



KIDNEY PATIENT UPDATE

SERVING RENAL PATIENTS IN ALABAMA, MISSISSIPPI AND TENNESSEE

FALL/WINTER 2003

A "FISTULA FIRST" CAN BE YOUR "ACCESS" TO LIVING LIFE TO THE FULLEST

If you are a hemodialysis patient, your vascular access is your lifeline. It is the way that you're able to reach your blood vessels for hemodialysis and hemodialysis keeps you alive.

There are three types of vascular access: (1) a fistula is your artery and vein sewed together. Blood from the artery makes the vein thicker so it can be used for dialysis; (2) a graft is a piece of man-made blood vessel. It is used to connect an artery and a vein together and; (3) A catheter is a plastic tube placed into a vein in the neck, chest or groin. Catheters can be used for a short time while a fistula or graft is healing. In a few patients with very poor veins and arteries, a permanent catheter may be placed in the chest.

It is very important for you to remember that you only have a few sites on your body that are appropriate for vascular access. So it is extremely important for you to ask for the best type of vascular access and to take very good care of it so it will last as long as possible.

The experts in kidney disease can all agree on one thing - that an A-V Fistula is the best access for most hemodialysis patients. You must have "good veins" to accommodate a fistula and this will have to be determined by a radiologist or a surgeon. Once a fistula is placed, it usually will take around 6 - 8 weeks to "mature" (the vein needs to become large enough to easily place the dialysis needles) before it can be used for dialysis. This type of access will take the most time to develop but is the longest lasting and the most trouble free. It is worth the wait!

Being prepared and having a "plan for dialysis" long

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TELL US WHY YOU LOVE YOUR FISTULA AND WIN FAME AND FORTUNE

Network 8 is sponsoring a contest to promote our new Quality Improvement Project. The project is called Fistula First and its goal is to increase the number of fistulas in Network 8. We know that a patient often will listen to another patient before they'll listen to their health care team.

So here's your chance to make a difference. Write a short essay (less than 500 words) about your fistula. Tell us how long you've had it, how well it's worked, and why you think it's the best possible access a patient can have. Also let us know if you've ever had any other access and why you prefer a fistula.

A small monetary prize will be given to the winner of the contest (Grand prize) and certificates of recognition will be sent to the honorable mention winners. All winning essays will be printed in future editions of Network 8's Kidney Patient Update. We look forward with great anticipation to reading all of your positive experiences with your fistulas. And don't forget that this is your opportunity to influence people and receive "fame" and maybe a little "fortune" in the process.

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"THE DOCTOR IS IN"



Our Physician columnist is Paul McGinnis, M.D. Dr. Paul is a kidney transplant recipient and a graduate of the University of Mississippi School of Medicine and is currently the Senior Staff Psychiatrist at Mississippi State Hospital. Dr. Paul will be happy to answer questions related to problems ESRD patients face in simple everyday language. Please send any questions, comments or topics for discussion to Brenda Dyson, Network 8., P.O. Box 55868, Jackson MS 39296-5858

QUESTION: I started dialysis a month ago and right now, I don't have any energy. When should I start thinking about being able to go back to work?

ANSWER: The time to think is now. The longer you wait, the more difficult it will be for you to go back to work. There is no such thing as the perfect time. But we as human beings are creatures of habit and I can tell you that if you have been working until recently, the easiest time to start back will be now. Since your recent start on dialysis your body will continue to become acclimatized and your energy should return as you become free of toxins that built up prior to the start of dialysis. Although you may not completely feel like starting back to work now, as you work you will continue to feel better and it will become easier for you. On the other hand, waiting will make it more difficult for you to get back into the habit of working. It is not my opinion that renal patients are always entirely disabled. Many of us do carry disabilities due to the other conditions that we have such as diabetes, but renal disease in and of itself does not equal disability.

In 1972 in order to fund dialysis for those people with end stage renal disease, patients were declared to be disabled. This was both good and bad. It gave birth to the industry of hemodialysis and made it available to many people. At the same time, it left us, the patients with the legacy of disability. There is no reason in the present day that we cannot contribute to society. It is the thing that makes us feel useful. One of the first things we want to know about a person when we first meet them is what do you do. We judge people by what they do in society. This is an important part of who we are and if we are to escape the idea of being disabled and having end stage renal disease control our lives then contributing to society is what we must do.

Not all of us can still contribute in 9:00 to 5:00 jobs that result in a paycheck. That does not mean that we cannot work. When I say work, I mean contribute to society, if that is helping the other patients in the dialysis center, volunteering at some program, these activities are all work. We are a group of beings who live as a society, each contributing to the overall good. It is in our nature to do this the same way it is in the nature of a group of bees to build a hive and we always feel better when we go with nature. It fulfills us; it gives us purpose, things that all people need in their lives.

Don't wait any longer. Make the arrangements you need to go back to work and show what you can give back to others.

WHAT IS REHABILITATION?

The following article is taken from *Life Options Rehabilitation Programs' Keys to a Long Life*. July, 1999. "Just the Facts: Rehabilitation."

The purpose of dialysis is not just to keep you alive. Dialysis is also meant to help you stay active and keep doing the things you love. **Rehabilitation** or rehab, for people on dialysis means being able to do things you need and want to do.

Rehab goals are different for each person. If you worked before your kidneys failed, rehab for you might mean keeping your job. If you did a sport or hobby before, rehab might mean doing those things again.

Why is rehab important to me?

Adjusting to a chronic disease can be very hard. It is even harder if you think your life will never be as good as it was before. Rehab can help you make a new life that may be different from your old life, but is still good.

Does my center do rehab:

Rehab can be very different from center to center. Some centers have exercise bikes to ride during dialysis. Some centers have support groups for patients or families. Some centers have bulletin boards with pictures of active patients. Some have newsletters. All of these - and more - are part of doing rehab.

One thing every center must have in order to do rehab is a caring staff who want patients to stay well and reach their goals.

How do I set rehab goals?

You know what you want to do with your life. Think about what steps you must take to get there. Your nurse or social worker may be able to help you. As you reach each new step, you will see that you can make your life better.

What is my part in my rehab?

There are three things you can do to help your rehab. (1) Have a positive attitude. Focus on the good side of things, not the bad. (2) Learn all you can about kidney failure and dialysis so you can stay as healthy as possible. (3) Take action to meet your goals.

You are the key person on your rehab team. By thinking positive, learning and taking action, you can live long and live well on dialysis.

How can I meet my rehab goals?

If you have trouble staying positive:

- Talk to other patients who are doing well
- Spend time with people who have positive attitudes
- Start a support group in your center

If you feel that you don't know enough about kidney failure and dialysis:

- Keep a list of questions to ask your doctor or the staff. Make an office appointment if you need more time. Ask for patient booklets to read and videos to watch.
- Do research at the library or on the internet
- Ask questions of other patients who are doing well.

If you don't know what goals to set:

- Talk to family, friends and staff to get ideas.
- Make a list of things you enjoy and see if the items have something in common.
- Start small at first. Goals can be in any area - building up strength to climb stairs, or learning to put in your own needles.

The important thing is to take some sort of action. Set a reachable goal and a time to achieve and then set another one. Keeping active is the key to a long and happy life on dialysis.

CDC WARNS OF SERIOUS FLU SEASON

ESRD PATIENTS ARE AT GREATER RISK THAN GENERAL POPULATION

The CDC (Centers for Disease Control) warns that this flu season will be a difficult one with an earlier start in reported cases and a more severe strain of the flu than the country has seen over the past few years. The vaccine is a slightly different strain of the flu virus than that which has been reported, but is close enough that it will still have a protective effect.

What is the flu and why should you be so concerned about it?

Influenza, also called the "flu" is a highly contagious respiratory infection. Flu can cause fever, chills, headache, dry cough, runny or stuffy nose, sore throat and muscle aches. Unlike other common respiratory infections such as the common cold, the flu can cause extreme fatigue lasting several days to more than a week. Both the flu and pneumonia are serious diseases and can lead to death.

The flu is spread easily from person-to-person primarily when an infected person coughs or sneezes. After a person has been infected with the virus, symptoms usually appear within 2 to 4 days. The infection is often contagious for another 3 to 4 days after symptoms appear. Most people are ill with the flu for only a few days, but some get much sicker and need to be hospitalized.

The virus that causes the flu changes often, therefore, the vaccine is updated each year. Protection develops about 2 weeks after getting the shot and may last up to a year. Some people who get the flu vaccine may still get the flu, but they will usually have a milder case than those who did not get the shot. This shot may be given at the same time as other immunizations such as the pneumococcal.

People who have long-term health problems such as kidney disease and their household members should get the vaccine.

The best time to receive the vaccine is in October or November. The flu season usually peaks between January and March, so if you still haven't gotten your vaccine in December, you still have time, but you need to have it done as soon as possible especially this year, when there is a shortage of the vaccine.

How will I pay for the vaccine?

YOUR FLU SHOT IS FREE, if you are enrolled in Medicare Part B and your health care provider accepts Medicare assignment. The Medicare program covers the flu shot and the cost of administration for beneficiaries. Medicare recipients do not have to pay a coinsurance or a deductible under the flu shot benefit. For HMO members, most must get their flu shot from their HMO. Check with your HMO first. For those covered under Medicaid, check first with your local social services or health department. Many private insurance plans also cover the flu vaccine. You can get a flu shot at your doctor's office and you may also be able to get the shot from your dialysis unit, your local health department or from other health-care providers. Medicare Part B will pay for the shot no matter where you get it, as long as the health care provider agrees not to charge you more than Medicare pays. Check with your doctor or dialysis center to find out how best to get the vaccination.

Remember the flu is serious business. It's not just a runny nose or upset stomach. It can lead to pneumonia especially in kidney patients. At least 45,000 Americans die each year from influenza and pneumonia, the sixth leading cause of death in the United States. Ninety percent of these deaths are among people 65 years of age or over. You need to talk to your health-care provider and let them know if you have any allergies (such as to eggs), but don't take the chance of not protecting yourself.

REMEMBER THE OLD SAYING....BE WISE, IMMUNIZE!

THE 20 YEAR CLUB



The 20 Year Club is a continuing feature of Network 8's Kidney Patient Update. This feature highlights Network 8 patients who have survived end stage renal disease for 20 years or more. If you or someone at your facility has been on dialysis, had a transplant or a combination of both for 20 years or more, please let us know. Contact Brenda Dyson at Network 8 at (877) 936-9260 or fax the information to (601) 932-4446. The mailing address for Network 8 is P.O. Box 55868, Jackson, MS 39296-5868. This article was written and submitted by Pam Arnold of the Tennessee Kidney Clinic in Humboldt, Tennessee.

Loretta Roberson began dialysis on June 2, 1983 in Jackson, Tennessee. She is pictured celebrating her 20th anniversary as a dialysis patient at her clinic. Ms. Roberson was born on July 17, 1948 in Fulton, Kentucky where most of her family still resides. She has two sons, Jerrod, 33 and Robert, 25, both of McKenzie, Tennessee. She has 10 grandchildren.

Ms. Roberson presently dialyzes at the Tennessee Kidney Clinic of Humboldt, Tennessee. She has previous knowledge of dialysis due to her father being a patient for many years. Ms. Roberson has her own specific beliefs as to why she has and continues to do well on dialysis. She states that she does not "dwell" on taking dialysis treatments three times a week and does not regard herself as "being sick". Dialysis is just a part of her routine. Staying active is very important to Ms. Roberson. She enjoys doing her housework, walking, shopping and cooking for her family.

Ms. Roberson's family is very supportive and encouraging. She lives with her sister, Beverly, grandson Justin, 13, and nephew, Adrian, 15. Ms. Roberson believes that a positive attitude and active lifestyle have contributed to her success with dialysis.

2003 - 2005 PAC OFFICERS ELECTED DURING ANNUAL PAC MEETINGS

The 2003 Annual Patient Advisory Council (PAC) Meetings were held this Fall. The Mississippi meeting was held on August 24 in Jackson, Mississippi and was a joint meeting with the NKF of Mississippi. The Alabama meeting was held on October 12 in Birmingham, Alabama and was a joint meeting with the Alabama Kidney Foundation. The Tennessee meeting was held on October 26 in Nashville, Tennessee and was a joint meeting with the AAKP chapter of Middle Tennessee. All three meetings were very successful and well attended.

The PAC officers for each state were elected during the meetings. They are as follows:

MISSISSIPPI

Chairperson - Delorse Craft

Vice-Chairperson - Leshia Toney Rich

Secretary - Sharon Chaney

Newsletter Correspondents - Cedric Cole and Cassondra Johnson

TENNESSEE

Chairperson - Rev. Ezell Garner

Vice-Chairperson - Laurie McCommon

Secretary - Ellie Durrett

Newsletter Correspondent - Mike Moneyham

ALABAMA

Chairperson - Michael Tharpe

Vice-Chairperson - Charles Weathington

Secretary - Johnnie Baker

Newsletter Correspondent - Louis Cooper

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before your actual starting date is important for the success of the fistula as your first access. But, even if a fistula isn't used when you first start dialysis, it can always be placed at a later date. If you have a graft that begins to fail, you need to ask your physician to refer you to be evaluated for a fistula. And if you start dialysis with a catheter, which should be used only as a bridge to a permanent access, you need to be evaluated for a fistula as soon as possible.

The advantages of a fistula include: (1) It's a simpler surgery than a graft; (2) This is the longest lasting access; (3) Infection rate is lowest of all types of access; (4) There is the least chance of clotting problems and (5) This is the preferred type of access.

Once you have a fistula it is extremely important that you take very good care of it. Always keep the following in mind:

- Do not wear tight clothing, purse-straps, or tight jewelry around your access.
- Do not sleep on your access arm.
- Be careful not to strike or cut your access arm.
- Do not carry heavy loads over your access (groceries, firewood).
- Do not let anyone take blood or put IV's into your access arm. Also, NO blood pressures on your access arm.
- Do not scratch or pick at the skin of your access arm.
- Keep the access arm clean and the skin moist and pliable.
- Be aware of the blood flow direction of your access. Make sure your needles are placed properly.
- Low blood pressure should be avoided to discourage the access from "clotting off".

So, please remember that a fistula will always be your best choice and will keep you OUT of the emergency room and IN the dialysis unit getting the kind of quality dialysis that will allow you to lead a good, healthy life.

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