

Jumping Over Obstacles by Melvin I. Coher

Do you remember the old television series, "The Naked City?" They always ended the program by saying, "There are eight million stories in the Naked City and this has been one of them." Well, to paraphrase the show, there are 20 million kidney patient stories in the country, and I am one of them.

I have been an end stage renal patient since 1981. I was on home hemodialysis for eight years and in March, I celebrated my seventh year with a transplant. During this period, I had been hospitalized 15 times, lost the sight in one eye, developed intestinal problems and had three career changes. However, I still consider myself lucky.

I am not recommending kidney failure for changing your life, but I feel the experiences that I've had from it have done much to make my life more meaningful and definitely given me a different perspective on things and, more than anything else, made me aware of how important my family and their support can be.

A little background... My mother had polycystic kidney disease and died from uremic poisoning in 1974 just six months after starting dialysis. As you may know this is a hereditary disease, caused by a defective gene. There's a 50 percent chance offspring of PKD patients will inherit the disease. It was discovered I had high blood pressure in 1971, an IVP confirmed I had PKD, but I wasn't told.

It was only after my mother's death that I learned of my illness, but doctors assured me, "Don't worry about it, it's not going to be a problem for many years to come."

"Many years to come," came in just seven years. With a creatinine closing in on 13, dialysis was just around the corner. I wasn't emotionally, mentally or otherwise ready for dialysis.

I was then told about the possibility of dialyzing at home. Could I really do this? Could I avoid the necessity of going to a kidney center on a regimented schedule? Could I take on the tremendous responsibilities involved in such an undertaking?

To many, the thought of dialyzing at home, to be ultimately responsible for one's own care, to be a totally compliant patient, is not an appealing thought. But to me, it was the answer. I needed this involvement to get me over the hump, to give me some flexibility with my working schedule, and to ultimately help me accept my situation.

There was a hitch, a big hitch. You need a partner to help you. Here is where my family became a factor. My wife, Linda, never hesitated. Yes, she would train with me; yes, she would learn to stick needles in my arm; yes, she would be prepared for emergencies; and yes, she would even help clean the machine after treatments.

In July 1981, I had AV fistula surgery performed on my arm to prepare me for dialysis. Rather routine I was told. Well, I soon found out nothing is routine. The fistula never developed properly, so a short time later I was back in the operating room for insertion of a gortex graft.

For the next two years we settled into a new way of life (I say "we" intentionally, when you dialyze at home, it's not just you, but you and your partner). We would dialyze Sunday night and Wednesday and Friday evenings after I came home from work. In those days I was a purchasing manager for an office supply distributor on Long Island and normally worked a 50 to 55 hour week, sometimes including Saturdays. I never missed a day of work because of my illness.

Things changed in 1983 when the company I worked for went belly-up and my wife was almost ecstatic. You see, she despised the cold weather. We sold the house, picked our two daughters and ourselves up and took off for the

palm trees and sunshine in Florida. Took off, mind you, with the kidney machine in the moving van and no job waiting for me.

It was at this time I decided this would be an ideal opportunity to pursue a career change. With an educational background in finance and accounting, I was fortunate to land a job as the southeast regional credit manager for a large national medical supply company. My wife was also lucky to resume her career as a school teacher.

Once again, we dialyzed at home. Rather routine, some might say. Over the next five years, I had numerous clots in the graft, which necessitated five revisions. Also a difficult bout with homolysis when my blood broke down because of a problem with our water purifying system. Not to mention the times when the machine didn't work and we had to make emergency trips to the kidney center for treatment.

As you may know, dialysis can be a strain, both emotionally and physically. I never felt good after getting off the machine. It usually was 11 - 11:30 at night and I inevitably had a headache and a terrible run down, washed-out feeling. Nevertheless, I was always up for work the following day. Once again, I prided myself in not missing a day of work because of my illness.

Your life does change being a dialysis patient, but that doesn't mean you have to stop living. There were many times when I would get down on myself, but with the support of family, you get on with your life.

Another turning point came in 1987 when one of my nephrologists asked if I had ever thought about a transplant. In spite of some setbacks, I considered myself as doing well on dialysis. Why upset the apple cart? Well, for one thing, my age. I was in my forties, and although transplants have been successful on those much older, no time would be better than the present when my physical condition was still pretty good.

Pretty good? Maybe, but whether I wanted to admit it or not, my energy level and endurance certainly weren't what they used to be. My present physiological condition was slowly getting worse with each additional year on the machine. Also, dialyzing three times a week for four hours at a shot was tiresome and did interrupt my life.

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Melvin Cohen (left) stands with his wife, Linda, and two daughters Amy and Sheryl.

Transplants, however are not an answer for everything. The excessive amount of medications can compromise the immune system as well as create a multitude of side effects.

My decision whether to pursue a transplant was kind of decided for me when my graft finally did the ultimate, it became infected. I ended up in the hospital for 30 days, required five transfusions and had to have the graft removed. With the graft gone, the vascular surgeon performed a minor miracle by getting my long forgotten fistula to function, not great, but good enough for the time being.

Back to the transplant. Did I mention that I have three brothers? One in fact, is my fraternal twin. None of them have PKD. During the seven years I spent on dialysis I never

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broached the subject of one of them donating a kidney. I felt very awkward about this subject. I didn't want to jeopardize the relationship I had with them. This is such a personal, individual decision. If the situation was reversed, would I be willing to give a kidney?

After my recovery from the graft infection, I did go for a kidney evaluation and tissue type at Shands Hospital in Gainesville, FL. My twin, an astronomy professor at the University of Florida, was also tissue typed. We still hadn't discussed the subject of kidney donation and I still had a lot of apprehension about this entire matter.

We were a perfect match! Under these circumstances, I was told I would be foolish not to go for it. But what about my brother? I'll never forget when he called me soon after and said, "Sure I'd be willing to donate a kidney, I was always willing to give you a kidney, but you never asked."

The operation was March 1, 1988 at Shands Hospital. The kidney worked immediately. My brother was doing fine and he went home in about 10 days, but not me. I had trouble ingesting food after the transplant. I had developed a stress ulcer and was rushed into emergency surgery on March 13 after an endoscopy resulted in a ruptured duodenum.

I finally went home some 30 days after the initial operation and returned to work full time two to three weeks later, feeling better than I had in years. Little did I know that the fun was just beginning.

The ulcer surgery resulted in a condition called dumping syndrome which causes all kinds of intestinal and eating problems, including lactose intolerance. I had been looking forward to eating all those foods that were strictly off limits when I was dialyzing. Now, with these new stomach problems, I've more eating restrictions than ever!

In June, the retina in my left eye detached. It was immediately operated on at Bascom Palmer Eye Institute in Miami where the retina was reattached, only to detach again a couple of months later. Two further operations were unsuccessful and I am now blind in that eye.

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During the years following the transplant I continued to work very hard. In fact, I compiled the best track record of anyone in my company in credit management. I was still somewhat limited by the transplant, but that was mainly because of the side effects of the medications.

In August 1993, I suffered another temporary setback when a retina tear developed in my other eye. Once again, I had to submit to the surgeon to correct the problem. The operation went well, however I was developing a cataract in this eye too. As you may know, cataract surgery is usually rather common place and uncomplicated. Not so in my case. The ophthalmologist was very hesitant to remove the cataract because I was a one-eyed person with an unstable retina in my seeing eye that could be compromised by further surgery.

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The decision was made to wait until my sight had deteriorated to the point where surgery became my only alternative. That time came this past December when the cataract was removed. I now have a new pair of glasses and am seeing pretty well again.

I mentioned at the beginning that I had gone through three career changes since my kidney problems began. Well, *deja vu* . . . the medical supply company I worked for recently was sold.

Ever since the transplant my wife and I had the chance to travel, especially cruising. In fact, it became somewhat of a hobby for me. I am now a cruise travel agent.

I can't say that every day is perfect. I still have my ups and downs and there are times when your problems can be upsetting. I've learned that the old cliché is true...there is always someone else worse off than you are. In fact, there are very few of us who are lucky to go through a life with no burdens. ■