



# KIDNEY CONCERNS

SUMMER/JULY

ISSUE 33

## *Adequacy of Hemodialysis*

The Health Care Financing Administration (HCFA), the Federal agency that administers [Medicare](#), [Medicaid](#) and the [State Children's Health Insurance Program \(SCHIP\)](#), has instructed Networks that all dialysis facilities focus on having 80 percent of their hemodialysis patients adequately dialyzed with a URR of  $\geq 65\%$ . What is your responsibility as a patient in accomplishing this goal? This edition of [KIDNEY CONCERNS](#) addresses some of these issues relating to access selection, fluid intake and dietary changes, and compliance to your dialysis prescription.

HCFA is taking action for several reasons. First and foremost is to ensure that every person receiving hemodialysis is getting the minimal acceptable level of dialysis as outlined in the NKF-DOQI\* guidelines. Attaining these guidelines will improve patients' health and quality of life. We are in the age of outcomes and accountability and HCFA wants to ensure that taxpayer money is being spent wisely and appropriately. Thus ensuring the survival of the ESRD program.

The Patient Advisory Committee (PAC) has a mission to educate the patients of Network 13 about their health care team role and their own participation in their treatment. After receiving education about the requirements of dialysis, you have control over these parts of your treatment. No one else can do self-care for your access, take your medications as directed, follow your diet, limit your fluid intake, and show up and stay for your full dialysis treatment but **you**. Others can assist, prod, plead, get upset and frustrated in wanting you to follow your prescription and make the lifestyle changes necessary to provide you with the best quality of life possible, but they cannot do it for you. Do you manage the disease or does the disease manage you?

"Do you as an ESRD patient fully realize the consequences of not following your dialysis prescription?" That was the question presented to the PAC. If not, what needs to be done? What kind of education can we do to assist every patient in understanding the critical importance of following his or her dialysis prescription? How can the PAC assist you in being in the 80% receiving adequate dialysis?

Hemodialysis is a difficult transition that initially requires time for the treatment to be effective so you start to feel better. You cannot feel your best unless you complete your full dialysis treatment. You cannot live your best unless you complete your full dialysis treatment every time.

Chronic disease takes a toll emotionally. Depression is a common effect of living with a chronic illness such as kidney failure. Depression affects motivation that impacts on follow-through with requirements of dialysis treatment. It is important to have support systems available to you such as family, friends, other patients, patient organizations, staff of the dialysis center, etc. to assist you in managing the emotional impact of your chronic disease. If professional services are needed, seek a referral from your dialysis social worker.

Exercise has also been shown to improve outcomes. It takes time and effort but is worth the outcome. Discuss with your doctor about an exercise program that can benefit you.

**NKF-DOQI** National Kidney Foundation-Dialysis Outcome Quality Initiative: scientific based guidelines for dialysis providers to follow to provide the minimal acceptable care for dialysis patients.

# "Glad You Asked That . . ."

## ***What are the differences between accesses? How do they affect adequacy?***

An important part of receiving adequate dialysis depends on how well your access works. A patient must have a vascular access placed before starting dialysis so that blood can flow to and from the dialysis machine to be filtered. This article will address the three types of accesses and what a patient can do to keep the access working well.

The different types of access include the fistula, graft and catheter. The best type of access provides an adequate blood flow, has a long life, and has few complications. Some accesses are better than others.

A fistula is the recommended choice of access because it is made from your own artery and vein, typically lasts longer and is less prone to infections. The preferred placement is in the forearm but it can be placed in the upper arm or thigh. Your artery is joined to your vein at the access site. A fistula normally takes two to four months to mature before it can be used for dialysis. The fistula is beneficial to adequacy as it typically provides the best flow rate and has less clotting difficulties resulting in better adequacy of dialysis.

The next preferred access is a synthetic graft. A graft is a piece of man-made material used to connect your artery and vein. The benefit is the graft can be used sooner for dialysis. The negatives of the graft are: it is more prone to infection, more prone to clotting that may require surgery to correct, and does not last as long. The graft is beneficial to adequacy in that a properly functioning graft can provide a high blood flow resulting in better adequacy of dialysis. Clotting can affect blood flow rate of the graft.

The least preferred type of access is a catheter. Unless medically necessary, a catheter should never be used as a permanent access. A catheter is an access device typically placed in the jugular vein of the neck. It is two pronged with an outflow and inflow tube. The benefits are the catheter can be used immediately for dialysis, it requires no skin sticks and is easier to declot. The negatives of a catheter are the use-life, higher incident of clotting and higher incident of infection. A sterile covering must be worn over the catheter site between dialysis sessions. A catheter provides a lower blood flow that requires longer dialysis time and less adequacy of dialysis. It is harder to get the minimally accepted URR of  $\geq 65\%$  with a catheter. This increases likelihood of complications and death.

Remember you are the most important person on your care team. Work with your dialysis team to keep yourself healthy.

### **Access Care**

- 1. Avoid cutting off circulation to the access, wear loose clothing and avoid heavy lifting.*
- 2. Do not sleep on your access site.*
- 3. Avoid sharp objects near your access site.*
- 4. Do not allow blood pressure to be taken in the arm of the access.*
- 5. Keep access site clean and dry.*
- 6. Check access daily for "thrill", signs of infection; redness, swelling, heat*
- 7. Report any changes to your access site to your doctor or facility staff.*

This article was written by Penney Pilkington, PAC Chairperson, Member of the Board of Directors and Outreach/Education Committee

If you have any questions for "Glad You Asked That", forward them to ESRD Network 13, 6600 N. Meridian, Suite 155, Oklahoma City, OK 73116-1411, or phone (800) 472-8664. Selected questions will appear in future issues of Kidney Concerns.

## NEW STUDY REVEALS VALUABLE ADVICE

By Liz Davies and Joanne Juhnke  
Life Options Rehabilitation Program

You can live long and live well-if you take action to help manage your kidney disease and your life. This is the view expressed by many of the 30 renal patients, aged 34 to 80, in a 1999 Patient Opinion Study by the Life Options Rehabilitation Program. Most were on hemodialysis, while some were on peritoneal dialysis or had transplants. During the 30- to 90-minute phone interviews, patients talked about how they manage their disease, thoughts on living long and living well, and many other issues.

In one part of the study, *Life Options* asked people what advice they had for other renal patients. These valuable themes emerged:

- Keep a positive attitude and stay motivated.
- Learn as much as you can about kidney failure and its treatment.
- Communicate openly with staff and other patients.
- Take responsibility and follow the treatment plan.
- Exercise on a regular basis.
- Live life to the fullest.

### ***Keep a Positive Attitude***

You have to keep a positive attitude, according to several patients. Admitting that it's hard to stay upbeat in the face of so many challenges, they indicated that attitude can have a powerful influence on quality of life-either good or bad.

"You've got to have, no matter what you do, a positive attitude," one patient said. "...Never give up," said another. "Always looking ahead, I know within myself if I stop thinking positive, and don't weigh things out pro and con, I stay in the rut that I was in, but I can't go back there."

Several patients noted that encouragement from family, friends, and others helped them to keep a positive outlook. Keeping your sense of humor can also foster a positive attitude. "I must be able to crack a joke and laugh at all times, because if I accept sadness, I lose...I don't want pity," said one patient.

You can serve as a role model to other patients by keeping a positive attitude and encouraging them to do the same. There will be "ups and downs," of course, so seek support and encouragement from others, too.

### ***Learn As Much As You Can***

Staff should teach patients about kidney failure and its treatment early in the disease process, according to some patients in the study. The individual's learning style and information needs should be taken into account. Some people said that being well informed helps control their fears about the future. "I think that the more I know about it, the better able I am going to be to live with it," said one patient. (Continued Page 4)

## **NEW STUDY REVEALS VALUABLE ADVICE (cont.)**

Several patients emphasized the need to actively seek answers. "I think information is absolutely critical...knowing what needs to be done, what's expected, what the consequences and outcomes are," said one patient. "And the only way to find that out is by gathering information from whatever source." Another person said: "I found out that unless I take the initiative to investigate and to find out and to aggressively look for information, that it just doesn't pop into your mailbox or on the telephone."

The message, then, is to learn all you can about kidney failure and its treatment. Talk with your healthcare team about your information needs and concerns. Several organizations offer free, helpful educational materials (see box).

### ***Educational Tools***

Ask for the latest free educational materials on kidney disease and its treatment from these resources:

- \* Life Options Rehabilitation Program (supported by Amgen Inc.)  
(800)468-7777, [www.lifeoptions.org](http://www.lifeoptions.org)
- \* American Association of Kidney Patients  
(800)749-2257, [www.aakp.org](http://www.aakp.org)
- \* National Kidney Foundation  
(800)622-9010, [www.kidney.org](http://www.kidney.org)

Through support from Amgen Inc., free patient and professional education materials are available from the Life Options Rehabilitation Program. For more information, call the Rehabilitation Resource Center at (800)468-7777, visit the website at [www.lifeoptions.org](http://www.lifeoptions.org), or e-mail [lifeoptions@medmed.com](mailto:lifeoptions@medmed.com).

### ***Communicate with Staff, Patients***

Communicate openly with staff, advised several patients. "Be sure you have a good relationship with your doctor and your nurse."

Staff should "...promote communication and connections between people on a dialysis unit," so patients don't feel isolated, said one patient. This person was "scared to death" when starting dialysis, not knowing what to expect. "I just started observing other patients who seemed to have it all together...even doing things like taking their own weight...."

Talk with other patients who are doing well, said another person. A suggestion was made that facilities keep a list of volunteer patients who can be advocates and encourage other patients.

In summary, learning how to live long and live well involves staying in frequent, open communication with your healthcare team and other patients. Keep a positive attitude, get answers, and take action.

# Nutrition and Adequacy of Dialysis

## ***Does how well you dialyze affect your nutrition?***

Like normal kidneys, dialysis works to get rid of toxins that come from the breakdown of the foods that you eat. If you do not get enough dialysis, these toxin levels build up in your body and remain too high. Kt/V and URR are two ways that are often used to measure the adequacy of your dialysis treatment. If these numbers are low, some changes in your treatment may need to be done. These changes may include an increase in blood flow rate or dialysate flow rate, an increase in time on dialysis, a change in the dialyzer (artificial kidney), or a new or revised dialysis access. Kt/V and URR, however, only measure the adequacy of the one dialysis treatment that is measured. So—if you skip some treatments or get off early from other treatments, even though you are not getting enough dialysis, this will not show in these numbers.

Inadequate dialysis can make you have a poor appetite. Not getting enough dialysis can also cause nausea or vomiting. It might give you a bad or bitter taste in your mouth. Insufficient dialysis can also keep your body from properly metabolizing nutrients (such as protein) from foods. If you don't eat enough of both protein-containing foods and calories you will become malnourished. You may become weak and have difficulty fighting infections. Malnourished people on dialysis do not live as well or as long as those that are well nourished. One way that your protein nutrition is measured is with your "Albumin" level. The higher the better—so 4.0 is a good goal. Another number that your dietitian may look at is PNA (Protein Nitrogen Appearance). This can be used as an estimate of your protein intake from food. If it is low, it may mean that you need to include more protein in your diet.

## ***What can you do to increase a low protein level?***

You need extra protein to replace what has been lost. Foods that have a lot of protein include eggs, beef, pork, lamb, fish, chicken, and turkey. Sometimes high protein foods have less smell and are better tolerated if they are served cold such as on a salad or sandwich. You also need plenty of calories to allow your body to use the protein eaten as building blocks. Eating frequently may help increase your total calorie and protein intake. In addition, there are commercially made nutritional supplements that are high in protein and/or calories that may help you out, at least until your appetite returns and your albumin level is good.

## ***What can you do as a patient to be sure you are getting enough dialysis?***

Ask about your Kt/V and URR numbers. Are they meeting the goals for your dialysis unit? What can be done to improve them?

Do not arrive late for dialysis, ask to get off early, or otherwise shorten your dialysis time. Do not skip any dialysis treatments. If you are doing home dialysis, be sure to do all of your treatments with the correct dialysis prescription.

Control your sodium and fluid intake between dialysis treatments. You are more likely to have blood pressure drops and muscle cramping during dialysis when excessive fluid needs to be removed which makes getting adequate dialysis difficult. In addition, eating too much just before or during hemodialysis may also cause blood pressure to drop.

Let your dietitian know if you are having problems with your appetite or eating. Your dialysis staff is there to assist you.

## ***Lessons to Unlearn - Fluid Overload and Adequacy***

Since we were kids we have been told to drink plenty of fluids and always eat the right kinds of food. As dialysis patients the total opposite is true; we must eat only certain foods and control our fluid intake. The old habits we grew up with must be broken. Complications from fluid overload affect your adequacy of dialysis in several ways. Dialysis time must be spent "pulling" the excess fluid off before any significant waste removal can occur. The time spent on fluid removal is "taken away" from true dialysis time as most patients will not remain on the dialysis machine more than the prescribed time, so you short change yourself. This decrease in waste removal leaves more toxins in the body, which brings on feelings of fatigue, nausea, and weakness. Another side effect in "pulling" off the excess fluid is severe cramping during dialysis. These side effects are commonly viewed by patients to be caused by the dialysis, not the fluid overload, and cause patients to skip or cut short treatments. This just makes the problem worse. Fluid overload also affects the heart as fluid builds up around the heart and causes it to work harder to function, stressing the heart. It affects the lungs by fluid building up in the lungs and affecting your ability to breathe. These conditions lead to increased hospitalizations in which more frequent dialysis occurs to correct the condition. It becomes a vicious cycle that takes a toll on our body and increases the likelihood of death.

It is important to monitor and control your fluid intake by watching what you eat and drink so that your dialysis time is spent cleaning the waste from your blood to improve your adequacy and not having to remove excess fluid. You will feel better, be healthier, and have more energy.

*This article was written by: Cedric Mark, PAC and Board of Directors member*

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### **NETWORK 13 INTRODUCES PAC AT-LARGE MEMBERS**

Network 13 would like to introduce the elected Patient Advisory Committee's At-Large members. These patients will represent the patient population of Network 13 in its effort to educate and provide a patient perspective in all the activities of the Network to improve the quality of care delivered.

The At-Large members are:

Julie Bradford- FMC Franklin, Franklin LA

Eaphen Brown- St. Bernard's Dialysis, Jonesboro AR

Carla Faith- Dialysis Center South, Lake Charles LA


Kathleen Mc Donald- Fayetteville Dialysis, Fayetteville AR

Sandy Taylor- FMC Amite, Amite LA

Rod "Smokey" Gwoompi- Tahlequah Dialysis Center,  
Tahlequah OK

Tammy Zondor- Integris Baptist Hospital Transplant Center,  
Oklahoma City OK

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NEEDS YOU!**

*Kidney Concerns* is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for FALL/OCTOBER. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

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