

ESRD NETWORK 13

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KIDNEY CONCERNS

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Fistula First

Articles are a collaborative effort of the 18 ESRD Network Patient Services Coordinators

Conquering Your Fistula Fear.

Deciding to get a fistula placed can be a lot like trying to stop smoking! Have you ever known something you *should* do, but for some reason you haven't been able to do it? Many dialysis patients hesitate to get a fistula placed because they are scared, anxious, or depressed. Some patients say, "What is my arm going to look like after this?" Other patients have a fear of having needle sticks. If these are some of your concerns, there are things you can do to take control and get a fistula placed!


What is anxiety?

Anxiety and fear can be as general as a dread of the whole treatment process or as specific as a fear of needle sticks. You can explore and identify the anxiety and fear you may experience through discussions with your social worker and/or nursing staff. Below are some common anxieties and fears:

Fear dialysis treatment including

- needle sticks,
- blood loss,
- anticipated physical pain,
- loss of control

What you can do:

- Ask questions.
- Address pain control with your nephrologist. Ask:
 - ❖ *Is Emla (Lidocaine) Cream an option?*
 - ❖ *Would anti-anxiety medication help?*
 - ❖ *Is self cannulation an option (sticking yourself)?*
 - ❖ *Can you learn the "buttonhole technique"?*
- Learn about relaxation exercises such as deep breathing. Practice them.
- Every patient experiences pain differently. Write down and keep track of your own "level of pain." Report your levels of pain to the nephrologist.
- Know what your access should look like and feel like.
- Assist the staff with needle placement. If the person is cannulating you and it feels right say, "*When you do it that way it feels right.*" If something feels wrong say, "*When you do it this way, I feel more pain, etc.*"
- Talk to your social worker about your concerns and/or fears. 

The Network 13 Patient Page (<http://www.network13.org/patients.htm>)

You can find:

- ◆ Patient Support
- ◆ Dialysis Facility Compare (DFC)
- ◆ Vocational Rehabilitation Information
- ◆ Educational Web site Links
- ◆ Grievance Information
- ◆ Past Issues of Kidney Concerns

Fear of the medical setting (i.e., dialysis unit, hospital, etc.)

What you can do:

- Ask questions such as
 - ❖ *Can I take a tour of the facility*
 - ❖ *Can you explain the different machines to me?*
 - ❖ *Can you explain the dialysis process to me?*
 - ❖ *Would anti-anxiety medication help?*
- Bring something from home as allowed by your facility (blanket, pillow, or book).

Fear of the health care providers (i.e. doctors, nurses, social workers, dietitians, technicians, etc.)

What you can do:

- Ask questions such as
 - ❖ *I am interested in learning more about the healthcare team. Can you tell me your name?*
 - ❖ *What is your role here? Are you a technician or a nurse?*
- If the facility allows, bring a family member to orientation with you.

Fear of the surgery

- Ask questions.
- Talk to other patients with fistulas. Ask thing such as:
 - ❖ *What was the worst part of the experience?*
 - ❖ *What are the benefits?*
- Get educational materials from the dialysis facility staff.
- Contact support agencies for information
 - ❖ *ESRD Network*
 - ❖ *American Association of Kidney Patients*
 - ❖ *American Kidney Fund*
 - ❖ *National Kidney Foundation*

A fistula will change the shape of your arm. Sometimes people dread that their arm might look different. A lot of patients think about how they will respond if people stare or ask questions. Most patients say they are more self-conscious about the change at first but it becomes more “normal” as time passes. There are ways you can become more comfortable with your access and how you view it. Below is a list of some of the concerns people have about a fistula, and different things patients can do to better cope with the concerns.

What if I injure my fistula?

What you can do:

- Ask questions such as
 - ❖ *Are there any limits to using my arm?*
 - ❖ *What should I not do?*
 - ❖ *Is it okay to lift heavy things?*
 - ❖ *Is it okay to wear tight clothing?*
 - ❖ *Wear an ID bracelet inscribed no BP or sticks in fistula arm*



<p>Seeing my fistula is a reminder that my health is not good.</p>	<p>What you can do:</p> <ul style="list-style-type: none"> ❑ Remind yourself that dialysis is life saving and you can live longer with a fistula. ❑ Accept that your fistula is the “best” access type. ❑ Remind yourself that the change in appearance is necessary.
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<p>Lots of people will ask “What is it?” and I don’t know what to say.</p>	<p>What you can do:</p> <ul style="list-style-type: none"> ❑ Consider this an opportunity to educate others. ❑ Coin a phrase: <ul style="list-style-type: none"> ❖ <i>It’s my access.</i> ❖ <i>It helps keep me alive.</i> ❖ <i>I have Chronic Kidney Disease.</i> ❖ <i>I am one of 312,000 people in the United States who have End Stage Renal Disease.</i>
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<p>I feel embarrassed about the way my fistula looks.</p>	<p>What you can do:</p> <ul style="list-style-type: none"> ❑ Talk to your Social Worker about the way you are feeling. ❑ Some patients consider their access their “badge of honor” or “lifeline”. ❑ Some patients cover their access with loose wraps or flowing sleeves.
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If you have any of the concerns listed above, find comfort in the fact that you are not alone. Most patients can identify with at least one of these fears. All of these can be managed with education, medical treatment or by just having a conversation with your social worker and other health care team members. If you are able to take control and address your concerns about getting a fistula, you will be improving your overall health and well-being.

Have more control over your dialysis and health

The best way to do this is an **Arterio-venous Fistula** (Fist-choo-la).
 “Fistulas are the ‘gold standard’ for establishing access to a patient’s circulatory system in order to provide life-sustaining dialysis. They last longer, need less rework, and are associated with lower rates of infections, hospitalizations, and death for Medicare beneficiaries than other types of access.”

[Quote by Centers For Medicare & Medicaid Services (CMS) Administrator, Mark B. McLellan, MD, PhD, in a CMS press release April 14, 2004]

One patient, who has been on dialysis for twenty-one years, noted that a fistula (a form of vascular access) is not about having a vascular access (a way to get to your blood) but about freedom and control: freedom to decide what works for you and control over your overall dialysis treatment. He further noted that over the years he has come to understand that dialysis works best when we have a measure of control over our



dialysis and our lives. His first four accesses were gortex grafts, which had the advantage of being immediately usable; however, they also required frequent hospital visits for declottings and revisions. When his nephrologist (kidney doctor) suggested an Arterio-venous fistula (AVF), he was concerned about the time it would take to develop after it was created. Once developed, a fistula will usually eliminate the need to have a declotting procedure (procedure done to remove a clot that has formed in the vascular access). He has since had a very successful eight years with his AVF, with zero revisions and zero declottings!

[From the article "Focus on Fistulas: A Patient's Perspective," Phillip Cade, MSW, available at: <http://www.nwrenalnetwork.org/fist1st/cade.htm>]

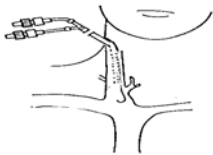
What It Looks Like



Fistula - An arterio-venous fistula (AVF) is created by sewing together the person's own native artery and vein



Graft - A graft is usually a soft, synthetic tube that is connected at one end to an artery and at the other end to a vein, usually in your arm.



Catheters - A catheter is a "y-shaped" plastic tube. It is surgically placed into a vein in your neck, chest, or, occasionally, groin.

There are many factors that go into deciding which type of vascular access is best for you. The most important factor, that is taken into consideration by the healthcare team, is the wishes of a well-informed and knowledgeable patient who has all the facts. Educating yourself is the first step in being in control of your dialysis and healthcare. Deciding to choose a fistula is a good choice.

The Advantages Of Fistulas Once Established

- ◆ Last a long time - years, not weeks or months as other accesses
- ◆ Fewer infections
- ◆ Fewer hospitalizations
- ◆ Better blood flow for better dialysis
- ◆ Least chance of clotting
- ◆ Preferred type of access

Where To Start

- ◆ Talk to your nephrologist
- ◆ Get a referral to an experienced surgeon who frequently places hemodialysis accesses
- ◆ Ask your surgeon if 'vein mapping' (ultrasonic test and physical assessment of arteries and veins) would be helpful
- ◆ Ask your surgeon about doing a 'venogram' (x-ray of the blood vessels)

Help For You

The social worker at your dialysis facility can support you as you talk with your nephrologist and surgeon. Ask questions and more questions. The choices you make should be well informed, and consulting with your nephrologist and treatment team is an important step.

You are the one who will live with the choice you make. CHOICE IS CONTROL.



Frequently Asked Questions about Arterio-Venous Fistula's (AVF)

1. Why should I get an arterio- venous fistula (AVF)?

It is widely accepted among the majority of nephrologists and other dialysis professionals that an AVF is the preferable access type by which to receive your dialysis. AVF's, with proper care tend to be the longest lasting type of dialysis accesses and require fewer interventions, such as de-clotting, which can be very painful. With an AVF, it is also likely that you will experience fewer infections, fewer days in the hospital, and receive more adequate dialysis, which in turn will improve the way you feel and improve your quality of life.

2. How do I get an AVF?

There are several members of your healthcare team who can provide you information about obtaining an AVF, but you might want to initiate this discussion with your physician or a nurse in the dialysis clinic. Prior to talking with your healthcare provider, you would probably benefit from educating yourself about the benefits of having an AVF. Several sources of educational information regarding AVF's (some of which are included at the end of this document) are available.

3. Who is a candidate for an AVF?

There are very few instances where a fistula is not indicated. Nowadays, in the majority (including those with diabetes or who are "older") of patients, a "mapping" study of the blood vessels in the arm is conducted, which will help select the best veins for a fistula and decrease the chance for an unsuccessful surgery. Be persistent. If the mapping study was not done, asking for a second opinion is quite reasonable.

4. I don't like needles, how do I cope with this fear?

There is no denying that having an AVF requires the insertion of two needles into the access site. However, there are many options for dealing with the needles. Many patients report that by learning to place their own needles, they are focusing more on the needle placement than the pain associated with the needles. Additionally, your clinic might have a topical or subcutaneous anesthetic available to numb the area prior to the needle sticks. There are relaxation techniques such as breathing and imagery exercises, which might help reduce the anxiety often related to a fear of needles. You might also ask your clinic or nephrologist if smaller needles might be appropriate or if other ideas for dealing with the pain exist.

5. An AVF will change the looks of my arm, how do I cope with this?

The way we view our bodies is very important to the way we feel about ourselves. If you are uncomfortable with your physical appearance, it is more likely that you won't feel good about yourself in general. The repeated insertion of needles into an AVF can cause scarring and a change of appearance in your arm or wherever the AVF is placed. What is important to remember is that you have the choice to not let your feelings about yourself be defined by the look of your access site. By opening up and talking to other dialysis patients with AVF's you will learn the methods or coping mechanisms they have used in integrating these physical changes into their daily lives.

6. How is an AVF different from a catheter or a graft?

An AVF is created by connecting (usually in your forearm) one of your own a veins and arteries together. A graft requires the surgical placement of a small flexible tube connecting your own artery and vein together. A catheter requires the placement of a small tube into a large vein in your neck, chest, or groin. The AVF uses your own anatomy and requires no insertion of a "foreign" substance into your body. Since an AVF uses your own vein and artery, it is less likely to clot or become infected and tends to last longer than catheters or grafts.



7. What additional care will my AVF require?

The application of pressure to the site is necessary following the end of your treatment. This will likely need to be completed by you and it will add some additional time to your time in the clinic as the access stops bleeding. It will be important that you keep your access clean and wash it thoroughly prior to initiating your dialysis run. You will want to make sure anyone caring for or inserting needles into your access site is wearing clean gloves and observing infection control techniques. You need to be very protective of the arm where your AVF is placed. This includes restricting others from inserting IV's, drawing blood, or taking your blood pressure. You will also want to check your access on a daily basis for any changes such as redness or swelling. You might be advised not to lift any heavy objects or put pressure on your access arm because this will limit circulation.

Additional Resources:

www.fistulafirst.org

www.kidneypatientguide.org.uk/site/contents.html

www.ikidney.org

www.kidneypatientnews.org/VascularAccesslinks.html

<http://kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess/>

www.ihl.org/IHI/Topics/ESRD/VascularAccess/Resources/

www.esrdnetworks.org

www.nephron.com/judy.html

www.lifeoptions.org

www.kidneyschool.org

www.cms.gov

www.aakp.org

This is a limited list to provide you with an initial list of resources to begin learning more about the benefits of having an AVF. This is not meant to be an exhaustive list and you can always speak with your physician, nurses, or other members of your healthcare team, or contact your local ESRD Network.

The information was gathered through a collaborative effort of Patient Services Coordinators from the 18 ESRD Networks across the nation. If you would like more information on AV Fistulas please contact the Network office at **800-472-8664**.



Contemporary Wonder Woman

By: Sandy Morant, Network 13 PAC Member

Althea Mouton Davis is truly a contemporary Wonder Woman. For although she has faced more physical trials and illnesses than the average person, she has maintained an active lifestyle and a zest for life. Althea has been an ESRD patient for about 27 years. She lost kidney function due to the complications of Type 1 (juvenile diabetes) and hypertension. She started treatment as a hemodialysis patient but had difficulty physically tolerating the treatments. After about nine months her brother, Mark Mouton, donated a kidney to her. Althea's transplant has been extremely successful in spite of other unrelated complications: surgeries to relieve pressure and pain resulting from glaucoma (which ultimately led to complete blindness), a stroke, osteoporosis, and hypoglycemic attacks.

But throughout all these physical setbacks, Althea keeps an upbeat attitude and a sense of adventure. She is very independent and, in spite of her lack of sight, Althea maintains an immaculate well ordered home on her own. She cooks nutritious meals every day, cleans her house herself, and even irons her own clothes. Althea also has a full social life as well. Family and friends are an important part of her daily routine; in fact, she is often the communication hub for family members. She attends church regularly, plays Pokeno, and actively supports her community through the Citizen Action Committee. Althea has functioned so well after her transplant and adapted to her lack of sight that she was able to find the time and the love to share with a child. Since she was unable to have children, Greg Jr. was adopted into the family as a newborn 21 years ago.

No, Althea does not have a fairy godmother that waves a magic wand and dissolves all of her problems. She is a very disciplined, hard working individual. She takes a very active part in her treatment; knows and memorizes all of her medicines, including exact dosage; keeps alert to potential problems and drug



interactions. Althea carefully follows her diet and monitors her blood sugar level several times a day. She helps herself by heeding the directives of various medical and health care personnel and making sure she keeps on hand all the supplies she may need. She plans ahead and tries to foresee the consequences of her actions. Most importantly, Althea has a system, which allows her to be independent. She keeps her home very neat and orderly; everything is assigned a particular place in which it is kept and returned immediately after use. She has trained her memory so that she can retain a phenomenal amount of information that she needs to keep at hand. She also uses the voice mail option on her phone to record information and reminders to herself.

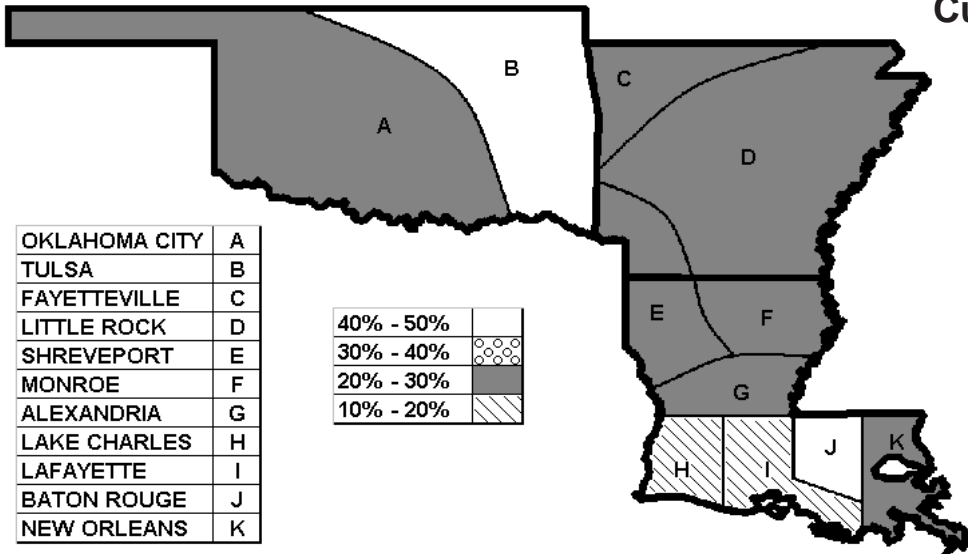
Althea attributes her courageous lifestyle to her faith in God and to the support of her family and friends. When faced with a problem or setback, Althea doesn't spend a lot of time feeling sorry for herself or lamenting the fact that this situation occurred. She acknowledges the anxiety or sorrow she is experiencing, prays for strength, discusses the problem with her family and friends, then moves on to solve the problem or adapt to the new situation. In short, Althea's positive attitude, great courage, sense of adventure and zest for life make her an inspiration to all who meet her but especially to those who are lucky enough to count her as a friend.



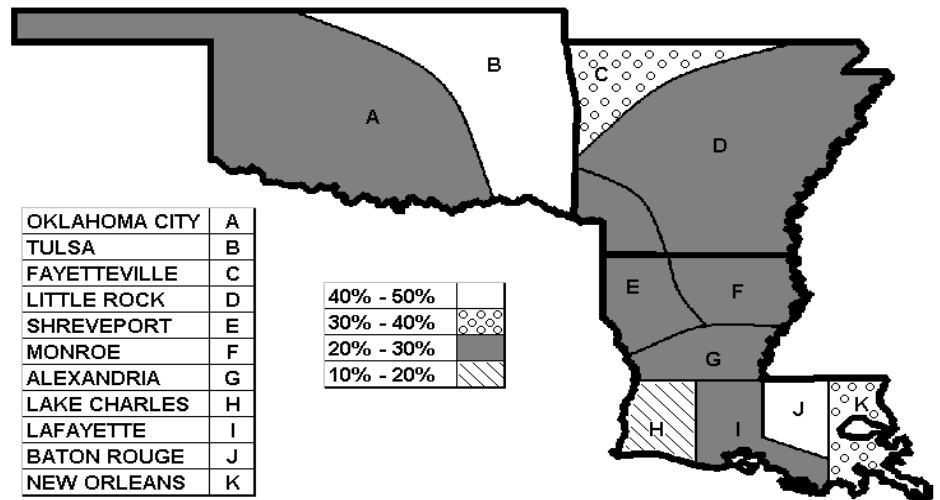
What is the Fistula Rate in your Region? Check Here.

Baseline AV Fistula Rates by Region

**Baseline = October 2003
Current = October 2004**



Current AV Fistula Rates by Region



What Are My Options If I Have A Grievance?

STEP 1

Try your facility first...
 Contact your facility's social worker...
 Ask for and follow the facility's written grievance procedures...
 If not satisfied...

STEP 2

Contact the Network...
 Ask for the Patient Grievance Policy...
 Visit our Web site for a copy of the policy...
 Speak with the person in charge of Patient Services.

What is a grievance?

A grievance is any concern about treatment in a dialysis or transplant facility.

A grievance may be filed by the patient, a family member, or another person acting on the patient's behalf (per HIPAA guidelines). Grievances referred to the Network are processed according to written grievance procedures.

What is the Network?

Network 13 is under contract with the Centers for Medicare & Medicaid Services (CMS) to serve the states of Arkansas, Louisiana, and Oklahoma.

The Network collects patient information and works to improve patient care in dialysis and transplant facilities. Processing written grievances and trying to resolve patient concerns is an important part of the quality improvement program.

Call 1.800.472.8664 for details.

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Vocational Rehabilitation Contact Information

Arkansas: Andrew Jones, Program Administrator
 Arkansas Kidney Disease Commission
 Phone: 1-800-330-0632
 Web site: www.state.ar.us/ars

Louisiana: Louisiana Rehabilitation Services
 Phone: 1-800-737-2963 (inside Louisiana only)
 Web site: www.dss.state.la.us/lrs

Oklahoma: David Couch, Programs Field Representative
 Oklahoma Department of Rehabilitation Services
 Phone: 1-800-487-4042
 Web site: www.drs.state.ok.us



KIDNEY CONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SUMMER/JULY. 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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