THE INSIDE WORD ON COMMUNICATION IN THE DIALYSIS UNIT

By Karren King, MSW, ACSW, LCSW

We asked and you responded! Several months ago the National Kidney Foundation randomly sent a survey to 5,000 people who receive Family Focus directly at their homes. Since the survey focused on communication between those on center hemodialysis and their health care providers, only those surveys (474 in total) returned by people who were currently on hemodialysis in a facility were examined.

SURVEY RESPONDENTS

So, who responded? Most have been on dialysis, not counting the time they were transplanted, from 4 to 10 years. About two-thirds of respondents dialyze in centers owned by corporations or large dialysis chains. The largest percentage of those who responded was between the ages of 50–69 (45%) and approximately 97% had completed high school or further education.

HOW OFTEN YOU TALK WITH TEAM MEMBERS

Most respondents named nurses, not surprisingly, as the staff person they most commonly talk with in the dialysis unit. Seventy percent of those who responded talk with their nurse once per week. One third of respondents said they talk with their kidney doctor one time per week. However, another third told us they see their kidney doctor only once per month. Almost half of those who responded also see their dietitian about once per month. The social worker is the team member seen least often, with approximately 17% of those responding saying they “almost never” see their social worker.

One of the reasons so many people on dialysis only occasionally see the social worker is likely related to a formula that most dialysis corporations have that limits the amount of time social workers and dietitians may be paid each month for working in the facility. For example, if your facility has 50 people who dialyze, the facility may only pay for one-hour social work and dietitian sessions per person on dialysis per month. This means that if someone has a crisis in the facility, the social worker may spend many of those hours working with that person, and as a result may not see many of the others who dialyze there.

WHAT YOU TALK ABOUT WITH TEAM MEMBERS

When you talk with these staff members, what do you typically discuss with them? According to the survey responses, the top five subjects discussed with each of these four groups of providers are listed in order of how often they are discussed in the next column:

- **Kidney Doctor**
  1. Medical problems related to dialysis
  2. Dialysis treatment
  3. Death of other patients
  4. Medical problems not related to dialysis
  5. Lab work

- **Nurse**
  1. Dialysis treatment
  2. Death of other patients
  3. Lab work
  4. Medical problems related to dialysis
  5. Medical problems not related to dialysis

- **Dietitian**
  1. Diet
  2. Meal planning
  3. Lab work
  4. Death of other patients
  5. Dialysis Treatment

- **Social Worker**
  1. Travel plans
  2. Insurance
  3. Transportation
  4. Financial concerns
  5. Death of other patients

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Communication is the cornerstone of our relationships: with those we meet in dialysis, our family, friends and others we encounter in everyday life. The National Kidney Foundation and the Family Focus Editorial Board strongly believe that you are not only a member of your health care team—you are the most important member. A large part of what makes that team run smoothly is good communication. We feel so strongly about this that we decided to devote this entire issue of Family Focus to communication and how we can all work to make it better.

I want to thank each of you who responded to the survey that was randomly distributed to our readers last winter. It is our hope that the results will help those who work in dialysis facilities around the country think about the way they communicate with people on dialysis. It is indeed a "two-way" street.

On the topic of communication, our Editorial Board recently met to talk about the past year’s work with Family Focus and to plan for our next. I am pleased to announce that our entire Editorial Board has agreed to return and continue to help Family Focus remain a great publication.

I would like to share the next four themes we selected for issues of Family Focus. The first will be called Toolbox For Life Part I: Your Life in the Dialysis Unit, and the issue will focus on things that you should know about in your own unit. The second issue, Toolbox For Life Part II: Dialyzing to Live, will include ways that you can make sure that you are "not living to dialyze but dialyzing to live"! Our third issue will highlight diseases that tend to run in the family that can result in chronic kidney disease. This is an issue that you will definitely want to share with your family members. The last issue will highlight all types of information about kidney transplantation, specifically focusing on what those who are currently on dialysis should know when considering a transplant.

We receive all types of wonderful submissions from our readers. To make this communication with you easier, we have created questions for each of the above issues. We encourage you to share your thoughts about them with us. The first question is, “What has made your time in the dialysis unit better by helping you cope with the challenges you may face with things such as relationships with staff and other people on dialysis, scheduling your treatment, etc.?” You can find this question and enter your response at www.familyfocusvoices.org. You may also mail your response to our editorial office (address listed below). We’re waiting to hear from you!

For the Editorial Board, Karren King
I enjoy Family Focus. I am pleased to read about the trials and success of the people that have dialysis full time.

I have been on dialysis for 15 years. I feel that is a record. I had a kidney transplant that lasted eight hours in the days they were not sure of what they were doing. My kidney failure is from a family gene. My dad and his brothers and sisters had it and all passed away at early ages of around 40. It started with my dad’s mother.

You may ask, “How have you been so successful with this health problem?” I would like to share the answer with you. First off, educate yourself about your health problems—the “can do” and the “no can do.”

I lived in the Bay Area in California when this happened to me. I would go to the Stanford University campus any time they would speak about kidney failure and the “dos and do nots.” Once you understand the “do nots”—for example, once you know the dangers of poor eating habits—do not keep doing the wrong thing. Be strong and keep all the rules.

Good luck in your challenge, and remember: Learn the rules of kidney failure and keep the rules. You can live a better life.

Bertha Meredith

The Inside Word on Communication in the Dialysis Unit

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For the most part, these results are encouraging. When people on dialysis have questions, they seem to be asking the right professional for help. The exception to this is the social worker. Dialysis facilities are required by the federal government to make social workers available to those on dialysis. Social workers are trained to provide psychological counseling for you and your family. However, in many busy dialysis clinics, social workers are placed in the role of financial counselor or transportation expert. This is not the most efficient use of Medicare’s precious dollars, and you should be aware that social workers are mainly available to you for psychological counseling and emotional support.

The topic least likely to be discussed with any team member was end-of-life care, with 324 survey respondents saying they had not discussed this with any team member. This finding can help guide us in understanding the areas that need more attention in the dialysis unit. Thinking about the various end-of-life care choices and talking about them with the health care team should be a basic part of every person’s treatment plan.

Of those who responded, approximately 67% had their medications reviewed with them at least monthly. Those who had their lab work reviewed with them more than once per month was even higher at 93%. A small percentage of respondents reported that they did not have their medications or lab work reviewed with them at least annually.

HOW YOU FEEL WHEN TALKING TO STAFF

Ninety-five percent of those who responded said that they felt comfortable asking staff questions about their care, and most people did talk with a staff member the last time they experienced problems. Again, not surprisingly, the staff member most respondents were likely to go to with a problem was a nurse. The respondents typically found the person they approached for assistance to be responsive. Although most found all of the staff to be available when they need to talk with them, at least 10% of those who responded found both the social worker and kidney doctor to rarely be available.

SUMMARY

To summarize, it seems those who responded are telling us that overall they feel communication with their center hemodialysis staff is good. Most find the staff to be responsive and available to them. While this “report card” is quite positive, there are always areas for improvement. For example, approximately 14% of those who responded are involved in planning their care by signing their care plan . . . without discussing it! This is unacceptable, as you truly are the most important member of your health care team. By continuing to work together, those on dialysis and health care professionals can continue not only to further enhance their communication, but as result also enhance the quality of care provided and received.
Why Stress About Stress?

By Pedro Recalde, MS

Recurring stress can be exhausting to our bodies, but we can learn what stresses us and how to control the ways we react to stress. In order to understand the concept of stress, we must first start by discussing WHAT stress is, HOW it affects our bodies and WHAT we can do to control our response.

What is stress?

You can think of stress as our body’s reaction to things going on around us. Stress can occur when something happens that is different from what we expected. It is important to remember that stress is normal—it is a natural response and in some cases it is necessary for survival. When we are stressed we can respond to our environment in either a positive or negative way. Our goal is not to eliminate stress, but to manage it and lessen its effects.

What does stress do?

Our bodies have a natural way of dealing with stress, commonly referred to as the “fight or flight” response. When facing a physical danger, our choice is usually to stay and fight or to run away. In either case, our body prepares by increasing available energy and raising our sensory perception to protect us from injury.

“FIGHT OR FLIGHT” RESPONSE

pupils and ear canals dilate (get bigger)
muscles get tense
heart rate goes up
blood pressure goes up
respiration (your rate of breathing) gets faster
need to urinate more
blood fats and sugars go up
blood clots more quickly
digestion slows down

WHY?

→ to improve our vision and hearing
→ to protect the body
→ to give more energy to muscles
→ to prevent shock, if injured
→ to supply more oxygen to the blood
→ to get rid of toxins
→ to give more energy to muscles
→ to lower chance of bleeding to death
→ to focus on protection instead of digestion

If stress is normal, how can it be bad?

The “fight or flight” response is designed for immediate survival during stressful situations. If you have heart disease, commonly associated with kidney disease, the “fight or flight” response becomes dangerous. The combination of more fats in the blood, higher heart rate and blood pressure and increased clotting factors all raise the likelihood of having complications with your heart.

What can we do to control stress?

We cannot get rid of stress or the “fight or flight” response from our lives. Stress is a natural part of our daily lives and we must learn how to control our responses to it. Although stress management will not get rid of your stress, learning to use stress management techniques can help to 1) lower the number of times your body uses the stress response and 2) lower the effects that daily stress can have on your health.

STRESS CAN BE:

- positive (getting married, retiring, holidays)
- negative (death of a loved one, divorce, finances)
- emotional (argument with your spouse, raising teenagers)
- physical (labor, physical exercise)

Watch out for “Overflow”!

Imagine that the body is a barrel with a spout on the bottom. Just as our lives are bombarded with stress, that barrel is being filled with water. The key to that barrel holding the water depends on how often someone opens the spout to let water out. If no water is let out, the barrel will overflow, making a mess.

The human mind and body can be seen in a similar way. We will always react to changes in our environment. If we are not careful in controlling how much stress we let in, versus how much stress we “drain out,” we might end up “overflowing.” This could have a negative impact on our lives and our loved ones.

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Communication—being able to listen and to talk about thoughts and feelings—is usually not easy. It is not surprising, therefore, that there are communication problems at dialysis and transplant clinics. Over half of the people in the building (those on dialysis) may be feeling angry, worried, afraid, frustrated, resentful, sick or just plain neglected. The rest of the people in the building (the staff) may be feeling stressed, rushed and worried about a sick person they are caring for or about the work they have to do. A dialysis unit is a communication problem waiting to happen!

Both staff and individuals on dialysis need to learn to communicate better. But wait—you may be asking, “Why should I learn how to communicate better with my dialysis staff? Isn’t it the staff’s responsibility to learn to communicate better with me?” Yes—staff members do need to learn communication skills; however, communication is a two-way street. It is never just one person’s responsibility. More importantly, it is to your benefit to learn to communicate your physical, emotional and daily needs to your staff in a way most likely to get those needs met. Below are some simple DO’s and DON’Ts that can help you learn to communicate more effectively with your staff (and your family and friends).

DO spend more time listening than speaking. Most of the time when people have trouble getting their “message” across, it is because one or both of the people are not really listening to each other.

DO clear your mind. Focus your attention on the person you are listening to and clear your mind of other thoughts.

DO clear the clutter. Ignore everything going on around you except for the speaker’s face and voice.

DO make eye contact. • When a person does not make eye contact during a conversation, people tend to think the person is being dishonest or has a hidden purpose. • If you have trouble making eye contact, focus your eyes somewhere else on the person’s face—for example, their nose or mouth. Be careful not to hold eye contact longer than a few seconds at a time. Looking into someone’s eyes too long may make listeners uncomfortable. After one or two seconds, look away and then look back at the person.

DO organize your thoughts. Before you start an important conversation, ask yourself, “What is the main purpose of this conversation? What do I need to communicate to the other person? What am I thinking, feeling and wanting?” You may need to run things over in your mind before you are ready to start talking. Some people write down what they want to say, so they do not get nervous and forget something.

DO “check out” the other person’s frame of mind and surroundings. Is he or she busy, rushed or upset? Is the person free to talk? Is it slow in the unit or is the person rushing around during change of shift? Ask the person if he or she is available to talk. If not, you may want to schedule an appointment.

DO send clear messages. Make sure your tone of voice and your body language send the same message as your words.

DO talk about your needs and feelings with your caregivers (and your family and friends). Do not assume people know what you think or want. Dropping hints or “beating around the bush” in the hope that people will get the message, usually does not work.

DO talk to people the way you would like to be spoken to. If you speak politely to people, they are more likely to speak that way to you. They are also more likely to listen.

DO ask yourself these two questions: “Do I want to win this discussion or do I want to communicate something?” “Do I want to be right or do I want mutual understanding?”

DON’T call people names, talk about them in a way that hurts their feelings or curse at them.

DON’T change the subject or make jokes when you get bored, anxious or uncomfortable with a topic.

DON’T make threats. Making threats may make you feel good because you can let off steam and it keeps you from talking about something that upsets you: but making threats (even if you do not mean them) makes people afraid of you and could result in your being dismissed from your clinic.

If you have problems communicating with someone at the clinic, such as your doctor, nurse or patient care technician, ask to speak to your social worker. Your social worker is trained in communication and it is his or her job to be part of your support system at the clinic. If you are still unhappy, other ways to solve the problem may be speaking to your facility administrator or Director of Nursing, contacting your facility’s regional representative (if your facility is part of a corporation) or calling your local End Stage Renal Disease (ESRD) Network. (See the article on page 9 for more information about the role of the ESRD Network in helping to resolve conflicts in dialysis units.) You can locate your ESRD Network at this Web site: www.esrdnetworks.org

About the Author
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Better Communication = Better Health: Improving Children’s Outcome with Good Communication
By Arlene C. Gerson, PhD, and Barbara Fivush, MD

Communicating with a health care team about one’s own care can be a challenge. When someone else is involved, particularly a child, the challenge becomes more complicated. But having strong communication between the health care team, a child and the child’s family can make a big difference.

Communicating with children

When a child has chronic kidney disease, that child is a very important member of his or her health care team. Improving their age-appropriate participation in decisions about the treatment of their kidney problems is key in achieving the best health outcome. Although communicating directly with children can be time consuming, research strongly indicates that improving communication between the health care team, a child and the child’s family can make a big difference.

**Useful tips:**

1. Look children in their eyes when talking about important topics and pay attention to what they say, what they do not talk about and their non-verbal communication, such as the expressions on their faces.
2. Encourage children to ask questions.
3. Answer children’s questions as honestly as possible using words they can understand.
4. Use diagrams, graphs, charts and pictures as often as possible.
5. Allow children to express both positive and negative feelings regarding their life and illness.

**Communicating with health care workers**

Many parents of children with kidney problems admit that it is stressful to take care of all the things that need to be done for their ill child along with other family needs and job responsibilities. Health care providers are also very busy trying to juggle their patients’ needs along with their other professional and personal responsibilities. Everyone’s time is valuable, and these days there never seems to be enough time in a day.

You have the right to expect the members of your child’s health care team to be patient and clear when communicating with both you and your child. If all three parts of the communication triangle are making an effort, your child will receive the best possible care.

**Why Stress About Stress?**

There is not any reason to think that one stress management technique is better than any other. It is a matter of finding out which one works best for you. Many people enjoy using physical exercise as a way to give stress an “exit” from their minds and bodies. While exercising, your heart rate and blood pressure rise and fall in relation to how hard you are working. This controlled rise and fall in workload may help to “drain out” stress, allowing us to clear our minds, or think of better ways to respond to the stress in our lives. Also, increasing muscle activity and blood circulation can help counteract the negative effects of stress mentioned earlier, such as rise in blood sugar and increase in blood clotting factor.

The ways you choose to lower your stress may change from day to day. One day you might be in the mood to meditate and another day you might feel like taking a long walk. You should try different methods of stress management, but as always, be sure to talk with your health care team to discuss which ones might be best for you.

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Social Work Services and How to Connect With Your Social Worker

By Beth Witten, MSW, ACSW, LSCSW

WHAT IS THE HISTORY OF SOCIAL WORK IN KIDNEY DISEASE?

Medicare has paid for dialysis and kidney transplants since 1973. Rules for dialysis and transplant programs since 1976 say that clinics need to have doctors, nurses, dietitians and social workers to help patients live well. The social workers must have master’s degrees in social work. They must also have counseling skills. Their role has always been to find out what people on dialysis or who are transplanted need emotionally, socially, financially and vocationally. They strive, through counseling and support, to help you overcome hardships that kidney disease can bring.

Treatment for kidney failure has changed since 1976. In 1976, transplant recipients stayed in the hospital for weeks or months. Many people did dialysis at home. Most dialysis clinics were non-profit, hospital-based and staffed with RNs. Dialysis treatments were often five hours or longer. Social workers and dietitians had more time to work very closely with patients and their families.

Today, transplant recipients are in the hospital for days, not weeks. Most people do dialysis at a clinic outside of a hospital and run by a for-profit corporation with more technicians than RNs. Most dialysis treatments last four hours or less. Many dietitians and social workers work in more than one clinic. Some travel a long way to see individuals who are on dialysis. Though people on dialysis and who have transplants today have just as many hardships as in the past, most social workers have much less time to spend with them and their families.

WHAT DOES A SOCIAL WORKER DO?

Soon after you start dialysis or when you are being evaluated for a transplant, you will meet a social worker. He or she will ask you questions about your health and psychological back- ground, education, work history, support system, how your health affects your life and goals and concerns that you or your family may have. Beginning with this meeting, your social worker will work to:

• Keep what you share with them in confidence
• Work with fellow health care providers to improve your care
• Offer you and your family emotional support and counseling
• Empower you to solve many of your own problems. For example, he or she may give you information about community resources to help you get the services you need.

WHAT DO PEOPLE ON DIALYSIS OR WHO HAVE A TRANSPLANT SAY ABOUT THE NEED FOR SOCIAL WORKERS?

About 10 years ago in a national survey, people on dialysis said they wanted social workers to help with a variety of services. They thought social workers could help them cope with the burden of kidney disease, return to activities, understand treatment, deal with concerns about sexual- ity and problems or complaints about treatment. Those who responded also wanted social workers to help with insurance questions and payments for treatment, transportation, home care, equipment and vacation and travel. Almost 91 percent of them said they needed social workers for these needs. Yet 40 percent said they did not have access to a social worker when they needed one.

HOW CAN YOU GET TO SEE A SOCIAL WORKER WHEN YOU NEED ONE?

1. Ask your social worker if you can schedule a time to meet. Tell your social worker what topics you want to discuss. This way, he or she can prepare to advise you and give you his or her full attention.

2. Tell the manager of your dialysis clinic or transplant program that having ready access to a social worker is important to you. Sharing this information with unit staff will help to ensure that social work services will continue to be made available to you and others who are on dialysis or have a kidney transplant.

3. If your social worker is not there when you need him or her and does not answer your messages, tell the clinic manager. Call or write a letter to your local ESRD (End Stage Renal Disease) Network and/or those who govern your dialysis or transplant program. Ask to see your facility grievance policy. Voice your concern.

Tell your clinic manager what you need and what your social worker can do (or has done) to help you. If you do, he or she may give your social worker more time to do what he or she was trained to do and wants to do—help you live a better life with kidney disease.

About the Author
Beth Witten has been a nephrology social worker since 1978 and is a past chairperson of the National Kidney Foundation Council of Nephrology Social Workers. She is a consultant with the Life Options Rehabilitation Program and the Missouri Kidney Program Patient Education Program.

Some days it seems as if a lot of the people in a dialysis clinic are simply not getting along with each other, or are thinking up ways to make each other crazy. This description is not just about people on dialysis or the dialysis staff, but everyone, including families and other visitors.

The TransPacific Renal Network in northern California is one of 18 End Stage Renal Disease (ESRD) Networks under contract to the Centers for Medicare & Medicaid Services (CMS) to provide leadership and guidance to dialysis and transplant facilities. We get more calls from staff and people on dialysis complaining about behaviors on both sides of the dialysis chair than we can handle. The words callers use to tell us about the problems sometimes do not give a real picture about what is happening. Yet the importance of correct reporting is crucial when attempting to develop solutions for the problems.

A dialysis facility is like a small town where everybody knows everybody, everybody sees what is going on and everybody has an opinion. A successful small town depends on respect among the inhabitants, good and fair rules and laws, law-abiding behavior by all citizens and having the laws applied equally to everybody.

What goes wrong in the small town of the dialysis center is that individuals on dialysis and the staff are not always clear on the rules, may not apply the rules or have forgotten the rules of correct behavior. Because people come to dialysis treatment three times a week for years, these people and staff may become too casual with each other, or think that the rules do not apply to them.

Our Network brought together people on dialysis and dialysis professionals to come up with ideas on how to describe and deal with the increasing numbers of negative situations that were reported to us. We quickly understood that definitions and rules about behaviors should be applied to both staff and people on dialysis.

Our first task was to look at the words that are most often used to describe negative behaviors to allow us to agree on descriptions that could be easily understood. Using the wrong words to describe behavior may result in harmful “labels,” making it difficult for an individual on dialysis to travel or transfer to another facility. Below are some examples of the behaviors we described:

**VERBAL ABUSE:**
Someone on dialysis or a staff member who intentionally uses language to intimidate, frighten or cause discomfort or emotional distress.

**Examples:**
Name-calling, shouting, use of obscenities and use of disparaging remarks.

**FAILURE TO CONFORM:**
(Replaces the phrase noncompliant behavior) Failure of a competent adult person on dialysis and/or a staff member to adhere to the policies and procedures of a facility.

**Examples of People on Dialysis:**
Interference with the treatment of others who are on dialysis, not cooperating with reimbursement requirements and unreasonable refusal to be treated by a particular staff member.

**Staff Examples:**
Unreasonable refusal to care for a particular individual on dialysis or to enforce policies and procedures and unauthorized manipulation or change of a prescribed treatment or physician’s order.

**THREATS:**
Behaviors or actions by individuals on dialysis or staff that communicate intent to inflict harm or the fear of harm on others.

**Examples:**
Verbal statements, physical actions or gestures that convey intent to commit harm and references to possession or access to weapons with the intent to intimidate.

**ATTENTION-SEEKING BEHAVIOR:**
Someone on dialysis or a staff member who uses negative behaviors or uses the expression of negative emotions to get attention.

**Examples of People on Dialysis:**
Showing up late or early and demanding dialysis, demeaning remarks about the staff or clinic to others who are on dialysis and refusal to let staff take vital signs.

**Staff Examples:**
Failure to comply with English-only policies, inappropriate words or behavior.
We then grouped all of our definitions into three “catch-all” categories: (1) those by people on dialysis that result in placing their own health, safety and well-being at risk; (2) those by people on dialysis and staff that put the safe and efficient operations of the facility at risk and (3) those that place the health, safety or well-being of others at risk.

It is easy to see how these categories can help staff and individuals on dialysis better understand how a certain behavior might affect others, as well as how the responses of the facilities might vary.

The response of the dialysis clinic, for example, will be very different to people who choose to make bad personal health decisions that can harm themselves, versus those who pose a threat to others. This is where words really make a difference.

A second goal of the group was to plan a model safety program for a dialysis clinic. We wanted to set up an environment free of hazards that could cause physical or mental harm and/or death, stressing that violence and intimidation will not be tolerated.

A “zero tolerance” policy should not be used to single out individuals on dialysis or staff, but to keep a violence-free environment. It must be applied equally to all who dialyze and to employees and address behaviors or actions that are not allowed in a dialysis facility.

The dialysis facility has a responsibility to tell people who dialyze about its rules and expectations. This “treatment agreement” or “town rules,” should clearly describe what happens if either party has violated the rules.

The next step for our Network is to create a teaching program for dialysis facilities. We also plan to make our report and suggestions widely available in the dialysis community.

If we hold ourselves, those on dialysis, and dialysis staff to the same reasonable and fair standards of behavior, the small town that is your dialysis facility and all of its citizens, will thrive.

The opinions expressed in this article are those of the author who assumes full responsibility for the ideas presented. The work was performed under Contract 500-00-NW17 sponsored by the Centers for Medicare and Medicaid Services.

About the Author
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What’s an ESRD Network, Anyway?

By Roberta Bacchelder, MA, Patient Services Manager
ESRD Network of New England (Network 1)

Whether you are new to dialysis or someone who has been on dialysis for a while, you may have heard about ESRD (End Stage Renal Disease) Networks... but the chances are you have never heard of ESRD Networks. Officially our name under the Centers for Medicare and Medicaid Services (CMS) is ESRD Network Organizations. When referring to us, folks often say “Network,” “The Network” or just “ESRD.” But for those who know us, we are correctly referred to as: ESRD Network... followed by a number (1 through 18). The numbers are assigned to the 18 regional ESRD Networks around the country serving clusters of states, from East to West.

When Medicare started paying for dialysis treatments back in 1973 under the ESRD program, the ESRD Networks were formed to do four main jobs for Medicare: collect and process “2728s,” or Medical Evidence Reports, (that is the form that records your lab values, which you were asked to sign when you went on dialysis), assure quality of dialysis care, provide educational resources regarding Medicare’s role in kidney replacement therapies, and respond to complaints from the kidney community. The Networks employ staff, which may include nurses and social workers, to do all of these jobs. Medicare established and directs our work, with quality of care for people on dialysis and with kidney transplants as the central purpose of ESRD Networks. As a current example of what ESRD Networks do, please see the article in this publication regarding negative situations in the dialysis unit (“Words Can Help,” page 8).

If you are on dialysis or are a kidney transplant recipient and you have a problem of any sort you should go to the staff members in your facility first for help in resolving it. If they cannot assist with your need, you can call the ESRD Network closest to you.

Is that the only reason to contact your ESRD Network? Not necessarily. You can also contact the Network if:

- you need information about kidney disease
- you need referral for a particular problem related to health care
- you want to contact your ESRD Network, your dialysis or transplant clinic can give you information on how to do so, or you can go to www.esrdnetoworks.org and click on the state where you live, or call 804-794-2586 for the telephone number of the ESRD Network in your region.

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Hospitals that perform kidney transplant surgery have transplant teams made up of surgeons, nurse coordinators, social workers, financial counselors and nephrologists (kidney specialists). They each specialize in transplantation and are a good group of people to know. Learn to contact them. They can answer questions you have about kidney transplantation.

**How do I know if I can get a kidney transplant?**

If you have kidney failure and are on dialysis, you have most likely asked this question. Transplantation should be discussed early in the diagnosis of kidney disease.

Not everyone who has chronic kidney disease (CKD) is a transplant candidate. Generally, people with CKD have to meet certain criteria. The ideal transplant candidate is less than 60 years old and does not have heart disease, severe complications from diabetes or other serious health risks. Also, transplant candidates must be compliant with diet, doctors’ appointments, dialysis and medications. These are just general “qualifications.” You should talk with your doctor and preferably a transplant nurse coordinator. The coordinator will meet with you to discuss your medical condition and explain the evaluation process. He or she can also connect you with other people who have had kidney transplants. Many transplant centers have support groups that meet and welcome new people seeking information. The local National Kidney Foundation affiliates are also good resources for people with CKD seeking information about kidney transplantation.

**How do I get on the transplant list?**

To be on the list you must complete an extensive medical and psychosocial evaluation by the transplant team. Your nephrologist will send you to the transplant center for the evaluation. Each member of the transplant team will meet with you. They will then meet as a group to review your case, decide if you are a good candidate for transplantation and then inform you and your nephrologist of their decision.

**What if I do not agree with or understand their decision?**

Keep asking questions. Call the transplant center as often as you want to be sure you understand. If you are still not satisfied, you can see the transplant team at another transplant hospital. Be sure that the transplant center is on your insurance plan. If you decide to go to another center, you will be allowed to take your records with you so that all of the tests you have already had do not have to be repeated. Remember, the transplant team is working to make the best recommendation for you. If transplantation is too risky for you, they will tell you and you need to fully understand this.

**What if I am on the list and get sick?**

You need to be free from any infections or most other illness to get a kidney. If you get a cold, flu or are in the hospital, it is important that the transplant team know this. Call the coordinator and let him or her know what is going on. You will

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*Communication with the Transplant Team:*

By Linda Harte, RN

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*How do I know if I am on the transplant list?*

Once you finish your testing and the transplant team has reviewed your case, the transplant coordinator will notify you and draw lab work so that you are on the list. You will be instructed to stay available at all times so you do not miss a call that a kidney is available for you. You may be given a pager so you can be contacted when you are away from your phone. It is important that you stay in touch with the transplant team and have your blood drawn and sent to the local transplant lab monthly. If you do not have this blood sent on time, you will be ineligible that month if a kidney comes up for you.

Communication also includes letting the transplant team know of any changes in your health, or if you are going to be out of town. If you are leaving town, you should let them know how you can be contacted and if you will be available if a kidney becomes available. You also have the option of coming off the list temporarily and then being activated again later.

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*Do I have to wait until I start dialysis to get a transplant?*

Kidney transplantation can be done before starting dialysis. This is called “preemptive transplantation,” and usually requires a living donor, because the waiting list for a non-living donor can take several years. You can also be put on the transplant waiting list before you start dialysis. Talk with your nephrologist about this. When you finish your evaluation and are placed on the waiting list, you could be called any time.
probably be listed as temporarily inactive on the list. As soon as you are over your illness, whoever treated you should send your records to the transplant team to review. If they feel it is safe to give you a transplant at that time, you will be placed back on the active list. You will not lose your place on the list.

**Who takes care of me after the transplant?**

This depends a lot on how far you live from the transplant center. Each transplant center is different, but they usually like to follow you very closely for several weeks after your transplant surgery. When your kidney function and the medications you take to prevent rejection are stable, you may want to go back to the kidney doctor who took care of you before your transplant. Of course, if you live close to the transplant center, you can continue to be followed there.

The transplant center will always want to keep track of your progress and will need records from your doctor regularly. There are many medicines that interfere with your anti-rejection medicine. Any time you see a doctor, for any reason, who is not familiar with kidney disease and transplantation, do not take any medication without the okay of the transplant center. Your anti-rejection medicines can react negatively with other medicines and many doctors are not familiar with this. Also, if you need surgery or are in another hospital for any reason, you or your doctor must let your transplant team know.

Communication with the transplant team is vital, both before and after the transplant. You are the most important member of the team. It is your responsibility to ask questions and to inform your transplant team of any changes in your health. Communication is the key to ensure consistent health care that is the best for you.

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**Web Resources on Transplantation**

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<thead>
<tr>
<th>Resource</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>The transAction Council</strong></td>
<td><a href="http://www.kidney.org/recips/transaction/index.cfm">www.kidney.org/recips/transaction/index.cfm</a> — Official Web site for the NKF’s transAction Council, a group dedicated to the needs and concerns of all individuals who have received or await a transplant of any type. Includes information about becoming a member, which is free.</td>
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<tr>
<td><strong>United Network for Organ Sharing</strong></td>
<td><a href="http://www.unos.org">www.unos.org</a> — UNOS administers the country’s Organ Procurement and Transplant Network. The Web site contains searchable data about every transplant in the U.S., as well as information about the transplant waiting lists and the matching process.</td>
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<tr>
<td><strong>Home for Living Donors Online</strong></td>
<td><a href="http://www.kidney.org/recips/livingdonors">www.kidney.org/recips/livingdonors</a> — The NKF has developed a new online resource for living donors that includes answers to frequently asked questions, message boards and the opportunity to chat with living donors or potential living donors.</td>
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<tr>
<td><strong>Coalition on Donation</strong></td>
<td><a href="http://www.shareyourlife.org">www.shareyourlife.org</a> — This is an alliance of national organizations from throughout the U.S. which are dedicated to inspiring all people to become organ and tissue donors.</td>
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<tr>
<td><strong>National Transplant Assistance Fund</strong></td>
<td><a href="http://www.transplantfund.org">www.transplantfund.org</a> — A resource that provides fundraising ideas and guidance for patients raising money for uninsured medically related expenses, $1,000 challenge grants for eligible patients and educational information regarding organ/tissue donors.</td>
</tr>
<tr>
<td><strong>Department of Health and Human Services, Division of Transplantation</strong></td>
<td><a href="http://www.organdonor.gov">www.organdonor.gov</a> — The government’s Web site on transplantation, focused on encouraging organ donation.</td>
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<tr>
<td><strong>The U.S. Transplant Games</strong></td>
<td><a href="http://www.transplantgames.org">www.transplantgames.org</a> — The largest sports event in the world for people with life-saving organ transplants. The Olympic-style event is held every two years, celebrating the second chance at life for thousands of athletes.</td>
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Helping to Achieve Well-Being

By William A. Craig, MS, RD, CDN

There is a team behind every single person who receives dialysis. It is your team! And you have the right to call them into action any time you need. It is the dietitian’s function on that team to give you information about the food you eat, how it can affect you and help you to chart a pathway toward feeling the best you can.

The dietitian usually reviews your monthly lab work. We have all heard the phrase, “Knowledge is power.” Well, we bring you knowledge of how that tasty morsel that you ate and enjoyed has affected your lab results and how you feel. The dietitian looks at those lab results and suggests food choices that might be both available and appealing to you, as well as good for you. This gives you the power to make healthy food choices. There is no argument about the importance of and need for an adequate, well-balanced daily meal plan.

Most of you are aware of the need to monitor and control the eating of certain nutrients. When you are diagnosed with kidney disease, it is very important to be aware of the foods you eat every day. If you were never given information about foods and nutrients, such as potassium, phosphorous and salt, and how they affect people with chronic kidney disease, now is the time to ask for it. This information is your key to that gateway which opens to the path of feeling good. It will give you an idea of how much of a certain food and/or food group you can eat.

Your dietitian has information about foods that might not be on the typical menu plan. By finding out in advance about foods you may be offered at a special event, such as a wedding, anniversary celebration or Bar Mitzvah, you can empower yourself to enjoy the occasion to its fullest extent. A philosophy shared by many dietitians is, “There are no foods that should not be consumed, only foods that should be consumed in moderation.”

Part of the nutritional education process includes learning how to read a label. By law, food manufacturers must reveal the ingredients of a food item and break down the nutrients per serving. However, some of the labeling on foods can be confusing. Recently, an individual in the dialysis unit pointed out two good examples of confusing food labels. The first case was a label that said “low sodium soy sauce.” It did not specify how much sodium—it just said “low.” This individual thought that because it was low, it could be used safely. After further examination, the dietitian discovered that this particular brand had lowered the sodium to seven grams per serving, which is still very high. Another incident occurred with a label that said “NO SUGAR ADDED” in big broad letters. Of course, the individual thought that she could use it and could not understand why her blood sugars were always running greater than 400. However, just because the manufacturer did not add more sugar did not mean that there was no sugar in the product.

Your dietitian can answer the questions you have about labels or about food in general. Try not to think of the dietitian as someone who tells you what you cannot eat. Think of the dietitian as the person who tells you what you can eat, and how you can feel your best.

EAT TO LIVE!

About the Author

William A. Craig, MS, RD, CDN, is employed as a renal nutritionist at the Auram Center for Kidney Disease in Brooklyn, NY. He has been a clinician within the field of renal nutrition for the last 14 years, and in the field of nutrition for the last 30 years. His health care career began as a pharmacist.

A Presumed Lack of Control

By Dale Ester

One problem I often hear about, from those on dialysis and from those who care for them, is related to the question of why so many people with chronic kidney disease (CKD) feel a lack of control when it comes to their health care. Keeping an open mind will help us as we examine reasons why this feeling might occur for so many individuals with CKD.

Although dialysis care has changed from a mere decade ago, have we, as patients, become more successful in talking with doctors about the treatment of kidney disease? Have we become better at understanding the medical conditions by educating ourselves through the Internet and other resources? Do we still believe that “Doctor always knows best”?

In my opinion, people who partner with their health care team do better than those who choose to “go it alone.” Learning how to use language to educate yourself will give you the power you need to be an effective communicator with the members of your health care team. Communication through the use of appropriate language skills will help staff members understand your thoughts on how you are feeling. Asking questions about topics you do not understand lets the team know you want to be an important part of improving your health. Remember that the way in which you convey ideas and perceptions will determine the kind of relationship you have with others in the dialysis unit.

You must place trust in professionals who say, “I know best.” They, too, must place the same trust in you too. Working together should not be difficult nor a problem.

Finally, control your attitude. Attitude is a personal choice of how you react to things around you. If your attitude is sour, try thinking cheerful ideas to help yourself feel more up. Do not pretend the face scowling back at you from the mirror is going to hide itself when you go outside to greet the world. If you smile, the world will smile back at you! If you grumble, growl and bicker, well, you will at least know what to expect from those with whom you come in contact. Your attitude influences—everyone including yourself!
Communication and Advocacy
By Dolph Chianchiano, JD, MPA

We know that health care workers may not be able to address our needs if we fail to communicate those needs to them. Similarly, we must make our needs clear to government decision makers when we expect their help. Communicating with government leaders to convince them about a certain course of action is known as advocacy. Members of Congress and state legislatures have to hear, first hand, about “true to life” experiences of people with kidney disease so that they can fully understand the need to support life saving therapies that is so obvious to us. Unfortunately, too few people with kidney disease and members of their families engage in that kind of advocacy with government leaders on a regular basis. Fortunately, we can learn from the success of advocacy campaigns by people who have other illnesses and build upon the recent advocacy efforts by the kidney community.

Advocacy does not necessarily require a lot of effort or special training. Phone calls and letters to legislators are the cornerstone of advocacy. For those who are willing to go to the next step, speaking up at town hall meetings or testifying at public hearings can have a very powerful impact. Another way to get the attention of government officials is by contacting reporters or writing articles for local newspapers.

Advocacy letters do not have to be fancy. In fact, they are most effective when they are hand-written. The National Kidney Foundation might provide sample letters that individuals or families could simply copy, sign and mail but, frankly, these are not as effective as letters that state detailed information about specific cases. For example, the United States Forest Service is rejecting public comments on proposed regulations when the comments come on preprinted postal cards. The agency is also barring other “duplicative materials,” like form letters, from consideration.

All that many government decision makers know about dialysis and transplantation is that they are rare and expensive treatments. To dispel misconceptions, the American Nephrology Nurses Association (ANNA) started End Stage Renal Disease (ESRD) Education Day on August 15, 2003. ESRD Education Day was a remarkable accomplishment that should serve as a model for future advocacy efforts.

The kidney community has additional success stories. Clamor for enhanced benefits from transplant recipients resulted in the extension of Medicare coverage for immunosuppressive drugs that was enacted in 2000. As part of the advocacy effort, one person with chronic kidney disease wrote an article that appeared in Newsweek magazine, explaining that he would like to go back to work but needed to maintain disability status so that he could continue to be eligible for drugs under the Medicaid program. Another transplant recipient agreed to be interviewed by the Wall Street Journal about the extreme methods to obtain immunosuppressive drugs to which people with transplants may resort after Medicare coverage ceases.

Hundreds of people who receive dialysis treatment, alarmed by a 1997 change in Medicare reimbursement for anemia therapy, wrote to their Congressional representatives. They were concerned that, as a result of the lower reimbursement for anemia treatment, many dialysis providers world lower doses of anemia medicine (erythropoetin). This direct advocacy very likely contributed to the government’s decision to reverse that policy.

If you want information about becoming a health care advocate, you can view “Public Policy Tips and Info” that is part of the Government Relations page on the Web site of the National Kidney Foundation, www.kidney.org or call the NKF’s Washington, DC, office at 1-800-889-9559.

About the Author
Dolph Chianchiano, JD, MPA, is the National Kidney Foundation’s Vice President of Health Policy and Research.

ESRD Education Day was a very likely contributed to the government’s decision to reverse that policy.

To find out about the many services and activities offered in your community or to become a member of the Patient and Family Council, call the National Kidney Foundation at

1-800-622-9010

or visit us at

www.kidney.org
Talking to My Doctor
By Leslie Spry, MD

After you visit your doctor, do you feel better or worse? Are you prepared for the visit? Is your doctor prepared for the visit? How can you make the most of each doctor visit? Here are some suggestions for what you can think about before walking into the office or clinic.

The first thing to think about is the type of visit planned. Is this a routine follow-up visit, or is this appointment to deal with a new or complicated set of problems, such as symptoms you have not discussed before or a reaction to a new medication? You should let the clinic staff know which it is and what information you will want to keep. This will save a lot of time and confusion over your medicine. Making a list of the medicines you are taking will also give you a chance to review all of your medication and supplements. If you keep track of any personal health information (blood pressure recordings, blood sugar records, insulin records, lab work from other health care providers, dates of your last visit) make sure to bring your records with you.

If you have received care somewhere else or from someone else since your last visit, make sure your physician has a copy of those records and lab work from other health care providers, dates of your last visit. Recent travel history can make it to your chart."

All visits with your doctor should be absolutely confidential. If your doctor's office or clinic is part of a university or teaching hospital, a student, intern or resident may visit patients with your doctor. This is how learning to care for patients takes place, but it does not change the privacy rules. If you feel you need privacy for your visit, please be sure the clinic staff are aware of this and let the doctor know. All offices should have a privacy statement, which should be given to you with your first visit to the clinic.

At the end of the visit, be sure all of your needs have been addressed and your questions answered. If they have not, please let your doctor know. If they can be taken care of in the time available, your physician may choose to do so. Sometimes another appointment may be needed. Your doctor may need to get more information (e.g., lab work or records) to answer certain questions.

Answers to complicated medical problems may require some research by the doctor. Consultation with other doctors, review of articles in medical journals or simply further time might be needed to review a case in order to make a good recommendation for care. Unless the problem is an emergency, taking some time to watch the course of a new symptom or complaint is often a better approach than jumping to conclusions and recommending the wrong treatment.

Obviously, there are many things to think about with any trip to the doctor's office, but if you consider the above recommendations, most visits with your physician should be pleasant and helpful. I find that individuals who take an active role in their own medical care make me a very good doctor. I learn from every one of them.

About the Author
Leslie Spry, MD, practices consultative nephrology and is the medical director of the Dialysis Center of Lincoln in Lincoln, Nebraska. Dr. Spry is an active member of the Public Policy Committee at the National Kidney Foundation.
Happy Valentine

By Ralph Mobley

I have realized through the years that there are all types of love—for family and friends, lover and spouse, and then you.

Your compassion and kindness have to come from up above.

Your treatment of me has been tried, tested and found true.

Your dialysis sessions have given me hope and made me strong.

Your kindness and caring has made me believe that here in this Center I do belong And with your care that I can achieve.

Your smiling faces always put me at ease.

When a problem arises, it is taken care of right then And you continue to smile, even when I tease.

Your strong constitutions never bend.

I can’t imagine getting a treatment any other place.

I simply perish the thought.

Without you, I couldn’t run this race For this battle I have long fought And I am winning and I owe that to you, The staff at this great Center.

You have turned my gray skies totally blue So life, once again, I may enter.

The mere thought of you brings a tear to my eye.

You save my life three times a week And I know on you, staff, I can always rely Because your professionalism will never reach its peak.

It just continues to get better and better each time I am there.

I just feel so safe and secure, it astounds me.

All the nurses have such zest and flair

I love having all of them around me.

The entire staff welcomed me with open arms And I think I appreciated that the most.

The doctors just bowled me over with their charms.

When I speak of this Center, I just have to boast The kind of love I feel for this place can’t be seen on any chart.

It is overflowing with gratitude and coming straight from the bottom of my heart.

Ralph Mobley of Queens, New York, wrote this Valentine’s Day poem for the staff at his dialysis unit.

Friends in Dialysis

By Rosa Whittington

Here at the dialysis center I have found friends left and right And when there are times I want to give up the fight And all I can do is cry in the night

When the next day back to the center I go I see all my new friends—what a wonderful sight

Here at the center everyone is the same And they know how to help you get through the pain

Who would ever have thought this would happen to me

To find so many friends in one place, you see

They are so kind and wonderful to all And when you are hurting and almost fall They are there to pick you up, sit you down And tell you there is no use to sit and frown

They tell you to hang in there and live day by day And things will get better along the way They are very sincere in what they say And tell me all that is left is to pray

You have in the office when you come in Judy with a smile to let you know she is your friend You have Joyce, who is the dietitian She is there to tell you about your nutrition Then there is John who is the social worker to help with financial needs And anything else he can do, you see

The caregivers who work in the back They are there to keep you on track They hook you up to the machines to save your life They are the best and so very nice There are too many names to mention here But I hold each and every one so very dear

Here is hoping I live a long time With my friends here at the center; that suits me just fine Here is to thank each and every one And hope we will always be friends ’til my life is done

Rosa Whittington wrote this poem when she began dialysis in January 2002. She lives in Clearwater, Florida.
The Dialysis Nurse

By Gregory A. Christmas

For so many years, I have been so blessed
To be able to travel, from east to west,
To a place that I can not explain.
To a place that sometimes I even felt pain,
By those who care so passionately.

The ones I speak of have hearts of gold,
While doing their job, your hands they’ll hold.
They wipe your head, hands and arm.
And with a cool towel, they show their charm.

They bring comfort to the patients they care for so much.
They are always giving, the angels’ gentle touch.
They do their job with love and care.
The love they have, so willingly they share.

So many have come and gone these years,
So many have left, it brings us to tears.
But their names and compassion will always stay.
Reminding us of when they had to go away.

Our lives are touched by the skill they possess.
This skill they share with such willingness.
I hope I never forget the loving hearts and caring smiles
Of those who lived so close, and those who traveled miles.

Kindness, compassion, love and care were first
On the hearts of the precious dialysis nurse.

Dedicated to all the dialysis nurses, techs and helpers.

Gregory Christmas, of Tell City, Indiana, has been on hemodialysis since 1988. A framed copy of this poem hangs in his dialysis unit.

Nurses

By Charles Joseph Nelson, Ill

They are here to help you, no matter what the task.
Most of the time they’re in the process, even before you get a chance to ask.

What they deal with each day is more than you can take.
A lot of the duties at hand, there’s quite a bit at stake.
Some people take them for granted, give them a hard time.

One day, you never know, they could save your life, or mine.
Nurses put up with a lot of guff if you don’t get your way.

You better have second thoughts about the nasty things you say.
Put yourself in their shoes, then maybe you’ll understand.

The job they do every day isn’t always grand.
They work so hard to fulfill our needs and always do their best.
No matter how rude some people are, they never take it out on the rest.

You have to give them credit, where credit is due.
Unless you’re a nurse, you’ll never understand what they have to go through.

They comfort you when you’re ill, no matter what the time.
Obviously they care for us, to keep our health in line.

Nurses deserve the utmost respect, but some people don’t seem to care.

They go way out on a limb to make sure when you need them, they are there.
If that’s not dedication, I don’t know what to say.

The next time you see your nurse, you should throw a “Thank you” their way!!

Charles Nelson, of Pierrepont Manor, New York, has been on dialysis since February 1999. He is 27.