

My experience with dialysis began on November 5, 2003. On that day I rushed my husband, Jim, to the emergency room with difficulty breathing. He had been somewhat lethargic the entire day, but tried to be hospitable to a visiting cousin that he had not seen in many years. During dinner, he excused himself from the table and went into the bedroom to lie down. I kept a close watch on him for several minutes and then decided to take him to the hospital.

The diagnosis...complete kidney failure. Our shock was predictable. Some months prior to this, we began seeing a nephrologist because Jim's creatinine was elevated. Blood work showed a creatinine level of 1.2. Nothing was done for him, except watching and observing. Several months went by and finally a biopsy was done without any result. No answers, much guesswork and watching. Each month, the doctor said nothing, "Let's just watch", or "If you have what I think you have, nothing can be done." The only treatment suggested was Tums! Finally, upon admittance to the emergency room and then a bed assignment in the hospital, another biopsy and the dreaded diagnosis, IGA Nephropathy, a somewhat rare disease that causes the filters in the kidney to close and eventually shut down the kidneys.

At first I let my husband take himself to dialysis. We both were completely ignorant of the process and abhorred it. In many respects, I tried to take myself out of the equation. I continued on that path for several months until January 25, 2004 when I had to rush Jim to the emergency room again about four hours after a dialysis treatment. He had a high fever of 104 degrees and was diagnosed with heart failure. Surgery for a cardio window was performed and Jim was in the ICCU for five days. He then was transferred to the kidney floor and his hospital stay was a total of two weeks. At that point I had enough! No answers were forthcoming from the doctor and when I mentioned transplant, Jim's nephrologist said these words to me... "All nephrologists and all transplant centers are not created equally." End of conversation!

My immediate thought was, "Doctor, you have that right! I'm going to get my husband a better doctor." That was my first assignment. Fortunately, in the city we lived in at that time, there were two dialysis units owned by different corporations. We had to drive for 45 minutes to a larger city to change doctors but that was a small price to pay to get better care. That doctor routinely came to our city to visit those patients in his care at that facility, so we transferred to him.

My career of 25 years has been as a designer! My sub-specialty was textile design, focusing on draperies and related accessories. I was National Sales Manager for two corporations and worked with companies that provided products to the department stores, specialty shoppes and catalog houses in the United States. I loved my work. I never wanted to do anything else but work in the field of home fashion. But what a turn my life has taken.

I now spend the major part of my day caring for my husband, serving as his advocate, and searching for information about dialysis and its ramifications. It was during my research that I met Pat Tate-Harris and other founding members of ADA, a group of

ordinary people who are dedicated to improving care and quality of life for dialysis patients and their families. And how fortuitous that has proven to be.

I joined in ADA's effort approximately nine months ago and am convinced that we can bring attention to a need for improvement in delivery of care to dialysis patients. Our goal is simply to improve the lives of those that are facing and will face what we, patients and families, have faced. Much is to be done.

I am a strong believer in the "power of two." One person can rarely make an impact; but two people can often change things. Can you just imagine what thousands of people could do?

I hope that you will join us in this effort. The goal is better healthcare and longer life for those we love. It is attainable!

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