



# Renal ROUNDUP

## Dialysis Access-- Messages From Patients to Patients

By Ray, Martin, and, Bill

**W**hen I felt very ill back in 2001 I went to several doctors to find out what was wrong; they were unable to pinpoint why I felt weak and sick until finally one doctor told me “Your kidneys have failed”.

I had known they were weak for several years but was surprised they had actually quit. This doc-

tor said, “You have such high levels of toxins in your blood that you need to dialyze as soon as possible.”

I was stunned. Dialysis looked horrible, being dependent on a machine, not to mention all that blood. It was a very difficult time in my life and I wondered if life would still be worth living.

I was so sick that I needed a temporary catheter put in my chest just to start treatment. At the same time they put this catheter in, they also put in what is called a fistula. Having a fistula is very, very important to the quality of your life. A fistula is the joining, usually a few inches above your wrist, of a vein to an artery in your arm. Fistulas take at least 8 weeks to be ready for use but are far superior to catheters.

I began dialysis using the temporary catheter and started feeling better after the first few treat-



*Ray, a Colorado patient, tells new dialysis patients what to expect.*

ments. Eight weeks later, out came the catheter and I started using my fistula. It allowed much more effective treatment. I continued to get even better and now am healthy and have a fulfilling lifestyle.

If you would like to take advantage of my experience, the most important thing you can do is have a fistula put in as soon as your doctor will allow it. It will pay off for you.

**Having a fistula is very, very important to the quality of your life.**

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## Messages From Patients to Patients *(Continued)*



My name is Martin and I started dialysis in January 2004 and had my ups and downs. Then in October 2004 a catheter I had for another medical condition developed an infection and I was hospitalized.

Just like when you have an infected sliver in your finger and it needs to come out for the infection to heal, my infected catheter had to come out. My infection was so severe I was put in intensive care. Twice I ceased breathing and had to be revived.

Now, if you are a new patient, this is not the kind of horror story you want to hear. In fact, my experience was not usual. But my story makes a point about the most important thing you, as a new patient, need to do. Foreign objects like catheters are not good things to have in your body if you can avoid them.

As one patient to another, I want to tell you that the most important thing you can do for your good health is to have a fistula put in now. Don't wait; the longer your fistula has to mature, the better it will be. While

a fistula can be used after about 8 weeks, it is much easier to use after it has matured a few months.

I am very lucky to still be alive today. I dialyze with a fistula and have not had any problems with it. Life has its joys for me. I am a retired engineer who lives in Arizona. I have already traveled to Hawaii while on dialysis. My wife Lois and I plan other trips for the future because we love to travel.

You need to know that dialysis is just another chapter in your life and you can make it a good one.

Don't wait; the longer your fistula has to mature, the better it will be.

## We're Wired!

*Have questions? We've got the answers!*

Find out by visiting our website at [www.esrdnet15.org](http://www.esrdnet15.org). The site is geared for renal professionals as well as patients.

Some of the information available for patients includes: dietary guidelines for ESRD patients, information about deciding if a transplant is right for you and how to get on a transplant list, a dialysis locator, a statement of patient's rights and responsibilities, a dialysis facility locator, and links to many other helpful websites.

### Bill, a long time dialysis patient, shares his opinion.

I was on dialysis 17 healthy years and then I received a transplant. I was asked, being on dialysis for so long, what I thought new patients need to know.

As Ray and Martin already said, there is no single more important thing you can do than have a fistula put in well before you need to start treatment.

Well cared for, a fistula can last for decades. Mine lasted all 17 years. A catheter lasts only months for most people. A graft often lasts only a couple of years.

A fistula provides great

blood flow to the dialysis machine—in some cases, twice as much as a catheter. This means your treatments are more effective and so you feel better. It will also resist infection better than catheters or even grafts do. Because fistulas naturally resist infection, some go as long as years without infection. My fistula never once had an infection in all 17 years of dialysis.

But wait, there's more. Because the fistula heals after each use, you can almost forget about it be-

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*Bill ..., continued*

tween treatments. One thing I really liked was that I could shower and bathe normally. I also like to swim and water ski and my fistula let me. Other than checking once each day to make sure it was working, I took good care of it by not hitting it on things and making sure it wasn't choked off by tight clothing. I didn't worry about it like you do when a catheter is sticking out of your chest.

Have your fistula put in as soon as possible. A fistula that has matured several months before use is stronger and works better right off the bat than one only 8 weeks old.

While dialysis is a big adjustment to make, after a while it is like having a part time job about 20 hours a week keeping healthy. Then you get on with your life. You will be able to do things you enjoy doing. Perhaps, like me, you will swim or water ski. Perhaps it will mean enjoying the company of friends or family.

All this will happen because the miracle of dialysis keeps you alive and well. ■

*Ray, Martin, and Bill are ESRD patients and members of the Network #15 Patient Advisory Committee.*

## Frequently Asked Questions about Arterial Venous Fistula's (AVF)

### Why should I get an Arterial 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.

### 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 websites that have educational materials are listed at the end of this article.

### 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") patients a "mapping" study of the blood vessels in the arm is conducted. The mapping helps identify the best veins for a fistula and increase the chance for

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## What is ESRD Network #15 ?

The Intermountain End-Stage Renal Disease Network (Network #15) is a corporation that contracts with the federal government Centers for Medicare and Medicaid Services to assure quality care to individuals with ESRD. Network #15 also collects and validates information about ESRD patients and their treatment. The territory of Network #15 includes: Arizona, Colorado, Nevada, New Mexico, Utah, and Wyoming.

For more information about Network #15 please visit our website at [www.esrdnet15.org](http://www.esrdnet15.org).

## Frequently Asked Questions ...

a successful surgery. Be persistent, if the mapping study was not done, asking for a second opinion is quite reasonable.

### 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. Ask your facility staff about other ways available to reduce pain. 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 MD if smaller needles might be appropriate, or for other ideas to help deal with the pain.

### 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. It is

important to remember that you have the choice to not let your feelings about yourself be defined by the look of your access site. By talking to other dialysis patients with AVF's you will learn the methods they have used in integrating these physical changes into their daily lives.

### 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 veins and arteries together. A graft requires the surgical placement of a small flexible tube, and 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.

### 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 to your time spent in the clinic as the access stops bleeding. It will be important to 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.kidneypatientguide.org.uk/site/contents.html](http://www.kidneypatientguide.org.uk/site/contents.html)  
[www.aakp.org](http://www.aakp.org)  
[www.kidneypatientnews.org/VascularAccesslinks.html](http://www.kidneypatientnews.org/VascularAccesslinks.html)  
<http://kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess/>  
[www.esrdnetworks.org](http://www.esrdnetworks.org)  
[www.nephron.com/judy.html](http://www.nephron.com/judy.html)  
[www.lifeoptions.org](http://www.lifeoptions.org)  
[www.kidneyschool.org](http://www.kidneyschool.org)  
[www.fistulafirst.org](http://www.fistulafirst.org)

This is a limited list provided as a starting point to learn more about the benefits of having an AVF. You can also speak with your physician, nurses, or other members of your healthcare team, or contact ESRD Network #15 for additional information.



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your Nephrologist. Ask:

- *Will anything reduce the pain?*
- *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.
- 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.*”
- Talk to your treatment team about your concerns and/or fears.

### **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 (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:
- *How can I learn 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.

*Remind yourself that ... you can live longer with a fistula.*

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.

### **Fear of the surgery**

#### ***What you can do:***

- Ask questions.
- Talk to other patients with fistulas. Ask things 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
  - *American Association of Kidney Patients at 1-800-749-2257*
  - *National Kidney Foundation at 1-800-622-9010.*

### **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?*

### **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:
  - *It’s my access.*
  - *It helps keep me alive.*
  - *I have Chronic Kidney Disease.*
  - *I am one of 312,000 people in the United States who have End Stage Renal 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. ■

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*This 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 #15 office at 1-800-783-8818.*

## Of Note . . .



Eating right, taking medications appropriately, and getting enough dialysis are key elements in maintaining your strength and stamina. An important way to monitor your success is to keep a close eye on your lab test results. So ask your healthcare team to discuss your lab tests with you so that you can optimize your treatment and stay as healthy as possible.



Studies have shown that between 15-30% of patients shorten their dialysis treatment times. Unfortunately, patients who shorten three or more treatments in a month have a **20% higher risk of death** than those who stay the entire treatment. Stay the course!!



In an emergency, knowing a person’s medical history is vitally important; and when you can’t speak for yourself, wearing a medical alert ID could save your life. There are a variety of medical systems/tags available including: Medic ID at 800-926-3342, Medic Alert at 888-633-4298, American Medical ID at 800-363-5985 to name just a few.

## Have a Problem?



Patients and family members should not be hesitant to discuss dialysis problems. To address a problem you should:

**Talk to facility staff members first (social worker, head nurse, administrator, or doctor).**

**Follow the steps of your facility's grievance procedure.**

If you have a quality of care problem that is unresolved you can contact:

**ESRD Network #15**  
**1301 Pennsylvania St, #750**  
**Denver, CO 80203**  
**1-800-783-8818**  
**Email: [info@nw15.esrd.net](mailto:info@nw15.esrd.net)**

Or contact your State Health Department:

**AZ:** 602-364-3030

**CO:** 303-692-2800

**NM:** 800-752-8649

**Northern NV:** 775-687-4475

**Southern NV:** 702-486-6515

**UT:** 800-662-4157

**WY:** 307-777-7123

## Understanding Medicare Part D

By now you should already be aware that Medicare has begun offering insurance coverage for prescription drugs (also known as Medicare Part D). Insurance companies and other private companies are working with Medicare to offer these plans. These plans may help you save money on your prescription drug costs, but you will need to do some research to determine if this is true.

You may get information about the plans offered, the drugs covered, and their costs by calling 1-800-Medicare, or by logging onto the Medicare website at [www.medicare.gov](http://www.medicare.gov).

You can also get free personalized Medicare Part D counseling from your State Health Insurance Assistance Program (SHIP). Here are the phone numbers for the SHIPs in Network #15. All numbers are toll-free unless noted otherwise.

<b>Arizona</b> 1 (800) 432-4040 Local: (602) 542-6595	<b>Colorado</b> 1(800) 503-5190	<b>Nevada</b> 1(800) 307-4444
<b>New Mexico</b> 1(800) 432-2080 (in-state only)	<b>Utah</b> 1(800) 439-3805 (in-state only) Local: (801) 538-3810	
<b>Wyoming</b> 1(800) 856-4398 Local: (307) 856-6880		

To find phone numbers for SHIP offices in other states, call the Eldercare locator at 1(800) 677-1116.

An additional resource that has “kidney-specific” Part D information can be found at the Kidney Medicare Drugs Awareness and Education Initiative website: [www.kidneydrugcoverage.org](http://www.kidneydrugcoverage.org). This website has information including articles, fact sheets, posters, booklets, tools for professionals, FAQs, and links to helpful resources. For questions, contact [info@kidneydrugcoverage.org](mailto:info@kidneydrugcoverage.org).

Lastly, you may discuss the Medicare Prescription Drug Program with the Social Worker at your dialysis or transplant facility. ■