

Renal ROUNDUP

For Patients in the InterMountain End-Stage Renal Disease Network (ESRD Network #15)

December 2003

A Smile for Treatment

by William Dant

Dialysis patient Afiba Kwarm smiles a lot and faces her machine. There is a connection. Her machine faces her because she cares for herself in important ways while on treatment.

For example, when her machine sounds an alarm, she knows what each alarm means and is able to correct many alarm situations herself. Her doctor has also

written orders allowing her to change the machine settings that control her temperature and also to change the rate the machine takes off weight.

So one reason she smiles is because she likes being in charge of her own treatment. This self-care is also helpful in her unit since she requires less care than is usual so technicians and nurses have more time to spend with other patients.

Afiba says, “When I first started dialysis I was frightened and bewildered, but now my machine is part of my family because it keeps me alive.” She also says, “It feels good to be in control if something goes wrong and to know what is happening during my treatment.”

Once while in treatment at another unit, she suggested to a young man dialyzing next to her that he ought to learn to control his machine. She said if he did, he would feel better. He replied, “Why should I, when it’s their job?”

Afiba told him, “It’s nobody’s job



but your own to keep you alive. You have the brain, you have the eyes, and you have the ears. Keeping yourself alive is your responsibility and no one is paid to do that.”

Her advice to other patients? “Take charge of your own body and learn the machine.”

If you want to follow Afiba’s advice, you ought to talk to your nephrologist or social worker about increasing your level of self care. ■

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Focus on Fistulas: A Patient's Perspective

By Phillip Cade, MSW

“A well-functioning dialysis access is the key to successful long-term dialysis.” I first heard this when I was a 21-year-old neophyte and my Nephrologist was explaining his choice for the type of access I was going to receive.

At the time I was feeling very fit and vigorous, but the blood tests showed highly elevated BUN and creatinine levels. Elevated to the point that it was decided that a Gore-Tex™ graft would be more expeditious and therefore more desirable. At that time I gave it very little thought because all I cared about was the end of my fledgling baseball career. Little did I know how big a part of my life my dialysis access would become!

When I was asked to write this article, I jumped at the chance because I really believe in the importance of knowing your access and how to keep it operating properly. But I must admit I found this concept difficult to write about.

Vascular access technology has changed drastically in the 21 years since I started dialysis. There are so many choices and techniques to choose from. How do I cover all the options and choices in a useful manner?

Should I interview professionals? Which materials should I use for my research? Then suddenly I realized, this is not about vascular accesses, this is an article about freedom and control. Freedom to decide what works for you and control over your overall dialysis treatment.

...dialysis works best when we have a measure of control over our dialysis and our lives...

Over the years I have come to understand that dialysis works best when we have a measure of control over our dialysis and our lives. I gained this control in part due to the access I am currently using for dialysis. My current access is an A-V (arterio-venous) fistula. This access replaced the

first four accesses I had which were Gore-Tex™ grafts.

All four Gore-Tex™ grafts were placed in my left arm and while they had the advantage of immediate usability, I found myself in the operating room far too often for my tastes. You see, although I was on dialysis, I still needed to indulge my two greatest passions - baseball and weightlifting.

These two activities have kept me healthy both mentally and physically for the last 18 years. But I also had to live with the spectre of frequent declottings and graft revisions. This was due primarily to the drop in blood pressure caused by my active lifestyle. At least that was what I

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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.

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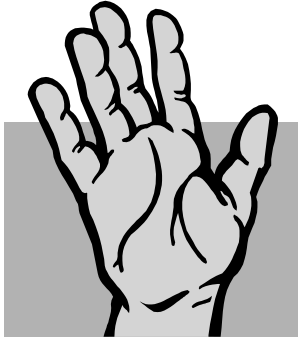
was told. I had begun to accept the reality of frequent declottings when my Nephrologist suggested an A-V fistula. I was told that it would take some time to develop after it was created but that once developed, it would virtually eliminate the need for declotting surgery.

And it was true! In the last eight years I have had zero revisions and zero declottings. I still check my access daily, but it is such a joy to know that I can pursue my passions without the fear that at any time I may have to report to the emergency room for a graft declotting procedure of some kind.

I want to stress that while I am so very happy with my fistula, this may not be the choice for you. There are many factors which go into the choice of dialysis access, but I firmly believe that the most important factor should be the wishes of a well-informed and knowledgeable patient who has all the facts. This process is the first step in being in control of your dialysis, a process which I hope will lead you to learn to put in your own needles!

Self-cannulation is a touchy subject in many units but as a patient who has been cannulating himself for 18 years I feel comfortable saying that it is the best decision I ever made. Self-cannulating is a skill which, once

Five Reasons to Have an A-V Fistula:



- Fewer infections
- Fewer hospitalizations
- Fewer clots
- Better blood flow for better treatment
- Usually lasts many years

Grafts and catheters are the other 2 types of vascular access. If your graft or catheter fails, you can (and should) be evaluated for a fistula.

Ask your doctor or healthcare team if you should have an A-V Fistula

learned, will provide you with a significant measure of control over your day to day dialysis treatments. Ask your staff or following physician if you can self-cannulate.

To conclude, there are many options for receiving dialysis today including many types of vascular accesses and cannulating techniques. While I am thoroughly satisfied with my A-V fistula, for the reasons previously stated, an AVF may not be for you. The choices you make should be well informed and should come after consulting your Nephrologist and treatment team. But ultimately your treatment choices are up to you and

you have to live with them. So choose well and while you're at it choose to live the best most productive life you can. Remember we are not defined by our illness, we are defined by how we live our lives! ■

Phillip Cade is a Legislative Liaison for the Washington State Department of Social and Health Services, and a Patient Services Consultant to Northwest Renal Network. This article was reprinted with permission from the Northwest Renal Network.

KIDNEY DISEASE, DEPRESSION, AND COPING

Groucho Marx once said, “I’ve had a wonderful time, but this wasn’t it.”

Many people with kidney disease could say the same thing about life with kidney disease. You may learn from it and you may find meaning in it. But it probably doesn’t rank up there with your best life experiences.

You don’t have to like having kidney disease. But you do need to learn to live fully with it. . .

You don’t have to like having kidney disease. But you do need to learn to live fully with it—since this is your life. And that part can be challenging.

How Common is Depression?

As many as 17 million adult Americans struggle with depression in any given year, according to the National Institute of Mental Health. People with chronic diseases are even more prone to depression.

Are My Feelings Normal?

Some period of adjustment is normal when a major life change happens. It takes time to get used to the idea that life is different than you expected. Figuring out how the hopes, dreams, and plans you had before can fit into your new life is part of adjusting. Feeling sad or cheated or frustrated is a common reaction.

What is True Depression?

Everyone has common mood swings. They may look like true depression, because you feel sad, discouraged, lack energy, may lose sleep, or doubt yourself over some circumstance or relationship. These moods last from a few hours to a few days, and then subside. Clinically speaking, this is not depression, but a normal response to life changes.

Symptoms of Depression

Ongoing depression is more serious. If you have more than one of the following symptoms for longer than 2 weeks, you may be depressed:

- Persistent sad, anxious, or empty feelings
- Loss of interest in usually fun activities
- Fatigue, loss of energy
- Feelings of worthlessness, helplessness, or guilt
- Significant weight loss—or gain
- Insomnia—or sleeping more than usual
- Restlessness and irritability
- Difficulty concentrating, remembering, or making decisions
- Thoughts of death or suicide

Some of the physical symptoms of depression, like fatigue, loss of energy, weight gain/loss, and sleeping problems, can also be caused by your kidney disease or its treatment. So, before you diagnose yourself with depression, talk to your healthcare team about your symptoms.

Treating Depression

If you are depressed, know that depression can be treated. But, if you don’t get help, depression can spiral into a deeper feeling of helplessness—and even affect your will to live.

If you are depressed, know that depression can be treated.

Depression creates self-talk that can reduce your well-being. Do you ever fall into these mindsets or follow these messages?

- **Incompetence:** I can’t handle this responsibility.
- **Low self-worth:** I’m not worth taking care of.
- **Hopelessness:** It doesn’t make any difference what I do, the outcome will be the same anyway.
- **Lack of motivation:** I’m too tired to do all that self-management.

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Dealing With Emotions

A key to fighting depression is understanding what you do with your emotions. Most people who struggle with depression tend to hold their feelings inside. Over time, these pent-up feelings begin to feel like heavy weights on your shoulders and “depress” your mood, draining your motivation and energy. You may start to feel like you’re walking through molasses just to get through your day—everything is harder to do, even just getting dressed or fixing something to eat.

Some people manage their mood swings and depressive feelings themselves with the kinds of empowering choices that are listed in the “Tips on Fighting Depression” box at right. But for many others, more direct help is also needed. Depression is a sickness, just as kidney disease is a sickness. It can be treated.

The two most common forms of professional help for depression are:

- Medication (antidepressants)
- Counseling (talk-therapy)

Usually a combination of both works best. Many medications are removed from the body by the kidneys, so it is important to talk with a pharmacist about which antidepressants are safe for you—especially when combined with other medications you are taking.

Most people see improvement between two weeks to two months. ■

Adapted from “Module 5: Coping with Kidney Failure” in Life Options Kidney School™ (www.KidneySchool.org), with permission from the Medical Education Institute, Inc.

Tips on Fighting Depression

Instead of trying to pretend I am not sad, discouraged, or frustrated, I will try to admit it to myself and feel the emotion.
(Emotion will not hurt me, although it may feel uncomfortable.)

I will make an effort to share my feelings with someone—a friend, family member, or counselor.
(This will help me to gain some perspective and reduce the burden that I’m carrying all alone.)

I will try to focus on right now, instead of overwhelming myself by worrying all the time about what the future holds, and what my health will be like a year from now.
(The decisions I make today will help to make my future. If I live in the moment and focus on making good decisions for the present, the future will arrive when it is time.)

I will start a regular exercise program, after talking with my healthcare team.
(Exercise has proven benefits for fighting depression. Setting small goals—and reaching them—will help me see that I *can* change my life for the better. Exercising is a good decision I can make today that will improve my future.)

I will reach out for support.
(Research has repeatedly shown that people with chronic illnesses who have good support systems manage their conditions better—and even live longer—than those who don’t. If I don’t have a good support system now, I will talk to my social worker or a counselor about how to build one.) ■

About Hope, Positive Thinking, and the Hereafter

by KaSandra Love

I had been diagnosed with kidney failure and had spent the next two years attempting to cope with my changed lifestyle when I finally reached the deepest point of my despair. I was, quite frankly, seriously depressed. I just didn't know what to do anymore. My metaphysical friends would tell me to keep a positive attitude, my Christian friends would ask me if I had been saved and the rest would offer a token word or two and sing me a chorus of how not to give up hope. None of them would be seen much afterward. Even an "I can't cope with what is going on with you" would have been so much easier to handle than the silent phone. I was so busy with my chronic illness and its demands that it actually took months to realize something else was wrong with my life. No one wanted to be around me. Yes, I needed. It wasn't neediness; it was honest, overwhelming need. Excuse me, but I had never been in this condition before so I was lost and overwhelmed too.

It took me months to begin to understand that some of the people closest to me suddenly didn't know how to communicate with me because they didn't know how to cope with my misfortune. They were traumatized by my

condition, too. The barrage of doctor's appointments, medicines, and routines filled up my calendar. My other life seemed lost forever and I couldn't identify myself anywhere. I hated my new life and grieved for what I had lost. No one listened. It was like everyone was shouting orders at me all of the time. It was as if I were a

. . . some of the people closest to me suddenly didn't know how to communicate with me . . .

mannequin standing in the corner, being taken out for various routine activities then shoved back into the corner again. My biggest pain wasn't in the dying anymore—I had survived. But I was in acute EMOTIONAL PAIN about what had been, about where I seemed to be now and about having no future. My life had been reduced to the daily survival routine of living. I didn't know whether to be embarrassed, humiliated or just plain angry. After a short time, I became silent.

I broke my silence, slowly at first, by asking doctors, nurses and dialysis technicians questions about my condition and treatments. There were questions for which I needed

answers. Ever so slowly, I began to build and catalog information. First, about kidney failure, about medicines, volumes of medicines, what each one does, how they might affect your body and what they won't do. About all of the people involved in my care—what they knew and in what way I could depend on them. Mostly I had to learn how to live life all over again from where I was. And that was a very confusing, scary, and shaky place for me, because I wasn't exactly sure about where I was in relationship to anything else.

I began to build a reality of sorts. First, the *have-to's*. Dialysis three times a week was *have-to*, along with medicines and doctors' appointments. Paying bills, shopping for food and cooking were *have-to's*. Laundry and cleaning were *have-to-as-best-as-able's* because I was still pretty weak. All I could do on

dialysis days was to come home and sleep. What more could an "unmade bed" do? It did offer me such comfort. Tomorrow I shall slay dragons and conquer worlds, for now comfort is at the top of the list. I have

found myself more anchored to the ground; perhaps because my condition has forced me to be.

Ever so slowly, I began to build and catalog information.

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I have taken a depression management class at my dialysis clinic recently, and have learned that I can face my disability and still move on. Learning to define my life into what's normal for me now was probably the best advice they gave me. I can have a normal now and pivot my life forward from that point into active happiness with different goals and newer terms. I still grieve occasionally about the things I can sometimes no longer do because of my physical limitations...but I love walking on the bay, enjoying the sunshine, feeding the ducks and loving my friends. What a wonderful life to live. And I know I'm living it now. I think I just took it for granted before.

My personal relationship with God is much stronger than ever before. I have learned that although humans will do whatever they will, God is the love that keeps me alive, helps me through bad days and stands with me when I am afraid.

... I can face my disability and still move on ...

The sunshine is a little brighter now and my relationship to it has changed. I've learned what I call "riding the edge." That's the phrase I use about living life by accepting it on a daily basis, not really knowing if I'll be here tomorrow—because I don't know. So sunshine has become an

important part of my day. It feels good on my body. It comes up usually every day and it is something that I can count on to be a stable part of my life. Riding the edge isn't so frightening any more. It takes a bit of balance, but then we could all use more balance in our lives. Tomorrow, I might die, but today...ah, today I am so much alive. ■

Reprinted with permission from *Family Focus* "About Hope, Positive Thinking and the Hereafter," © National Kidney Foundation, Inc.

Of Note . . .



Working Pays Big Dividends - Studies show that ESRD patients who are able to find or maintain work respond better to treatment, and report better quality of life. See your Social Worker about vocational rehabilitation, it could boost more than just your income.



Don't Get Into Hot Water - Doctors recommend that people who are being treated for kidney disease or high blood pressure avoid using jacuzzis and hot tubs, as the strong pressure and high temperature from water jets could pose serious health risks.



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



Tired of Feeling Tired? - People with chronic kidney disease are more prone to anemia, a condition in which the body doesn't have enough red blood cells. If your healthcare team has not yet discussed anemia with you, and you feel unusually tired, talk to your doctor or nurse about your symptoms. They can determine if you have anemia and need treatment. ■

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:

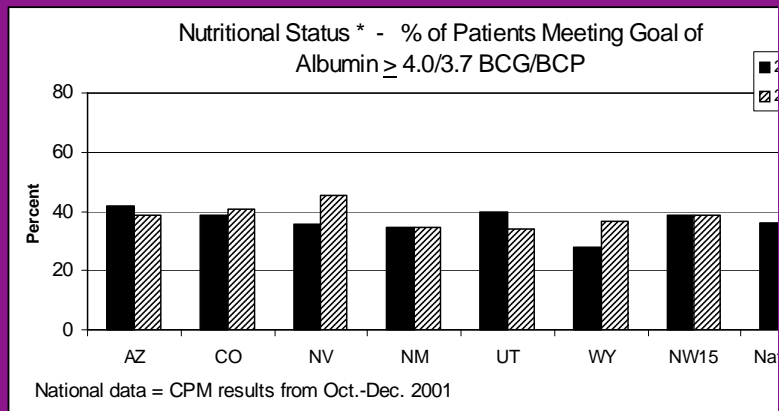
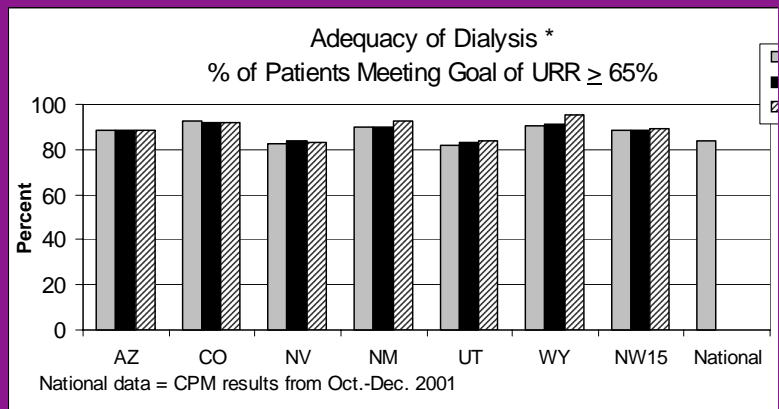
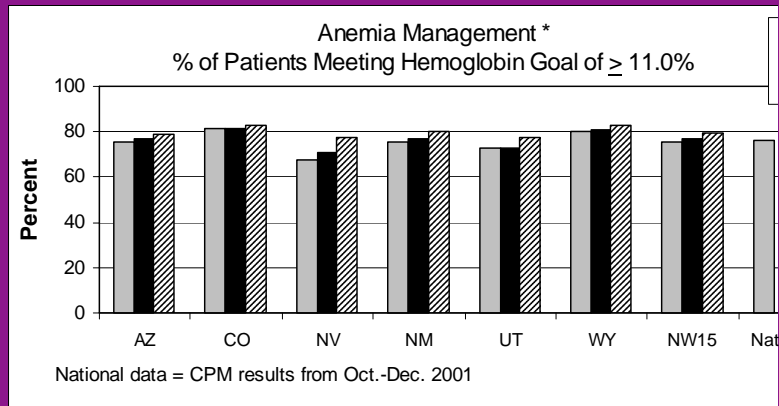
ESRD Network #15
1301 Pennsylvania St, #750
Denver, CO 80203
1-800-783-8818
E-mail: info@nw15.esrd.net

Or contact your State Health Department:

AZ: 602-364-3030
CO: 800-886-7689
NM: 800-752-8649
NV: 775-687-4475
UT: 800-662-4157
WY: 307-777-7123

Network #15: A Cut Above the Rest!

Each year ESRD Networks collect information about patients' health outcomes. Graphs on this page show how Network #15 facilities' Anemia Management, Adequacy of Dialysis, and Nutritional Status compare to the national average. Results for Network #15 continue to rank among the best in the nation.



* Data Source: Network #15 Key Data Project, January through March of 2001-2003 / National Clinical Performance Measures, October - December 2001.