

Thomas V. Carr dialysis journey begins..

It seems like it was just yesterday (1999), that I was told I was going to have to start dialysis. At that same appointment, the doctor wanted to discuss which type of dialysis I would prefer.

First of all, after the words "you're going to have to start kidney dialysis" were said, everything else in the world seemed to be just a blur. Ten minutes later I was sitting in another office talking to a dialysis coordinator asking me if I would prefer hemodialysis or peritoneal dialysis. If I were to choose hemodialysis then would I prefer in-center or at home dialysis? How about nocturnal dialysis?

"Will I want a fistula?" she asked.

"What's a fistula?" I thought.

Things were going pretty fast for me at this point. All I could think of at the time was "This can't be real." Isn't this where you live on a machine? My mind was going a million miles an hour and at the same time people are telling me about all of these technical and confusing acronyms and medical terms. "I DON'T KNOW!" was all I could think.

I knew I was feeling my overall health declining lately, but I was totally surprised to find myself sitting in the office of a nephrologist. "What is a nephrologist?"

I felt as though somebody had crept up behind me and hit me over the head with a baseball bat. BAM!!! It was time to sit back and calm down. I was about to hear news that would change my life forever.

I thought something was up since I was here on a referral from another physician. I realized something was very different when instead of placing me in an examination room to wait for the doctor, they brought me straight into his office. I was greeted by a friendly gentleman in a white coat with a lot of certificates on the walls of a very nice office. After some small talk about the weather he asked me -

"Do you know why you are here?"

"I don't have the slightest idea" I responded.

He smiled. He said "A lot of people don't know why they are sitting in the office a nephrologist for the first time. You are here because you're kidneys are failing."

"WHAT?"

I can't recall exactly what he said next but I do remember how calm and reassuring he was. And that was it. In the blink of an eye my life had changed forever.

That particular nephrologist was based in Sacramento, California. I only saw him a few times after that first visit. I had been assigned a different doctor from the same group once I started dialysis. His calm demeanor that day saved my life. Thanks Doc, you are a good man.

All of this happened in less than an hour. My first treatment was a big day. I found myself sitting in the clinic waiting for the nurse to start my treatment and I started asking questions about the machine. I asked her to turn the machine a little more

towards me so I could see what was going on. I figured that it was time to get acquainted with my new kidney.

And now I find myself over a decade later writing these words. A lot of things and people have touched my life over these years. I had decided from day one that I was going to embrace dialysis. Yes, I decided to put my arms around this situation and see where I would end up. I think the biggest thing that has helped me over time is a positive and proactive attitude.

I have ended up in a good place. Marissa and I now have the opportunity to share our experiences with patients and groups from all over the kidney community. Helping others go through what we have experienced firsthand is very rewarding. We volunteer for everything we can. It is the most rewarding life I could ever have imagined.

When it comes to being a knowledgeable and well educated person regarding medical issues, I don't even show up on the radar. I am a patient, not a doctor. There are thousands of patients out there that know far more than I do about kidney failure. I do feel however that I am a very good example of a happy and active patient. I have seen over and over again that if you listen to and comply with your medical teams' instructions then you will be a happier and healthier patient. I have learned to listen and at the same time question what I am being told.

Marissa and I were recently featured in a short film about a day in the life of a dialysis patient. One of the things I remember the most about that project is our Director Barbara Freeman, of Freeman Pictures, and our Producer Erin Walsh, of ewandcompany.com, constantly standing next to the camera saying, "And we're smiling and we're smiling and we're happy,,,,,". It eventually became our running punch line throughout the project and it worked every time. We were always smiling. We're all still smiling today!!