AVF & Self-Cannulation: A Patient's Story by Andrew Williams

I knew about my kidney disease 7 years before starting dialysis. I was seeing my regular doctors, but no one mentioned preparation for dialysis or referred me to a nephrologist either.

A year before my kidneys completely stopped working, I was informed that I had less than 20% kidney function but again it was not a kidney doctor. These doctors may not have known to or how to prepare a patient for dialysis, but it seems like common sense to have sent me to a nephrologist. So, I did not get my access before starting dialysis. In March 2000 I was at home and not feeling well and starting to bloat/swell. I knew what was going on. I had my mom take me to hospital.

Of course the ER did blood tests on me and placed a catheter in my groin. The next day I had my first dialysis treatment in the hospital. About a week into my hospital stay I was informed that I would have to have a vein fixed in my arm in order for me to be able to have my dialysis treatments. I had no idea what a fistula was then or whether there were other options; *the doctors made that decision.* Today I am so glad that a graft was not placed for my access, which was most popular then. This coming March I will have had my access for ten (10) years. Yes, I have had some problems that were easily repaired. By now I have had quite a few repairs to my access. I have wonderful blood flows today almost better than when I first got the access.

Not much after the use of my access I began to instruct the staff how and where to place my needles. I knew then that I had the know-how to do it myself but it was most definitely not something I was at all ready or interested in doing myself. **Needles hurt**. I couldn't fathom the idea of doing this to myself. I would get so angry at the staff for not placing my needles right, I began to pick and choose who would put my needles in. This was said to not be allowed. I demanded it. They still messed up sometimes but I definitely picked the best cannulators available. I had my one regular tech; she was the one who encouraged me to learn to stick myself. I was four years in at the time. I used numbing spray to get over the initial prick of the needles when I placed my own needles myself. They told me that my skin would turn if I continued to use it, so one day I just did it without the spray and I haven't used it since. I use a technique where I rotate my sites every time. I still have to do it very slowly to allow for that pinch to pass. And, yes, it still hurts sometimes.

I am now a home hemodialysis patient for 4 years this December. I do dialysis (cannulate) six days a week. I rotate my site daily. I am used to what I have been doing and do not see a need to try another technique, like Button Hole. Self-cannulation is the best thing that happened to me. I strongly recommend it. You can always find your spot in your access that is best accessible because it's your arm/body. You have a connection to it that a staff member could never have. Since I started placing my own needles, I do not remember that I have ever missed!

Andrew Williams is a member of the Mid-Atlantic Renal Coalition's Patient Advisory Committee. He was diagnosed with renal disease in 1993 and has been on dialysis since 2000. He is currently on the NxStage system, and has been doing home hemodialysis for almost 4 years.



Self-Cannulation: Another Patient's Story by Jim Seymour

I started dialysis in July of 1998. At the time I knew nothing about dialysis, so when my doctor said he was putting in a fistula I said, "O.K." Well, it was three months before they could use it for dialysis. The second time I went for treatment the technician infiltrated the vessel. Those of you to whom this has happened know the feeling, the pain, and the swelling that goes on for days.

For the next several years it happened again at various times, and I just accepted it as part of dialysis. Then I met a doctor at a meeting who was all for the patient sticking themselves using the Buttonhole Method. After a very long talk with him, I decided that was the way to go. I asked my doctor if I could start sticking myself and he said, "Sure, if you have the nerve to do it!" That was not a problem, as I tend to do what I think is best for myself.

When the time came for me to do the first one, they assigned a tech who was very good to watch me. To my surprise it was easy! Yes, there was some pain, but with the Buttonhole Method you stick yourself in the same place at the same angle each time. In about two weeks you have created a channel of scar tissue that you use each time, thus no more pain. The biggest advantage to self-cannulation is the reduced chance of infiltration and long life of the vessel regardless of which method you use. I have found that I have constant blood blow values and almost no machine alarms.

I would ask anyone that has a fistula to think about selfcannulation. After all, it's your vessel and you have to live with it for the rest of your life. You may as well have the best outcomes with your treatment.

Buttonhole Technique

Buttonhole technique is another way of cannulating (putting needles in) your fistula. With buttonhole, the needle goes in *the exact same hole* every time –this does not cause an aneurysm. Aneurysms are caused when the needle is placed *in the same small area* over and over, which weakens the vessel wall.

With buttonhole, a track is developed, like a pierced ear. Once the track is well healed, there are no nerves or tissue in the path of the needle to cause you pain. Because there is little to no pain associated with buttonhole cannulation, patients are more willing to learn to cannulate their own access using this technique.

Research has shown that there are:

- Fewer infiltrations (swelling from the needle going through the fistula wall).
- Fewer missed attempts to place needles.
- Less pain when inserting needles.

Contact the Network for more information about the Buttonhole Technique on our Patient Toll-Free Line (**1-866-651-6272**) or visit <u>www.fistulafirst.org</u> and <u>www.homedialysis.org</u>.

Mr. Seymour has been on dialysis since 1998. He is the immediate past chairman of the Mid-Atlantic Renal Coalition's Patient Advisory Committee and currently serves on the Board of Directors. He is currently transplanted and continues to check his fistula for its thrill.