the care they need. At this point it is uncertain how capitation and managed care will affect the care of kidney patients, and whether new treatments and equipment will be limited because they are expensive. Capitation and managed care may not be the best way to care for kidney patients, who have a complicated disease and need expensive treatments and medication. It is possible that the more traditional way of caring for kidney patients combined with advances in treatment, education and the proper use of clinical practice guidelines and other standards may be more appropriate to ensure the quality of care kidney patients deserve.

Chaim Charytan, MD, is the president of the Renal Physicians Association. He is a clinical professor of medicine at Cornell University College of Medicine and chief of the Renal Division at New York Hospital Medical Center of Queens in Flushing, New York. 

The Health Care Team: Playing To Win


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how they can help you succeed. You can also bring others onto your team: your pastor, rabbi, priest or other counselor. Don't try to play this game alone!

④ Of course there's a lot to learn, whatever the stage of your kidney function. But be of good cheer; you are not expected to learn everything at once! Over time, following the coaching of qualified professionals and with the help of your supporting players, you can become a competent and confident manager of your health. You can learn what you need to do so you can do what you want to do with

your life and time, beyond whatever medical condition you may have. So it's your decision. Yes, you have the disease; but the disease doesn't have to have you!

Paul Teschan is a professor of medicine, emeritus, at Vanderbilt University in Nashville, Tennessee.

The NKF brochure "The Health Care Team" is available to provide additional information about the people involved in your health care and treatment. To get a copy, call the NKF at (800) 622-9010. 



What You Should Know About and Expect From Your Social Worker

by Rosa A. Rivera-Mizzoni, MSW, LCSW

As a dialysis or transplant patient, you should know who your social worker is and the services he or she provides.

It is important for you to know the qualifications of your social worker. You want your doctor and other team members to be qualified, so you should expect your social worker to be qualified, too. According to the rules that govern end stage renal disease (ESRD) programs, every patient is to have access to a "qualified social worker." This means that the social worker has a master's degree from a college/university social work program that is approved by the Council on Social Work Education (CSWE). If your social worker does not have a master's degree, then he or she must have been hired to work in ESRD prior to September 1, 1976.



"When it comes to information and referrals, you should expect your social worker to be knowledgeable about the resources and services available in your area."



There are eight basic services you should expect from your social worker:

1. psychosocial evaluation
2. service coordination
3. group work
4. information and referrals
5. counseling of patient and family/loved ones
6. treatment planning and collaboration
7. advocacy
8. patient and family/loved ones education

Each of these eight areas is meant to enhance your emotional and social quality of life and ensure positive outcomes. You may need some or all of these services at any point in your life. We will look at these areas briefly and see how they can impact you.

The **psychosocial evaluation** is one of the first points of contact between you and the social worker. It is important for you to share your story of how you view your family, health

care, losses, finances, rehabilitation, cultural and spiritual beliefs, as well as your successes. This information forms the foundation for how best to provide your care, given your strengths and areas that could benefit from interventions. This evaluation will be repeated at times as a way of updating your story and documenting your journey through ESRD.

In the area of **service coordination**, you can expect your social worker to work with you to arrange whatever services you need, such as home health or financial services. You may also be asked to work with your social worker to secure new services and decrease duplicative services wherever possible.

Group work is an area that can result in many creative activities in a facility. Some facilities, instead of running their own groups, will refer patients and their loved ones to the National Kidney Foundation (NKF) or American Association of Kidney Patients (AAKP) chapter meetings, local patient groups or patient/family education days. The main functions of group work are to provide peer support and education. Some creative forms of group work include informal support in the waiting area between dialysis shifts or during transplant or home dialysis clinics; informational sessions in the unit during hemodialysis; and video screenings during hemodialysis or clinic visits.

When it comes to **information and referrals**, you should expect your social worker to be knowledgeable about the resources and services available in your area. This knowledge will help your social worker quickly find services to meet your needs. You, as patients, should also share information on programs in your community that you hear or read about. This will help your social worker to keep a current directory of services that will benefit all patients.

Your social worker, as part of the **treatment planning and collaboration** team, while maintaining confidentiality, provides and exchanges information about you that will help the entire health care team to meet your medical needs. It is your responsibility to keep your social worker up to date with what is going



on in your life so he or she can represent you fully.

Oftentimes, **advocacy** is seen as directly defending the patient. This is one aspect of advocacy, but other opportunities to work on your behalf include educating community agencies on the needs of ESRD patients so services can be made available to you. Lobbying before local, state and federal committees can help ensure that programs, monies and access to services include ESRD rather than exclude it. Some examples of this type of advocacy have been the extension of Medicare programs to include ESRD and the changes in the Medicare coverage of transplant medications. Don't be surprised if your social worker asks you or your family to write letters to government officials on legislative issues that will impact you and other ESRD patients.

The last two areas, which are critical to the emotional health of patients and their loved ones as they journey through ESRD, are **patient and family education and counseling**. Remember when you first heard about ESRD and how you and your loved ones felt? In order to begin to understand and cope with the many aspects of ESRD, you need information. Oftentimes, however, because you are overwhelmed and frightened, you cannot really clearly hear or understand the information that is given. In such cases, it is helpful for information also to be shared with your loved ones. They, like you, need to know and understand what is happening and how this will affect you and them. Social workers are specifically trained to provide information to help you make choices, such as treatment type, based upon





PATIENT AND FAMILY CORNER

The Balancing Act

by Maurie Ferriter

Have you ever signed a piece of paper while on dialysis that a nurse or social worker said was necessary for the facility's records? You are not the only one. This is how many people are approached to sign their long- and short-term care plans. Care plans are documents that dialysis facilities are required by federal regulations to have for all the patients they are treating. Each person is supposed to participate in designing his or her care plan. Most people, however, do not participate and wind up signing a piece of paper brought around by a nurse or social worker. A lot of people don't even bother to read their own plans. Care plans should reflect the treatment strategy of the health care team, of which the patient is an active member. People with kidney disease have the right to participate in planning their own care.

Patients' rights go further than helping to develop care plans. You have a right to be educated about your disease and treatment options. You should be able to ask questions of your caregivers and get answers that are clear and easy to understand. Sometimes you can do this by making an appointment to see the doctor, dietitian or other team members when they are not so pressed for time. The bottom line, however, is to get all of your questions answered by the right people. At times, there may not be a clear-cut answer. You may have choices to sort through. The main

thing is to be involved in looking at the possible choices and deciding which option to act on.


Making decisions is a way that patients exercise their right to be involved in their health care and own up to the responsibilities that go along with that right. It's kind of like driving down the highway. Someone has a right to drive a car on the road but



also has the responsibility of driving on the correct side of the road and obeying the speed limit. People receiving treatment for end stage renal disease have many rights, but also many responsibilities. Rights and responsibilities must be kept in a state of balance in order for them to work effectively for all people involved. Many people hear the words when being told of their responsibilities, but choose not to act responsibly. Skipping or arriving late to dialysis treatments is an example of this. Many people think actions like these only impact the person who is on dialysis, but they are also not fair to other patients and other health care team members.

People have a right to be treated with dignity and respect. This applies to both patients and other members of the health care team. When starting a dialysis treatment, nurses or technicians do not put the needles in with the intention of having a problem. We all know bad sticks happen and, when they do, chances are the nurses or technicians feel bad about them. After all, it reflects on their ability to perform their job well. People who are abusive or threaten nurses or technicians in these situations are not acting responsibly. There are many ways to get your point across without attacking a person's dignity or threatening personal harm.

Reaching a balance between rights and responsibilities as a member of the health care team can be a lot of hard work. It can also be a very rewarding experience for all involved. There are many ways to measure this balance. One opportunity to measure yourself can be the next time a nurse or social worker brings around a care plan for you to sign. If you know the plan, had input in formulating it and feel it is what you want for your care, then chances are things are balanced and will stay that way.

Maurie Ferriter has been receiving treatment for kidney disease for 16 years. He was a home hemodialysis patient and currently has a kidney transplant. 

What You Should Know...

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your own personal circumstances. They can also help you deal with your fears and concerns as you work with the information you receive. Social workers can assist you in reorganizing your life in ways that will allow you to make good choices about rehabilitation, finances, treatment modalities, sexuality, family life, child rearing and child bearing, and many other aspects of life.

Counseling is a key intervention, which impacts your emotional health and the outcomes of your ESRD journey. You can expect the social worker on the health care team to provide you with counseling in areas such as crisis intervention; behavioral therapies; individual, couples and

family counseling; termination of treatment; rehabilitation; advanced care planning; sexuality and stress reduction, to name a few.

As an ESRD patient or family member, you have access to qualified social workers as part of your team. They are there to help you achieve the best outcomes possible, not only medically, but emotionally and socially. Your social worker can become a key supporter on your journey through ESRD.

Rosa Rivera-Mizzoni, MSW, LCSW, is a social worker at Circle Medical Management in Chicago, Illinois. 

KEEPING YOU FIT:

The Role of the Fitness Professional

by Susan Carey, MS

As fitness and exercise become more important for the rehabilitation of renal patients, there is a great need for experienced, professional fitness experts. While most dialysis units do not have a fitness professional on staff, they could prove to be valuable contributors to the care and rehabilitation of renal patients. Responsibilities of the fitness professional on the health care team may include patient assessment, exercise education, exercise prescription, referral to physical therapy or cardiac rehabilitation, and involvement in the long- and short-term care plans of the patient.

Once you have expressed interest in an exercise program, you would typically be assessed by the fitness professional. This assessment may include simple physical function tests to find out your gait, endurance, balance, flexibility and/or strength. You may also have to answer a questionnaire about your quality of life and your ability to do household chores or physical activities. Such assessments are useful tools in developing your exercise prescription and learning which exercise education issues relate to your individual needs. Physical function tests are also important in monitoring your progress or decline in physical ability.

After determining your current physical ability, the fitness professional would then educate you on the benefits of exercise. Education may include videos, brochures, booklets, or simply discussion between the fitness professional and you. The educational materials would be specific to your individual needs based on the results of the physical activity assessment. You would then receive an individualized exercise prescription, which would have to be approved by your doctor before you actually start. A complete exercise prescription would include cardiovascular, stretching and strengthening exercises. During the course of your exercise program, the fitness professional would also take care of follow-up, monitoring your progress and trouble-shooting.

In planning and developing the exercise prescription, the fitness professional may decide that a

referral to a physical therapy or cardiac rehabilitation program might be a more beneficial approach to exercise. Discussion would then take place between the fitness professional, your doctor and the social worker to enable such a referral. The social worker and the fitness professional could then work together on issues related to the referral, such as insurance or transportation. Full integration of exercise into the care plan depends on the involvement of the fitness expert, as well as the entire dialysis center staff.

The ongoing involvement of the fitness professional would ensure that exercise is included as a form of rehabilitation in your long- and short-term care plan. The fitness professional would also participate in the monthly patient review meetings to update the doctors and primary care nurses on your progress.

Who Is the Fitness Professional?

The role of the fitness professional is very specialized and best filled by an individual who has a formal education and experience in clinical exercise physiology. Professionals with this background typically have titles such as exercise physiologist, exercise specialist or physical therapist. Most clinical exercise physiologists/specialists are found within the cardiac or pulmonary rehabilitation arena. Within this setting, the fitness professional prescribes cardiovascular, strengthening and stretching exercises to help the patient rehabilitate and cope with disease. Physical therapists generally work with patients on a referral basis, assisting them after an injury or fall, or they work with patients with musculoskeletal problems, helping them develop the strength and techniques needed to do daily activities.

If the fitness professional is not a part of the full-time or part-time staff at the dialysis unit, it may be possible to hire an exercise physiologist/specialist or physical therapist on a contract basis. The unit's staff may be able to handle the majority of the responsibility of developing an exercise program (recruiting patients, assessment, getting

physician approval), and then the contracted fitness professional would come in to do the exercise education and prescription. Follow-up and monitoring progress would then be the responsibility of the unit's main staff. The fitness professional could also offer an educational in-service training to the staff and patients about exercise for people on dialysis. As new patients enter the unit or patients express interest in the exercise program, the contracted professional can be invited back to start them on their individual programs.

Another way to get a fitness professional is to invite student interns into the unit. Under the supervision of the head nurse or social worker, the interns can work with the patients in prescribing an exercise program and checking their progress. These student interns should be upperclassmen at a college or university, pursuing degrees in exercise physiology/science, physical therapy, health education or biology. The students in the exercise physiology/science and physical therapy programs should have a firm grasp of the basic concepts of exercise prescription. However, they may need to learn more about end stage renal disease (ESRD) and its potential physical limitations. There is quite a bit of current material available that will help students to educate themselves on specific concerns of exercise for ESRD patients.

How to Stay Fit Without a Fitness Professional

Since using exercise to rehabilitate dialysis patients is a relatively new practice, it may be very likely that a fitness professional is not available at your unit. A few units, however, have implemented some form of an exercise program without a fitness expert. If your unit has not, you need to be proactive. Take it upon yourself to ask the staff at your unit (nurses, social worker, doctors) for some information about exercise. Specifically, you can ask to view the video *Feeling Better with Exercise: A Video Guide for People on Dialysis*. An accompaniment to this video is the booklet "Exercise: A Guide for People on Dialysis." The video and booklet will provide you with



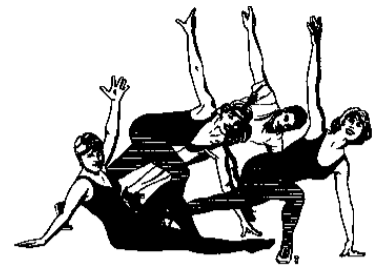
information on getting started with exercise, as well as describing specific exercises for you to do to increase your strength and flexibility. Your social worker is probably aware of this video and booklet and should be able to provide them for you. You can also receive this information directly from the Renal Rehabilitation Resource




Center by calling (800) 468-7777. The National Kidney Foundation's brochure "Staying Fit With Kidney Disease" can also help you understand the importance of exercise while on dialysis and get you started with a program.

Being proactive in your health care is the first step to rehabilitation. Exercise can help you to feel better by allowing you to have more energy and a sense of control over your own well-being.

Be sure to let your health care team know that you want exercise to be an important part of your treatment. By impressing this upon them, they will be better prepared to help you start your exercise program. If a fitness profes-



sional is not a part of your unit's current staff, then you may have to take control and exercise on your own. Check with your doctor before you begin any exercise program and then... GO FOR IT! 

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

Patients and Families Participate in NKF Annual Meeting

The National Kidney Foundation held its 48th Annual Meeting October 23-25 in Philadelphia, Pennsylvania. Thanks to some instrumental Maryland volunteers and the New York/New Jersey affiliate, busloads of registrants came from Maryland and the New York/New Jersey areas to attend the program. More than 269 participants attended to learn from one another and share common experiences.


In keeping with the constituent councils' overall goal of empowerment, all registrants could participate in various forums that presented them with the necessary information and skills to make informed decisions to take control of their lives and look toward the future. Topics covered ranged from "Knowledge, Choice, Control" and "Self Empowerment" to "Coping." Many joint sessions were held with the transAction and National Donor Family Councils, where patients and

families were able to learn about a variety of topics including "Exercise and a Healthy Attitude" and "Living Donation."

A highlight of the program was the open-mic coffee house, which was an open session for people to share personal stories, read poetry and give thanks and

acknowledgment to their loved ones and donors. As participants shared smiles, tears and embraces with new friends, the bond and energy between patients, recipients and donor families grew stronger. A roundtable forum was also offered, where participants could learn about transplantation, diet, living donation, laparoscopic surgery, as well as many other topics of interest.

The weekend concluded with a moving keynote address and candlelight ceremony honoring those living with kidney disease,

those who have been transplanted and those who have given the gift of life. 



Information for patients, donor families and recipients was available at the NKF exhibit.

The Grievance Process

by Mary Sundell, LRD

What is a grievance?

For individuals with end stage renal disease (ESRD), a grievance refers to a serious problem with the services received for the treatment of kidney failure. Examples of this could be quality-of-care or access-to-care concerns, or communication difficulty with the health care team involved in the treatment process.

How can concerns be resolved?

Resolution of grievances at the facility level is strongly encouraged. This may be done informally by simply discussing your concern with the appropriate people and coming to an agreement. If this approach is not used or does not work for you, you may try a more formal approach.

What do I do if I have a serious concern?

Each ESRD facility is required to have a written procedure for resolving patient grievances. Patients must be allowed access to these policies and procedures for examination and use.

A grievance policy is designed with the following in mind:


- to encourage open communication between patients and facility staff regarding issues, problems or complaints
- to help deal with problems as quickly as possible
- to help patients feel comfortable discussing their concerns without fear of retaliation

If an ESRD patient chooses to write a grievance, it is important to state the facts. Include the who, what, where and when regarding the concern. An opinion of what should be done to resolve the issue could also be included. If the grievance is not settled in a manner that is satisfactory at the facility level, the concern may then be reported to the local renal network.

How can ESRD Networks help?

The ESRD Networks are under contract with the Health Care Financing Administration (HCFA) to fulfill a set of requirements within a specific geographic area. These

requirements include: quality improvement, grievance resolution, vocational rehabilitation, information sharing, and management of provider and patient information. All Networks are required to have a grievance process so they can act as an objective third party to review written grievances from patients. These grievances are confidential, so patients do not need to fear discrimination or retaliation. The Network may then act as investigator, facilitator or referral agent. The outcome of the Network's decision will be provided by written notification to the person who began the grievance process.

ESRD facilities and ESRD Networks respond to many patient concerns every year. Frequently, concerns are the result of poor communication. The importance of good communication cannot be stressed enough to effectively identify and respond to concerns before they become grievances. 

Mary Sundell is a consumer services coordinator of Renal Network 11.

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Lori James is a product specialist in Riverdale, Utah.

The Patient and Family Council:

Helping You Realize Your Role as a Member of the Health Care Team

As the patient, you are the most important member of the health care team. Other team members have a responsibility to ensure that the patient receives the best possible care, and it is the right of patients and families to make informed choices about treatment. Sometimes, however, the physical and emotional demands associated with kidney disease make it difficult for patients and families to take an active role on the health care team. Also, many patients, even if they know they have a right to participate in their care, remain passive because they don't have all the information about their health care and treatment options.

In 1996, the National Kidney Foundation (NKF) created the Patient and Family Council (PFC) as a way for patients and their families to become actively involved in the activities of the NKF. Being a member of the PFC gives patients and families access to the latest information on the treatment of kidney disease so they can make informed choices and decisions about care and communicate with the health care team.

The PFC provides information and services to its members, including:

- free subscription to the renal community's premiere publication, the NKF's *Family Focus* newspaper, distributed quarterly, which features articles by individuals with kidney disease, their families and renal professionals
- the Patient and Family Council Legislative Report, which keeps members up to date on legislative issues relevant to the renal community



The 1998 Patient and Family Council Executive Committee.

- Medical Updates, which inform patients about the latest happenings in the treatment of kidney disease
- patient surveys, which collect input on NKF projects and assess patient needs in order to create relevant future programs and services
- an Internet site for patients and families (www.kidney.org)
- the opportunity for members to review NKF materials to ensure that they are written in patient-friendly terms
- an educational program for patients and families at the NKF Annual Meeting
- access to all NKF publications

The input of the Patient and Family Council members is crucial to the work of the NKF in accomplishing its ultimate goal: the total eradication of all diseases of the kidney and urinary tract. With the PFC's rapidly-growing membership of over 8,000, the NKF draws on its support and input in addressing many of the issues affecting patients with kidney disease. The PFC acts as a liaison between the NKF and the renal community and as a legislative voice within the NKF on patient issues. Here is a look at how active the Patient and Family Council members have been in the NKF and in the fight against kidney disease:

- Members serve as volunteers at the national and local levels of the National Kidney Foundation. Many members are advocates in their dialysis centers and local areas, motivating other patients to become actively involved in their care.
- In 1997, the PFC conducted its first membership needs assessment and 723 members participated. The data that was collected will help identify the current needs of the PFC membership so that necessary programs for patients and families can be developed. Needs assessments will continue to be conducted on a regular basis.
- A random sample of PFC members took part in a survey to determine what patients with kidney disease feel is their role in implementing the NKF-


DOQI Clinical Practice Guidelines.

Information from this survey will be published in a later issue of *Family Focus*.



- In winter 1997, many PFC members lobbied their congressional representatives and others volunteered to participate in a patient testimonial to respond to the Health Care Financing Administration's (HCFA) policy to deny Medicare coverage for erythropoietin (EPO) for dialysis patients with an average hematocrit rate above 36.5 percent. The result of these and other efforts was successful, and in March 1998, HCFA restored the option of medical justification for patients who need a hematocrit target above the 36.5 percent ceiling, but it did not raise the ceiling for other dialysis patients.

- PFC members were involved in planning and providing topic and speaker suggestions for the PFC patient educational program at the NKF's Annual Meeting. The patient educational program was open to patients, families and friends, and provided an opportunity for participants to learn about important issues in the renal community, have many of their questions answered, and meet the Patient and Family Council and NKF leadership, as well as other patients and families. The 1998 program topics included: "Rehabilitation," "Depression Before and After Transplant," "NKF DOQI: Adequacy, Anemia and You" and "Self-Empowerment: The Patient as a Member of the Health Care Team."

These are only some of the ways in which the PFC has taken an active role in issues related to kidney disease and its treatment. Membership in the Patient and Family Council is free and your involvement can be as little or as much as you want. In becoming a member of the PFC, you can take advantage of the many opportunities to empower yourself and become more active in your health care. For more information on membership, call the NKF at (800) 622-9010. *Remember, you are the most important member of the health care team!* 



MAIL BOX



We want to

hear from you!

Drop a note in our

mail box at:

Family Focus

c/o National Kidney Foundation

30 East 33rd Street

New York, NY 10016

Dear Editor:

I am currently having dialysis treatments at Alquippa DCI in Alquippa, PA. The reason for this letter is to acknowledge the people involved in my treatments, such as doctors, social workers, dietitians, and especially the nurses. I've only been on dialysis for a short time now. From what I know and have seen, these people deserve a thank you for doing their jobs well. Without them, I do not know where I would be physically, mentally, spiritually, and most important, emotionally. All people associated with dialysis treatment deserve a lot of credit and should be recognized. They are a great and special bunch of people. Thank you and keep up the good work.

*Joseph T. Sims
Alquippa, PA*



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