

One Day at A Time

Allow me to introduce myself. My name is Sandra Roberts and I am the wife of a dialysis patient. A horrific disease called IGA Nephropathy came upon my husband very quickly with little warning, and all of a sudden he was faced with dialysis.

Many will say that dialysis is a life saver and it truly is. However, it is also a life stealer because the patient generally goes to a clinic three times a week to be hooked up to a very scary machine and sits there for three or four hours among strangers who many times are a lot sicker than he is. The clinics are not well maintained; they are understaffed and cold. The thermostat control is set for the comfort of the working staff and not the patient. There is almost no communication with the patient about the treatment process and most questions by the patient go unanswered. There is generally a pervasive fear in that treatment room. An eerie stillness is felt. Not a friendly environment to spend so much time in.

After treatment, my husband would come home and make a very slow beeline for our bed, and there he would stay for the rest of the day and evening. The day after dialysis would be better for him, but towards evening he would begin to feel the effects of too much fluid build-up and with some reluctance begin to look forward to the next day and a dialysis treatment again. Not much of a life, huh?

In the meantime while he is going thru this virtually alone, I am looking for answers and ways to help him. The internet provided me with the answers I was looking for. I found a web-site for a dialysis company called NxStage. I read about home hemo dialysis. It sounded pretty complicated and since I am not a nurse, I doubted that I could help him with this, but I made a call anyway and talked to a very fine man named Curt Scovil about NxStage and the possibility of training on that machine. He encouraged me and told me he would see if I could be trained to be a partner for my husband on that system.

Over the course of the next several weeks, I called him repeatedly for information. He continued to encourage me and also began to talk to a Doctor in Winston-Salem, North Carolina about my husband. The Doctor agreed to evaluate my husband and me for home hemo dialysis and afterwards he agreed that we would be candidates for this method. The only hurdle we had to clear was trying to persuade the Dialysis Center in Winston-Salem to train us. With a great deal of reluctance on their part, we went into training in January 2005. After three and one-half weeks, we were on our own.

I wish I could say that was easy. In truth, I was scared to death. As I have said, I am not a nurse. I am not even a good caregiver. However, I so want my husband to be like he used to be. I am willing to pay the price to get him there, if we can.

One day at a time, NxStage never promised to be easy, only better. And it truly is better. Although daily dialysis is by its very nature confining to us, it does provide us with a better quality of life. I keep hearing the reader say "us . . . you mean you are on dialysis too?" No, I

mean that the effect of dialysis is on both of us. As my husband's life partner and his helpmate all things concerning his care concern me too, and in a way more powerfully than with any other disease. One of the many tasks that fall to me is that of his Nutritionist. Dialysis patients must adhere to a pretty strict diet. So, naturally I have to take charge of that also.

The process of daily dialysis takes about 5 hours. The machine has to be set up and torn down before and after each treatment. For Jim, the setting up consists of handing 25 liters of sterile dialysate fluids and a bag of saline fluid. Next comes the priming of the machine, which is actually a computer generated machine. The priming process takes 18 minutes and during that time, I get his medicines and the tools necessary for treatment gathered. After this process we are ready to hook him up to the machine. I do not touch his catheter. He gloves up and we both put on masks. A sterile or nearly sterile process is used. I only hand him the syringes to remove the Heparin that we put in the catheter the preceding day and then he puts in another dose of Heparin to keep the catheter flowing during treatment. We then begin to hook up the two lines of the machine to him. We wait 5 minutes and then start the machine. At that point, we quote this Scripture: "Where two or more are joined together, there I will be also". And blessedly, He Is!

Over the last couple of months, the treatments became easier and easier. We no longer feel stifled by it. It no longer consumes my every thought. I find an inner peace now, knowing that we have accomplished something that we so feared. Dialysis is not fun. Home hemo dialysis is not for everyone. And for two independent souls such as us, it is confining. But you can LIVE with it. And for that I will be eternally grateful.

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