

A Medical Education Institute/Life Options Publication

VOL. 1 | NO. 1 MARCH 2004

New Name, New Look

The *Renal Rehabilitation Report* has gotten a makeover! After more than 10 years, we've re-designed our newsletter to make it easier for dialysis professionals and patients to use.

New name. Our new name reflects the Life Options philosophy that being *In Control* is key to a long life with chronic kidney disease. What you learn here will help put you and your patients *In Control*—with practical, how-to guides and tips.

2-in-1 design. Our new look makes it easy to find content that meets your needs. For you, there are 4 pages of important issues and information on how to put key concepts into practice. For your patients, there 4 pages of easy-to-use patient education, complete with a quiz to test their knowledge.

We encourage you to make copies of the patient pages and use them as supplements to your own educational materials.

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Focus on Fistulas

We're kicking off this first issue of *In Control* by focusing on one of the most challenging topics you face today: Fistulas. How can we increase the numbers of hemodialysis patients who use fistulas for vascular access?

Good access is key to patient confidence and well-being, and fistulas are the best access choice. Compared to catheters, fistulas have fewer complications and provide better blood flow for better dialysis. They last longer, cause fewer hospitalizations, permit greater longevity... and they even cost less.

The advantages of fistulas are so extensive that the ESRD Networks and CMS have made a new Fistula First initiative their top priority: working toward a goal of 50% of new patients and 40% of all current patients using fistulas for access. "If dialysis professionals and providers can work together to increase fistula placement, it will have a significant impact on quality of care," says Jenny Kitsen, Executive Director of the ESRD Network of New England and a member of the Fistula First leadership group.

Fistula First

The Fistula First initiative has identified 11 key clinical and organizational changes to help increase fistula use. (See resource list on page S8.) All are critical, but "we're discovering that the most important factor in improvement is having someone (in the center) take the initiative and pay attention to access," says Kitsen. "Get a handle on who's got what type of access and how long they've had it: then put a plan in place for the future," she advises. "That way the issue of access won't just fall through the cracks."

Improving access "is going to be a challenge," Kitsen admits. "We will have to be creative in reaching out beyond our comfort zone in the center—to surgeons, to hospitals, etc.—in dealing with the problem."

Patients, too, can play a role to increase the likelihood that they will get and keep a fistula, by learning more about access, participating in active self-care, and speaking up: in fact, by being "in control."



Nursing Protocol Increases Fistula Placements

The nursing staff at UVA Augusta Dialysis Center, led by Clinical Director Kim Deaver, RN, BSN, CNN, were able to increase fistula use from 51% to 76% of all hemodialysis patients in their unit—and reduce catheters and graft use by half—in just 18 months! Here's how.

Targeted Analysis

In July 2002, Deaver and her staff undertook an analysis of exactly what happened when new dialysis patients came to the center. What they found surprised them. Most patients were in the center for more than a month before the issue of access was addressed. In addition, surgeons, radiologists, and patients were not well-informed about reasons for choosing a fistula.

New Protocols

Working together, the staff developed new protocols to ensure that access got more attention. In acute centers, new patients now receive access information right away. Nephrology and surgical consults are set up automatically, vein mapping is always ordered, and patients are discharged with an appointment for access placement. "That eliminates a month of delay right there!" said Deaver.

In the chronic center, a charge nurse evaluates each new patient's vascular access within the first 5 days. Anyone with a catheter automatically gets information about fistula placement and vein mapping, and surgical appointments are scheduled.

Preventive Measures

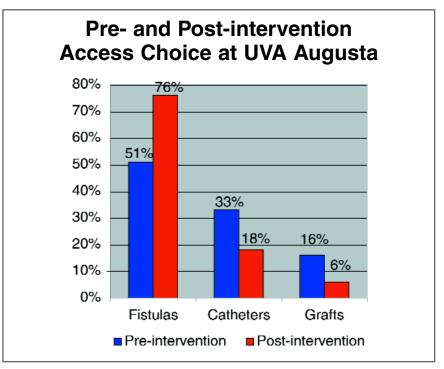
Treatment protocols routinely include preventive access care, too. Venous pressure monitoring is done at every dialysis treatment, and primary nurses are responsible for tracking average pressure ranges on a monthly basis. Any signs of stenosis are promptly investigated with radiographic testing.

Too much work? Not at all, said Deaver. "We actually have less. Monitoring takes less than 1 minute per treatment, but now we rarely have to deal with the problems of clotted accesses, like difficult needle sticks, longer treatments, or missed and rescheduled treatments." In a unit of 87 patients, Deaver reports only one clotted access every 6 months!

Lots of Education

"We had *many* meetings," said Deaver, "with surgeons, nephrologists, and radiologists in multiple hospitals."

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Q & A: Ask the Experts

We interviewed Carolyn Barclay, RN, CNN, Vascular Access Program Manager, Kaiser-Permanente; Anne Campbell, MSPH, Pre-dialysis Patient Educator, DCI Mid-Missouri; Lesley Dinwiddie, MSN, RN, FNP, CNN, Nephrology Nurse Consultant, Cary, North Carolina; and MaryLou Pederson, RN, MA, Patient Services Coordinator, Northwest Renal Network

Nephrologists, surgeons, radiologists, primary care physicians, and dialysis care professionals must work together as a team to increase the use of fistulas. But patients also play a critical role in making decisions about vascular access.

Q: Why is it important to focus on the *patient* side of this issue?

A: From signing on the dotted line for fistula surgery to taking good care of an existing access, patients can influence the success of a team effort to use fistulas. Improved outcomes and good quality of life are tied to patients' active participation in decision-making and adherence to treatment plans. Patients who "buy into" a decision to choose a fistula will be likely to get better results than those who just "do what the doctor tells them."

Q. What is the best way to convince new patients to choose a fistula?

A: Start early! Ideally, every new patient would

establish an access 6 months before dialysis. The long lead time allows for education (and repetition). access maturation, and problem solving. Even for urgent start patients, timing is important. Start talking about a fistula as soon as possible, and clearly state that catheters are temporary. It often gets harder to convert catheter patients to fistulas as time goes by. Resistance to change and complacency can be real obstacles.

Q. What advantages of fistulas have you found are most appealing to patients?

A: Although individual patients may vary, many patients find these arguments compelling:

Medical benefits – fistulas reduce the risk of serious infection, provide better blood flows for better dialysis, and are associated with feeling better and living longer.

Fewer surgeries -

establishing a fistula usually takes just one surgery, and may help patients avoid multiple de-clotting procedures and additional surgeries for replacement.

It's my own body – there's nothing "artificial" about a fistula; it's completely natural and uses the amazing biological powers of the human body. Also, there is nothing that "sticks out," like a catheter.

Q. How do you help patients overcome fear of needle sticks?

A: Cannulation is not pleasant, but it is a means to a better end. De-sensitization with local anesthetics to help patients get used to the process often works. Peer counseling can help, too. Sharing with another patient who has had good results can reduce fears. Also, there is always the option of self-cannulation. Being in control of the situation can help reduce anxiety.

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For More Fistula Information...

Internet Resources

- Kidney School™ Module 8: Vascular Access – A Lifeline for Dialysis at www.kidneyschool.org
- K/DOQI guidelines on vascular access at www.kidney.org/professionals/kdoqi/guidelines_updates
- Forum of ESRD Networks website with links to websites of all 18 Networks at www.esrdnetworks.org
- Patient's perspective on the importance of a fistula at www. nwrenalnetwork.org/cade.htm
- Clinical performance measure information at www.cms.hhs.gov/ esrd/1.asp
- Change concepts summary at www. networkofnewengland.org/ffirst.htm

- Description of how and why a vascular access coordinator can improve the rate of fistula placement at www. ikidney.com/iKidney/community/pro2pro/nurses/TheRoleofthe VascularAccessCoordinator.htm
- Presentation by RN Lesley Dinwiddie at www.nwrenal network.org/vsmeet99.ppt

Journal Articles

- Dhingra RK, Young EW, Hulbert-Shearon TE, Leavey SF, Port FK.
 Type of vascular access and mortality in US hemodialysis patients.
 Kidney Int 60(4):1443–1451, 2001
- Pastan S, Soucia M, McClellan WM.
 Vascular access and increased risk of death among hemodialysis patients.
 Kidney Int 62:620–626, 2002 ^(a)

Quiz Answers

- 1. False. A fistula is the type of access most likely to let you live a long life.
- 2. False. A fistula is made by linking together an artery and a vein.
- **3.** False. Fistulas are *less* prone to clotting and infection because veins and arteries are a part of your body.
- 4. True
- 5. True

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Nursing Protocol Increases Fistula Placements

And, the dialysis nurses had to provide their professional colleagues with rafts of clinical information, including the K/DOQI guidelines for vascular access. (See resource list, above.)

"Patient education plays a big part," said Deaver. "We explain to all our patients that catheters are temporary, and really a last resort." The UVA Augusta staff also talk to patients about why it's important to get a fistula, and how to ask for a fistula when they go to the surgeon.

Impressive Results

"It took about 6 months for us to begin to see results," noted Deaver, "but then everything started to fall into place." UVA Augusta now reports 76% AVFs, 6% grafts, and 18% catheters (with only 14% of catheters older than 90 days.)

For more information about the UVA Augusta protocols, contact Kim Deaver at *kcd6v@virginia.edu*. ©

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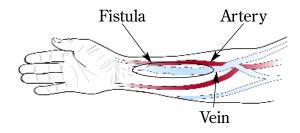
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Your Access: A Choice for a Better Life

Choosing your vascular access is a life and death issue. A recent study of more than 5,000 hemodialysis (HD) patients showed that people with fistulas lived longest, with grafts placing second, and catheters last of all.¹

What's a fistula? It's the best type of vascular access—a pathway to your blood-stream that makes it possible to do HD.



A *fistula* is made by linking two blood vessels: a fast-flowing artery and an easy-to-reach vein. (A *graft* links an artery and a vein with a piece of manmade vein, and a *catheter* is a plastic tube placed into a vein in the neck, chest,

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Fistulas are the "Cadillac" accesses, mainly because:

or groin).

- They are less prone to infections, because veins and arteries are part of your body.
- They are less prone to blood clots, because blood vessels have a smooth, inner lining that clots can't stick to.
- They can last a long time, because veins and arteries self-heal after each needle stick.

Choose a Fistula

If you don't have a fistula now, but would like one, speak up—this is your lifeline:

- Ask your doctor for a letter telling other healthcare workers not to take your blood pressure or draw blood from your access arm. Keep the letter with you all the time.
- Ask for an *internal jugular (II)* if you must have a catheter for a while. An IJ is less likely to cause blood vessels in your arm to become too narrow for a fistula.
- Ask your doctor about making a new fistula if a graft or fistula fails.
- Ask to see a vascular (blood vessel) surgeon who creates a lot of fistulas. Some surgeons are better at this than others.

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Take Charge of Your Dialysis Needles

A fistula is the best access. And the best way to ensure that your fistula will serve you well for a long time is to put in your own needles. Scary? Yes! But as Ann tells you in this story, you'll feel more in control, have less pain, and know that you are helping yourself as much as you can.

Setting the Stage for Dialysis

Ann's kidneys first failed in 1988, as a result of lupus. She did peritoneal dialysis (PD), for a year, then received

a transplant that failed right away. When the surgeons removed the failing kidney, they created a fistula in her arm, in case she would need it in the future. "I went on PD again for a short time, but had to stop due to infection," recalls Ann. "I then began

in-center hemo using a temporary catheter, since my fistula was not ready to use."

After about 7 months, Ann's doctor told her the fistula was ready to use. But it wasn't. "I would bruise and swell and they couldn't run me on the machine," says Ann. "So they used my catheter since I still had it in." Ann felt limited by the catheter and was determined to stop using it. "I started exercising my fistula arm with a squeeze ball, even though I had read articles by doctors that said exercise doesn't help. I think

it was starting to use it plus exercise that built my fistula up for me."

A Fistula for Life

Since Ann began using her fistula in 1989, her quality of life has improved. "I was not informed in the early days of my treatment and didn't even know what a fistula was," says Ann. "It has been so liberating—I don't have to be as careful taking a shower or even swimming. I love my lifeline!"

Ann feels that many patients don't ask

their doctors about their access options. "Check with your health care team members about getting a fistula over a graft—take charge," advises Ann. "A fistula provides more efficient and faster dialysis, with

better blood flow rates."

Though Ann loves her fistula, she has had to make some changes to safeguard her lifeline. "As a woman, I have to be careful with my purse because I carry it on my access arm," she says. "I try to buy purses with wide, double cloth straps, which seems to help." Ann also wears a loose-fitting watch and tries not to sleep on her access arm.

Needle Control

Early in her treatment, Ann asked for lidocaine to numb her needle sticks



sites—for a total of four sticks at each treatment. But a concerned technician I de urged her to change her ways. "He said and I should really try to preserve my access by sticking it just twice with the larger needles," Ann remembers. "I thank him for that advice, because I've found that getting two sticks with larger needles hurts no more—and it helps preserve my fistula!"

Through the on-line *dialysis_support* group, Ann also learned that it was better to put in her own needles, a process called self-cannulation. "I had needle phobia and never watched when my needles were put in," declares Ann.

"But once I learned about self-cannulation, I decided to watch. It took my fear away and I said, 'I can do that!"

Ann has been self-cannulating without numbing cream since 1996. "It's about more than being in control—you get to

> know your fistula intimately and can feel and sense everything inside it," she explains. "If you are too close to the wall of your

fistula, for example, you can feel that and adjust your stick before you puncture it." Ann also rotates her needle sticks between three different sites so no one place is overused. "Doing my own needle sticks has been just a wonderful change."

Are You Worried About Needle Sticks?

Do needles make you cringe—or even pass out? If so, you may be among the estimated one in 10 people with needle phobia. Some people's fear is so great that they insist on a catheter instead of a fistula. Luckily, there is help!

Lidocaine creams or gels can numb needle sites without extra injections so you don't feel the sticks. These may be covered by your insurance. Ask your center what pain control it offers, check local or on-line pharmacies for over-the-counter products (e.g, ELA-Max® or Topicaine®), or ask your doctor about prescribing EMLA® cream.*

Other steps you can take to feel better about needles include:

- **Desensitize yourself:** Ask your social worker to refer you to a therapist or hypnotist.
- **Share your feelings:** Talk to other patients about how *they* handle needles.
- **Take control:** Learn how to put in your *own* needles.
- **Avoid them:** Ask your doctor if PD or a transplant is an option for you.

*Note: Life Options does not endorse any products.

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Your Access: A Choice for a Better Life

You may have to look outside your area for a good fistula surgeon. (Check with your insurer).

- Ask the surgeon to do *venous mapping* or a *venogram*, to see if your blood vessels will work for a fistula.
- Get a second opinion if one surgeon tells you a fistula cannot be done.

Planning Ahead

Even with the best care, a fistula can fail. Since you have only a few sites where an access can be created, you and your doctor need to think ahead and have a plan. If your fistula fails, where will your next site be? And the one after that? A written plan that is updated any time a fistula problem occurs will help you feel more in control of your access and future.

Learn All You Can

Getting answers to your questions about kidney disease is important to living long and well. You've taken the first step by reading this issue of *In Control*. To learn more, talk to your doctor or visit these resources:

- Kidney School™ Module 8: Vascular Access A Lifeline for Dialysis at www.kidneyschool.org.
- Keys to a Long Life Vascular Access Fact Sheet at www.lifeoptions.org/combined/ materials/indexpr.shtml
- Getting the Most from Your Treatment: What You Need to Know About Hemodialysis Access at www.kidney.org/general/atoz/
- Understanding Your Hemodialysis Access Options at www.aakp.org/Programs_And_Services.htm

Reference

Dhingra RK, Young EW, Hulbert-Shearon TE, Leavey SF, Port FK. Type of vascular access and mortality in US hemodialysis patients. *Kidney Int* 60(4):1443-51, 2001 <a>©

Fistula Quiz

Now that you've read about fistulas, let's see how much you've learned! See if you can answer the questions below (the answers are on page S8):

- 1. A graft is the type of access most likely to let you live a long life. ☐ True ☐ False
- 2. A catheter is made by linking an artery and a vein together. □ True □ False
- **3.** Fistulas are more prone to infection because veins and arteries are part of your body. □ True □ False
- **4.** Lidocaine creams and gels can numb needle sites so you don't feel the sticks. □ True □ False
- **5.** In case your fistula fails, you and your doctor should have a written plan. □ True □ False

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