

RENAL OUTREACH

ESRD Network 9/10

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The Renal Network's Annual Nephrology Conference

The 2007 Annual Nephrology Conference will be held on March 15 - 16 at the Drake Hotel in Chicago. Patients do not have to pay any registration fees to attend the meetings although mailing or faxing a completed registration form is required. Information about the meeting can be downloaded from the Network Web site (www.therenalnetwor.org).

The Naked Arm

Are the nurses at your dialysis unit constantly nagging you about uncovering your arm so your fistula is exposed? Are you tired of hearing them and explaining that your arm gets cold so you want it covered up? Do you understand why they want your arm uncovered?

It is not because they just want to harass you. There really is a good reason!! They need to keep an eye on your vascular access.



Evernard "Bill" Davis demonstrates.

Many complications can occur during hemodialysis.

One potential complication could be the dialysis blood tubing could become disconnected.

This issue...

...of the Renal Outreach focuses on patient independence and self-care. Members of the Patient Leadership Committee (PLC) contributed many of the articles.

My Journey

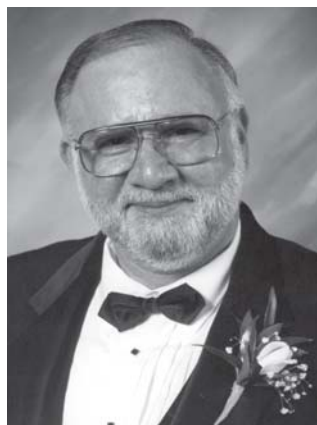
At the last Patient Leadership Committee (PLC) meeting, I was asked to write two articles – one on what independence means to me and one about my experiences on the PLC. After a great deal of reflection, I could not separate the two. I feel it is far better to tell my story, which includes many facets.

I was diabetic since my early thirties and I just didn't take seriously what my doctors told me. So, slowly, my health began to decline. Six years ago my kidneys wouldn't filter enough waste products out so I was told hemodialysis was the next option available to me. Not unlike many ESRD patients, I was devastated. I had a temporary catheter placed in me, and started my dialysis shortly thereafter. I had an access placed in my left forearm.

I have never felt so helpless and not in control of my life. I was angry and deeply depressed. I had two major arguments in my unit. There was plenty of screaming and hollering. To this day I don't know why they didn't discharge me from the unit. For the next year and a half I was verbally abusive to the staff. I didn't swear at them or anything like that, but I was indeed a handful. My finest moments were not in that year and a half.

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At that time our renal social worker came to me and said she thought that I should apply to be on the PLC of The Renal Network. I said okay, filled out the application and sent it in.

To my surprise, I was accepted and attended my first PLC meeting. As it turned out, it was a very important day for me.

At that meeting, sitting across the room from me, was another patient representative who was also attending his first meeting. Ironically, I have never seen this person at any meetings after this. But for me, a miracle occurred. This person was both angry and depressed and the light bulb went on in my head – I was looking at myself. It was not a pretty picture. Right then and there I knew my attitude needed to change. No more verbal abuse, no more arguing, non-compliance, and things like that.

When I returned to my unit the following Monday, I told anyone I could get to listen what I was going to do and how much I had learned at the PLC meeting. I have kept my word and have never missed a dialysis treatment. All of a sudden, I had an enlarged family who I developed strong, loving feelings for. I owe it all to the PLC and that one distressed man – I hope he found himself.

I really don't know whom to thank. When I think of all the people who stood by me and helped me, I become very emotional. I don't think I deserved what they gave me, but as true professionals, they showered me with hope and support. I thank God for them and what they do day after day, year after year.

I am humbled and have great gratitude to them. I am now on Peritoneal Dialysis (PD) and enjoy more freedom and responsibility for my own care. I truly have my life back.

Evaret (Ed) Lesser (pictured at left), Patient Leadership Committee and Medical Review Board Member

Self Care Increases Personal Control

Federal guidelines require that patients be informed of their suitability for transplantation or home dialysis. To meet this requirement, dialysis facilities should inform patients about hemodialysis, both home and in-center, peritoneal dialysis, and transplantation

The guidelines state that "*Home dialysis affords patients' control over scheduling and setting and it can be done in comfortable familiar surroundings.*" It is also perceived to be less disruptive to family life and employment. One modality that is not offered as frequently is in-center self care. Patients who would prefer to do home hemodialysis but lack a suitable partner may be interested in this option. Patients who prefer to be independent rather than trust the staff with their care may also prefer to do their own dialysis.

Although this option is not offered in all facilities, having an in-center self-care unit may be an attractive alternative. In this type of setting the patients would come into the facility, set up their own machine, insert their needles and begin dialysis. They would be responsible for monitoring their own vital signs during their treatment. Afterwards, they would clean the machine before going home. A staff member would be present and available for any problems or questions that may arise or to assist in cannulation if the patient is having difficulty. Some units offer daily dialysis treatments of two hours per day, six days a week.

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Self-care dialysis encourages patients to become involved and be responsible for their own dialysis treatments. Patient participation in their own dialysis treatment fosters independence and control which provides a greater sense of well-being. It is thought that the quality of their lives will improve both physically and mentally when they manage their own treatment. Many patients desire to return to work because they feel so much better than they did on other modes of dialysis therapy.

If you think you might be interested in pursuing self-care, talk to your facility staff about training. One place to start might be in the area of self-cannulation. Patients can be trained to insert their own fistula needles usually using the buttonhole technique where the needle is inserted into the same hole each time. If this skill is mastered, you might be interested in pursuing more self-care tasks.

*MaryAnn Webb, RN, CNN
Network Quality Improvement Coordinator*

Transplantation as an Alternative to Dialysis

In addition to hemodialysis and peritoneal dialysis, another treatment for kidney disease is transplantation. Kidneys for transplant either come from people who have died and donated their kidneys (cadavers); living related donors (usually a sibling or a parent); or living unrelated donors (i.e. spouse, friend). Making the decision to pursue a transplant can be both exciting and scary. You may experience anxiety and/or fear, and you may feel overwhelmed trying to complete the many tests required for the work-up while continuing your dialysis treatments.

If you are interested in receiving a transplant, the first thing that needs to be done is to determine if you are medically eligible.

Talk to your nephrologist and express your interest in seeking a transplant. Your physician should be able to determine if you have any medical conditions that might prevent you from getting a transplant. Your nephrologist should then refer you to a transplant facility to meet with the transplant team. The transplant team will make the final decision if you are a candidate. When you meet with them they will be available to answer any questions you and your family have and to explain what testing is necessary for you to complete prior to transplant surgery. They may also give you written information to take home to read.

Hopefully, after meeting with the transplant team you will know much more about the transplant process. Read whatever information you were given by the transplant team. Educate yourself about the transplant process to relieve some of the anxiety you may be experiencing. Discuss your thoughts and feelings with your family and close friends so you can make your decision on how to proceed. It may be helpful to talk to other transplant patients. Ask the transplant staff or your dialysis staff if they know someone who has gotten a transplant who could talk to you. Call the transplant center if you have any more questions. If you are still interested in proceeding, the next step is to start the pre-transplant work-up.

The work-up may be somewhat different at every transplant facility. Various blood tests and x-rays are required to determine that there are no active infections or uncorrectable health problems present. The detection of cancer, HIV, Hepatitis or any infectious process may prevent you from being considered a candidate. Most work-ups even include a dental exam, and sometimes psychological testing is included. Good communication with your transplant

Promoting Independence Through Home Dialysis

The term independence is synonymous with autonomy. When patients are told that their kidneys are failing and they will need to begin thinking about dialysis in the near future, the first thing most patients think about is a loss of autonomy. Suddenly one is forced to think about life within a framework of machines, schedules and a loss of independent functioning.

One way to recapture a sense of independence is to consider home dialysis, either Peritoneal Dialysis or Home Hemodialysis, as an option. When faced with all of the uncertainty and fear of needing dialysis, many people do not even consider home dialysis as an option. Or, they are not well informed about what the possible options are. But the reality is many people are excellent candidates for home dialysis and haven't even considered it!

Home dialysis allows people to have a better quality of life because they are in control of their own care to a large extent. For example, patients on home dialysis can be offered a less restrictive diet. Research suggests that these patients also need less medication to control blood pressure and other secondary medical issues. There is some flexibility in terms of when they will dialyze, so people are not tied to a center's schedule.

People often have more energy and are physically stronger because home dialysis is performed more frequently than in-center dialysis, and more frequent dialysis mimics true kidney functioning. Many people on home dialysis continue to work and travel as they always have. Both Peritoneal Dialysis as well as some forms of Home Hemodialysis are portable and people are able to travel with their own dialysis equipment, including out of the country.

So let's explore the various home dialysis options.

There are currently five home dialysis options available:

1. Continuous Ambulatory Peritoneal Dialysis or CAPD,
2. Continuous Cycling Peritoneal Dialysis or CCPD,
3. Conventional Home Hemodialysis,
4. Short Daily Home Hemodialysis, and
5. Nocturnal Home Hemodialysis.

In both types of Peritoneal Dialysis, a small flexible tube called a catheter is surgically placed into the lower abdomen, and the build-up of toxins and waste is removed by utilizing the body's own peritoneum. Neither blood nor needles are involved in this type of dialysis. The catheter is used to insert and remove fluid, known as dialysate into the peritoneal cavity. Once inserted, this fluid is allowed to sit in the peritoneum for a period of time.

This is considered a "dwell time." During the dwell phase, as determined by the nephrologist, the waste flows and is collected in the dialysate. At the end of the dwell time, the fluid is drained from the body again using the catheter. This entire process is called an exchange.

Depending on the doctor's orders, patients have an average of five exchanges per day, therefore peritoneal episodic. After surgery, the catheter needs to heal for approximately two weeks and after this, training can begin.

Training for peritoneal dialysis is usually one to two weeks depending on how many hours of training are done in a day and how fast a patient learns. Training is offered by a peritoneal dialysis nurse and patients are taught to perform all aspects of their dialysis care, including how to perform the actual

exchanges, monitor blood pressure and fluid balance, education about kidney disease in general and how to deal with any issues that may arise. Patients are not sent home to perform any type of home dialysis without ensuring the patient feels comfortable and well informed and the staff feels the patient is ready and the home environment is suitable.

Lastly, people need to be able to store two to four weeks worth of dialysis supplies in the home, in a dry place that is free of extreme temperature changes.

The only difference between CAPD and CCPD is the manner in which the exchange is performed. In CAPD the individual performs manual exchanges, meaning *they* are performing the procedure several times intermittently throughout the day. In CCPD a machine known as a cycler is performing the exchanges in timed succession throughout the night while a person is sleeping. For both types of Peritoneal Dialysis, the entire dialysis time is usually between 10-12 hours depending upon how much dialysis is needed.

A great benefit of peritoneal dialysis is that it is performed every day and thus is similar to the real kidney function of daily waste removal.

Home Hemodialysis is the other available option. Home Hemodialysis utilizes a vascular access. The best vascular access is the fistula. A fistula is the joining of an artery and vein to form a connection and it allows the vein to develop to accommodate needles for dialysis. The usual placement of the fistula is in the arm.

Other types of vascular access are the graft and the catheter. A graft is the linkage of an artery and vein together with a piece of artificial vein. A catheter is a plastic access usually placed in the chest or neck region.

Both the graft and catheter allow for needles to be inserted and for dialysis to take place.

Catheters are the least recommended because they can harbor infection at a higher rate.

Home hemodialysis utilizes a machine with a dialyzer, also known as an artificial kidney, to clean the blood of excess fluid, waste and other toxins. Needles are inserted into the vascular access and are connected to the artificial kidney. This is how the blood is cleaned.

There are three types of home hemodialysis:

1. Conventional Home Hemodialysis,
2. Short Daily Home Hemodialysis, and
3. Nocturnal Home Hemodialysis.

In all forms of home hemodialysis, the patient and a dialysis helper are trained in all aspects of hemodialysis including how to operate the machine, insert the dialysis needles (cannulation), the timing of treatment, completion of home treatment record keeping, fluid balance and education on kidney disease in general.

Home hemodialysis training occurs in a home dialysis unit by a dialysis nurse. The training period is longer than that of peritoneal dialysis, usually three to six weeks, which includes cannulation training.

Patients need to be able to accommodate the hemodialysis machine, a reclining chair, approximately two weeks worth of supplies at a time and consider whether the machine they will be using will require any electrical, plumbing or other home modifications.

Conventional Home Hemodialysis is performed in the same manner as in-center hemodialysis. Patients perform all aspects of dialysis care, occurring three times per week

for the prescribed number of hours each time. Sometimes with conventional home hemodialysis, patients even have the option of adding a couple of extra treatments per month.

In Short Daily Home Hemodialysis the dialysis is performed five to seven times per week for a shorter period each time.

Nocturnal Hemodialysis is performed at night while a person is sleeping, three to seven nights per week. This type of dialysis allows ones blood to run through the machine at a much slower rate than in other types of hemodialysis.

Both short daily and nocturnal home hemodialysis offer “better” dialysis because dialysis is performed more frequently, closer to the body’s natural toxin and fluid removal, as opposed to just three times per week.

All forms of home hemodialysis are approved and paid for by Medicare and most private insurance companies. More importantly all forms of home dialysis therapies work to promote independence. Patients on home dialysis are afforded a more flexible schedule. This means the patient can choose the hours in which they will be dialyzing.

This ability to adjust dialysis scheduling often allows patients to resume or continue working and then perform dialysis either before or after work. Choosing your own dialysis times also allows flexibility for people to plan for recreational outings and family gatherings.

Many home machines are portable, so patients can travel without having to schedule transient dialysis treatments at centers that are unfamiliar to them or at inconvenient times during their travel plans, or even travel out of the country. When patients do travel, supplies can often be shipped to the travel destination and all the patient is bringing is

the actual machine and minor ancillary supplies either in the car, bus, train or on an airplane.

Because dialysis is being provided more frequently at home, patients actually feel better because the waste, toxins and excess fluid is being removed daily or almost every day; thus, people experience less “highs and lows” of in-center dialysis only three times per week. They have more energy to perform daily tasks, work, volunteer or other things that are important to them personally.

Home dialysis often offers a less restrictive diet and less renal disease related medications, again because the dialysis is performed more frequently. Patients have the independence and freedom to eat some of those foods that they enjoy but would not be permitted to have if they were receiving in-center dialysis.

It is very difficult when one first hears that dialysis is needed. This is a scary time, and often when options are being discussed they are unheard, missed or unfortunately untold. There is always an opportunity to rethink these dialysis options with family members and the team providing dialysis care.

What is most important is that information is provided and discussed at a time when it can be fully absorbed. It is only in this manner that dialysis patients can work toward keeping or gaining independence in a situation that often appears hopeless on first consideration.

*Karen Habercoss, MSW,LCSW,
Patient Leadership Committee Member*

To learn more about home dialysis and home dialysis options visit Home Dialysis Central at <http://www.homedialysis.org/>.

The Naked Arm cont'd

During dialysis, one tubing removes blood from your body and the other returns the blood after running through the dialysis machine. This blood moves rapidly through the system, often at speeds of 500cc per minute. The faster the blood circulates, the more blood goes through the dialyzer (artificial kidney) and the better you are dialyzed. You can imagine how quickly the blood will be lost if the tubing were to come apart. If this has ever happened to you during dialysis you know what I am talking about.

Here's another way to help you understand. Your body contains approximately 5000cc of blood. If your dialysis machine is pumping blood at 500cc per minute and would become disconnected, well you do the math! All your blood could be drained from your body in just 10 minutes. If not discovered quickly, you would soon be unconscious.

Nobody wants this to happen to you! This is why your nurses want you to keep your access arm uncovered so they can keep an eye on it. If the tubing does become disconnected, they will be able to see it much quicker than if it was covered up with blankets. If this does happen to you during your dialysis, notify a nurse or technician immediately! You can also grab the end of the tubing yourself and clamp it so you lose as little blood as possible.

Now you ask, what are you supposed to do about your arm getting cold? Be creative! You can wear a glove to keep your hand warm. You can cover up the rest of your body with warm clothing and/or a blanket if your facility allows you to have one. The only part of your access that needs to be exposed is the area where the needles are inserted and the tubing is connected. Everything else can be covered. Depending on where your access is located will determine how you can cover it. Some patients with sewing skills have cut a slit in a long sleeve shirt and sewed a zipper in it for

access. See what you can come up with to keep you warm and allow the staff to see your access at the same time.

The message of this story is to keep your access arm uncovered! Help make your dialysis treatment as safe as possible.

*MaryAnn Webb, RN, CNN
Network Quality Improvement Coordinator*

Volunteer with The Renal Network

If you are interested in volunteering with The Renal Network, you have a couple of options. One, which you can do from the comfort of your own home, is to write articles for our patient newsletter.

We are interested in your personal stories and poetry on such topics as coping with kidney disease, employment with kidney disease, or any other topic that you think would benefit other kidney patients. Just send or email your articles to the Network office and include your name and phone number.

You may also be interested in serving on a Network committee. The Patient Leadership Committee (PLC) acts as an advisory group to the Patient Services Department and assists in the development of new patient and staff resources. Members serve for three-year terms, attend three meetings a year, and patients are eligible to also serve on the Board of Trustees and the Medical Review Board. More information is available on the Network's web site, www.therenalnetwork.org.

PLC applications for the next term of office (2008-2010) will be mailed to the facilities later in the year. Let your social worker know if you are interested in an application.

Transplantation cont'd

coordinator is essential to keep you up to date on where you are in the process. Keeping you and your family informed may help keep your mood positive while you are waiting for a kidney.

Once the work-up is completed and approved by the transplant team, the transplant can be scheduled if it is to be from a living donor. If the donor is deceased, you will be put on a waiting list until a suitable donor kidney becomes available. The waiting can be very long and it can become discouraging. To help yourself during this waiting process, talk to other patients, continue to communicate with the transplant center, or join a support group if one is available. Try to remain as healthy as possible. Follow your diet and fluid restrictions, dialyze as your doctor prescribes, take your medications and maintain a healthy lifestyle. Being as healthy as you can be, both mentally and physically before you go to surgery, may contribute to the success of the transplant.

After your surgery you will need to take many medications and keep many appointments with the transplant doctors and nephrologists. It might help to keep a calendar for your appointments and take a family member or

friend with you to help remember what has been said. It is important to remember that, like dialysis, transplant is a treatment not a cure. Immunosuppressant medications are necessary to prevent the new kidney from being rejected by your body. It is necessary to take them for as long as you have your new kidney. Transplanted kidneys have been known to last as long as 25 years in some patients!

For more information regarding transplantation, there are many Web sites available. A few are listed below.

www.kidney.org
<http://kidney.niddk.nih.gov>
www.kidneypatientnews.org
www.kidneyschool.org
www.transweb.org

MaryAnn Webb, RN, CNN , Network Quality Improvement Coordinator and Kalisha Nance, Network Patient Services Coordinator

March is National Kidney Month

...celebrate by educating someone - a family member, friend, neighbor - on the risks of chronic kidney disease especially high blood pressure and diabetes.

Share Your Story!

RENAL OUTREACH

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