

## **Coach's Corner**

### **Take charge, choose life**

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By Sharon Pahlka, NKC Transplant Patient

I am a "good news" story. Thirty years ago I started dialysis. This morning I ran around Greenlake for an hour. But I learned to manage my kidney disease through a bad example.

You can be a good news story, too. You can have a long, productive, happy life. You can feel good, but you have to learn to take charge. That's what I learned from my bad example. Her name was Betty.

I am so grateful to Betty. Betty was my hospital roommate when I was first diagnosed with kidney failure. Her body had rejected her kidney transplant because she had stopped taking her anti-rejection medicine. She did not like the side effects, such as weight gain, puffy moon-face, and mood swings. Betty had a new boyfriend and wanted to be attractive. She probably thought she could get away with not taking her medicine. Bad choice. Instead, she ended up in the hospital again, back on a dialysis. From there it got worse.

First, a surgeon nicked an artery while removing the rejected kidney causing internal bleeding, and Betty had to be opened up again. Next, Betty fell out of her high hospital bed and got a massive blood clot on her thigh. After that, Betty continued to have a high temperature they couldn't explain. They opened her up again and found an infection in her small intestine. Part of the small intestine was removed. From then on she lost weight and had to stay in the hospital. One of her last visitors said that Betty had become very withdrawn and didn't want to see anyone. Betty was on dialysis and had covered herself with a white sheet and only peeked out from under the sheet to talk with her visitor. While on a two-day home leave, Betty ended her life by taking an overdose of heroin.

Betty's life affected me a lot. I was 23 years old and knew nothing about kidneys. Betty was 25 and was a veteran. I saw that my choices could determine how long I would live and how well. I took charge. I became proactive and involved in all the things that were happening to me. I questioned everything the doctors told me, asked questions of people on dialysis and who had transplants, and read as much as I could.

The truth is— I drove people crazy. But it has been proven that people who take an active role in their care do better and feel more in control. I took a "fight for life" attitude.

Two examples of my fight for life: After getting out of the hospital, I needed a "fistula" put in my arm so I could go on dialysis. A fistula is a surgically-made blood vessel used to connect a person to dialysis. Mine showed signs of not working right. The fistula doc told me not to worry and that it would be fine. I didn't accept that answer. I insisted we check it out. I was given blood thinners, which corrected the problem. I am convinced that my persistence saved my fistula. Your fistula or graft is your lifeline on dialysis. Take charge!

My second example is the choice I made to dialyze five hours, three times a week rather than the average three or four hours per treatment. Most people on dialysis want to rush the process of cleaning their kidneys in less time, not more. For me, it was gentler on my

body, and I felt better. Now, year's later, studies show that people who dialyze longer live significantly longer. That choice served me well. Take charge!

After 19 years on dialysis my body was tired and going downhill. I needed a transplant. I received one from my wonderful brother 9 years ago. I became healthier and was able to live a more normal life with energy. I was blessed with a 2<sup>nd</sup> chance for life. But I am still taking charge of that, too. I exercise daily. I lift weights, which I am convinced has prevented osteoporosis. I eat a healthy diet. I take my rejection drugs without fail. I have a quiet time each morning for myself, and I take regular time to value my friends and family. I pay attention to what is happening with my body and get involved right away when anything changes. Right now, I am working on getting my blood pressure down with diet and medications. Sometimes, it is hard to have to spend so much effort on my health, but I have made that commitment for life.

My message to other kidney patients is that each of you has something unique to offer the world. You cannot be replaced. Your life cannot be repeated.

I wish I could go back to my last visit with Betty, take her hand and convince her of the precious gift that life is and to make better choices for it. I can't do that. But I can stand in front of you today and say with passion and conviction: **Take charge and Choose Life!**



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