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 doctor. Ask: o *Is Emla (Lidocaine) Cream an option?* o *Would anti-anxiety medication help?* o *Is self cannulation an option (sticking yourself)* o *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 doctor. • Know what your access should look and feel like. • Assist the staff with needle placement. If the person is sticking 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.
Fear of the medical	**What you can do:**

setting (i.e. dialysis unit, hospital, etc.)	• Ask questions such as:
	  o *Can I take a tour of the facility?*
	  o *Can you explain the different machines to me?*
	  o *Can you explain the dialysis process to me?*
	• *Would anti-anxiety medication help?*
	• Bring something from home (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 thehealthcare 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	**What you can do:**
	• Ask questions.
	• Talk to other patients with fistulas. Ask thing such as:
	  o *What was the worst part of the experience?*
	  o *What are the benefits?*
	• Get educational materials from the dialysis facility staff.
	• Contact support agencies for information, such as:
	  o *ESRD Network*
	  o *American Association of Kidney Patients*
	  o *American Kidney Fund*
	  o *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: o *Are there any limits to using*

	my arm? o *What should I not do?* o *Is it okay to lift heavy things?* o *Is it okay to wear tight clothing?*
Seeing my fistula is a reminder that my health is not good.	**What you can do:** • 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.
Lots of people will ask "What is it?" and I don't know what to say.	**What you can do:** • Consider this an opportunity to educate others. • Coin a phrase: o *It's my access.* o *It helps keep me alive.* o *I have Chronic Kidney Disease.* o *I am one of 312,000 people in the United States who have End StageRenal Disease.*
I feel embarrassed about the way my fistula looks.	**What you can do:** • 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.

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.

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 your local Network office.