Renal Network 11

Common Concerns

News and Information

For kidney patients and their families

From the Committee Chair

Maggie Carey, Chair, Consumer Committee

Those of you who are used to reading this column will realize that the name of the Consumer Committee Chair has changed. We were all very saddened by the sudden loss of Judy McLaughlin, who served in the position of Chair so beautifully. It is a sad fact that End Stage Renal Disease (ESRD) is a life threatening condition that often takes us away too soon. This fact highlights how important it is to stay informed of new findings, treatment options, and all those little things we can do to help keep us strong and healthy. Judy did all of that and, as a result, she was strong and vital right up to the moment that she was called home. She was an inspiration to all of us as she led the fight against ESRD. She was dedicated, motivated, and one of the most active people I have ever known. Her life was full and she followed her passions with an energy that would have put a young Olympic hopeful to shame. One of her passions was staying informed on all aspects of Chronic Kidney Disease.

With these thoughts in mind, you will find three main themes in this issue of *Common Concerns*. The last issue was focused on Hemodialysis. This issue examines Peritoneal Dialysis. Even if this is not the modality that you are using, please read each article carefully. Information is power when dealing with ESRD and you never know when you can put one of these facts to use. *ImoGene's Corner* is a wonderful resource. ImoGene has an incredible knack for researching and identifying Web sites that are full of useful information. In this and future issues, she will share some of the "best of the best" in resources for ESRD patients and families. Check them all out. They just might give you the very information you need to know.

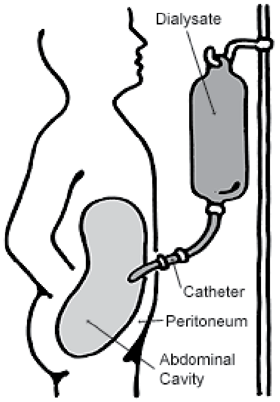
Lastly, you will find our "Stop Signs". This was the Special Project that the Consumer Committee worked on during 2009. The thought was that there may be a time when you end up in the hospital for a non-kidney related issue like a broken leg, gall bladder problem, etc. If you are not on a renal ward, the staff needs to know that you have renal issues and that you require special care. Choose the card that applies to your treatment and place it in your wallet next to your Medicare or insurance card. That way it will be seen by Admissions and your needs will be known. We have also developed full page versions of these Stop Signs that can be taped to the hospital wall near your bed. This is a very important level of protection that we are proud to be able to offer you.

Information is power—don't be afraid to use it.

Peritoneal Dialysis

Peritoneal Dialysis

Peritoneal Dialysis (PD) is a type of dialysis that has been available for many years. It is a wonderful alternative for those patients who would like to do their dialysis at home. PD serves the same function as hemodialysis but in a very different way. There are several types of PD but all work in the same general way. PD is done in the home, either during the day by continuous ambulatory peritoneal dialysis (CAPD), or overnight by continuous cycling peritoneal dialysis (CCPD). In either case, the dialysis process takes place



(continued on page 2)

(continued from page 1)

continuously, which is more like the work of your own kidneys. Some PD methods use a machine, while some do not. Whether or not a machine is used, there are three major components to peritoneal dialysis.

The Peritoneal Membrane

In hemodialysis, the hemodialysis machine takes blood out of your body and the dialysis process takes place using a synthetic device known as a dialyzer. With peritoneal dialysis, the dialysis process itself takes place inside the abdomen. The vital organs located inside each person's abdomen are covered by a membrane or clear film called the peritoneum. The peritoneum has microscopic pores and lies next to many large blood vessels. Impurities are filtered from the blood vessels through the pores in the peritoneum and into your abdominal cavity.

Dialysate

Dialysate, a chemical solution much like the normal chemical make-up of your blood, is released into your abdomen. This solution is used to pull poisons, excess amounts of chemicals and water through the tiny pores of the peritoneum and into the open spaces of your abdomen. This process has two parts, diffusion and osmosis. The filtration of poisons and chemicals is known as diffusion. The removal of excess water is known as osmosis. The amount of glucose (sugar) in the dialysate solution regulates the amount of water that is removed from your blood.

Dialysis Access

As with hemodialysis, PD requires an access to get the solution into your abdomen. This is done by means of a soft, flexible plastic tube, known as a catheter. The catheter is inserted into your abdomen by your physician. The catheter is kept in place by a stitch just under the skin. After a period of time, your body heals around the catheter and scar tissue holds it in place. There are several different styles of catheters. You and your physician will decide which is right for you.

Continuous Ambulatory Peritoneal Dialysis (CAPD)

CAPD does not require any type of machine. Dialysate solution, in clear plastic bags, is placed on a hook above your head and the solution is allowed to drain into your abdomen through your catheter. Generally, 1.5-2 liters (1 liter is approximately equal to one quart) are allowed to drain into your abdomen. This solution then remains (dwells) in your abdomen for about 4 hours while you go about your daily activities. At the end of the four hours, the fluid in your abdomen is drained out and fresh dialysate is put into your abdomen. This process of fill, dwell, drain, refill is known as an exchange. Most people do 4-5 exchanges during the day. Many people put fresh dialysate into their abdomen at bedtime. The dialysate remains there while they sleep, and is drained out at the first exchange of the morning.

Continuous Cycling Peritoneal Dialysis (CCPD)

This type of PD is also known as Automated Peritoneal Dialysis or APD. As the name implies, a machine is used to perform the exchanges mentioned above. This type of dialysis is done overnight while you are sleeping. A small machine sits on a table by your bed and the dialysis takes place while you sleep.
You and your doctor will decide what type of PD is right for you. Occasionally doctors will order a combination of CAPD and CCPD but again, that depends on your specific needs. The choice to do peritoneal dialysis is one that gives you the freedom to travel and schedule your exchange times into your normal everyday activities. If you decide to do PD, your PD nurse will train you and help you to learn everything you need to know. You will come into the clinic every 4-6 weeks to be seen by the PD team, which includes the nurse, your physician, a social worker, and a dietitian.

The type of dialysis you choose is a decision you can make with your health care team. If you are interested in PD, talk to your team. Ask questions. You are a very important member of your health care team. The more you learn about the different dialysis and transplant options, the more likely you are to make a well informed decision.

Peritoneal Dialysis: A Patient's Perspective

There are many reasons that I preferred Peritoneal Dialysis (PD). First and foremost, I only had to visit the dialysis center two times a month: One time for a blood draw and one time to see the nephrologist. In total, both visits normally lasted two to four hours.

I have performed PD exchanges under a number of conditions and circumstances: In my bedroom, my living room, my basement, hotel rooms, hospital rooms, vehicles, the homes of relatives and friends, and in dialysis centers. However, the most interesting exchange that I ever performed was during an August 2003 blackout. At that time, I had only been on dialysis for one month, and PD was my modality of choice. Why PD? Because in 2003, I was a self-sustaining, independent, "yes, I can" type of woman. My theory was that the person who could and would take the best care of me was . . . me. I was younger then, and my theory had not been fully tested before dialysis. It is believed that the blackout that struck the Northeast and Upper Midwest (as well as parts of Canada) began in Ohio. Quite frankly, I did not care where it began. When the lights went out that Thursday afternoon, I panicked for approximately 30 minutes before I realized that I had nothing to fear, because I did not have to go anywhere to sustain my renal health. My exchanges were powered purely by my own tenacity and energy. I dared to take an active, direct role in my renal care. I felt empowered! At the time the blackout occurred, I had already performed two of my four daily-required exchanges. All of my necessary supplies were at their workstation, on hand for my manual exchanges. According to my lifestyle, my next exchange was scheduled for 8 p.m. and my last exchange was scheduled for 1 a.m. I soon found out that my state-of-the-art $179.99 telephone did not work — but my $10.99 telephone did. So, I performed my exchanges by candlelight while talking to relatives and friends. Each exchange was only 40 minutes in duration, and I was planning what to barbeque the following day. I survived that two-day experience untethered because peritoneal dialysis was my modality. I did not even contact the dialysis center until my regularly scheduled appointment. As a rule, PD patients should have a 10-14 day supply of dialysis solution on hand at all times. Because I had all of my supplies, I experienced no interruption in my treatment during this catastrophe. All was right with my world.

Footnote: I was on PD for five years.
In that time I never had a PD infection.
As of April 2009, I have been on nocturnal hemodialysis. Explore your options.

ImoGene's Corner

The first time a doctor mentioned "Dialysis" to me, I felt as though a 10-ton truck had fallen on my mind. I literally thought that he had misspoken. Renal failure . . . dialysis.
It was difficult to form the words, and impossible to grasp the concept of me and dialysis being mentioned in the same sentence. I immediately became angry—angry with the doctor and angry at the world. For days I was angry with everyone except myself.

Later, after talking to several dialysis patients, I found out that this period of mourning and denial is not uncommon to pre-dialysis patients. I was mourning the loss of my old way of life, and I was denying the life-changing trials and tribulations that were coming my way. I felt isolated at the time. Yet... you are not alone!!
There are a vast number of resources to help pre- and existing dialysis patients.

Find a Doctor

For those kidney patients who would like to seek a second opinion or find a doctor, the US Department of Health and Human Resources has a Web site called DocFinder to help you find a doctor either by name or medical specialty anywhere in the US. Visit the DocFinder Web site at **www.docboard.org/docfinder**.

Find a Dialysis Center

Medicare provides information to those patients looking for a dialysis center, in an on-line format. The Dialysis Facility Compare (DFC) Web site:

- Allows patients to find and compare different dialysis centers by name or location
- Explains what questions to ask the dialysis centers
- Informs patients of their rights.

Visit the DFC Web site at **www.medicare.gov/Dialysis**.

Contact Medicare

Medicare also provides contact telephone numbers for patients who are concerned about their health care. You can talk to real-live people. For contact information listings visit the Medicare Healthful Contacts Web site at
www.medicare.gov/contacts

If you have resource questions or would just like to share some of your dialysis and/or renal experiences, you may contact me at:

ImoGene's Corner
Renal Network 11
1360 Energy Park Drive, Suite 200
St.Paul, MN 55108

Check out the new Patient Rights and Responsibilities Poster in your facility. Renal Network 11 has sent each dialysis and transplant facility a poster that outlines your rights, as stated in the Centers for Medicare & Medicaid Services (CMS) new Conditions for Coverage. It also contains contact information for Renal Network 11 and for your State Survey Agency.

ESRD Patient Rights and Responsibilities

Patient Rights

- Respect, dignity, and recognition of individuality and personal needs.
- Receive all information in a way that can be understood.
- Privacy and confidentiality in all aspects of treatment and in medical records, including the right to view and receive a copy of your medical record (a nominal charge may be assessed).
- Be informed about and participate, if desired, in all aspects of your care. Be informed of the right to refuse treatment, to discontinue treatment, or to refuse to participate in experimental research.
- Be informed about your right to execute advance directives.
- Be informed about all treatment modalities and settings, including transplant, all home dialysis modalities and in-center dialysis.
- Be informed of facility policies regarding patient care including isolation of patients.
- Be informed of facility policies regarding the reuse of any dialysis supplies.
- Be informed of your medical status by your physician or physician extender as documented in the medical record.
- Be informed of services available in the facility and charges for services not covered by Medicare.
- Receive the necessary services outlined in the patient plan of care.
- Be informed of the rules and expectations of the facility regarding patient conduct and responsibilities.
- Be informed of the facility's internal grievance process.
- Be informed of external grievance processes, including how to contact the ESRD Network and the State Survey Agency.
- Be informed of the right to file internal grievances or external grievances or both without reprisal or denial of services. The grievance may be filed personally, anonymously or through a representative of your choosing.
- Be informed of the facility's policies for transfer, routine or involuntary discharge, and discontinuation of services to patients.
- Equal consideration of treatment without regard to age, sex, race, religion, or ethnic origin.
- Receive written 30-day notice before involuntary discharge after the facility follows the involuntary discharge procedure. In case of immediate threat to the health and safety of others an abbreviated procedure may be followed.

Patient Responsibilities

- Learn all you can about your disease, its treatment, options, and your rights and responsibilities as a renal patient.
- Recognize what an emergency is and what actions must be taken in emergency situations.
- Provide a complete and accurate medical history to the professional team supervising your care.
- Let a member of your professional team know if you do not understand information about your care and treatment.
- Tell a member of your professional care team if there is a sudden change in your condition.
- Obtain and take the medications prescribed for you or discuss with the professional care team why you are unable to do so.
- Follow your diet or request further instructions if you do not understand or are unable to follow your diet.
- Make every effort to arrive for your scheduled dialysis treatments on time and inform the dialysis unit if you are unable to come.
- Stay on dialysis for the prescribed length of your treatment run.
- Consider the needs of other patients and understand that the professional team has a responsibility for all of the patients under their care.
- Tell a member of your professional care team if you are diagnosed with a communicable disease.

Contact Network 11
Renal Network 11
1360 Energy Park Drive, Suite 200
Saint Paul, MN 55108
Toll free 1-800-973-3773

Contact Your State Survey Agency

Dialysis Facility Compare

www.medicare.gov/dialysis is a Web site that provides important information and resources for patients and family members who want to learn more about chronic kidney disease and dialysis. You can find and compare information about the services and quality of care provided at dialysis facilities in any state. You can also find addresses and phone numbers for each facility.

Be Wise – Immunize!

Immunization is one of the most important things you can do to protect yourself from serious diseases such as pneumonia, hepatitis B, and influenza. The Centers for Disease Control and Prevention (CDC) recommends that all chronic dialysis patients be immunized for these diseases. Talk to your dialysis staff about your immunization options.

BE WISE—IMMUNIZE!

This newsletter was developed under contract Number HHSM-500-2006-NW011C sponsored by Centers for Medicare & Medicaid Services, Department of Health and Human Services. The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government. The authors assume full responsibility for the accuracy and completeness of this newsletter.

Nonprofit Org.
U.S. Postage
PAID
Minneapolis, MN
Permit No. 26469

Renal Network 11
1360 Energy Park Drive
Suite 200
St. Paul, MN 55108