



American Association of
Kidney Patients

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Take Your Life Back - Go Home

In January of 2011, my husband was diagnosed with failed kidneys, and doctors placed him on dialysis right away. As we got use to our new lives, he immediately commented that our travelling would end. We knew nothing about the kidneys, kidney function, dialysis, home dialysis - nothing. John needed dialysis that very day, so while he did that, I went to visit a Satellite WellBound dialysis center. That's where I learned about home dialysis options. My first thought was that it would be too complicated of a procedure for my husband and I do at home. I saw the dialysis machines they used in hospitals – there was no way I could possibly do that!

However, the heavens sent a nurse, Katherine, to me. She calmly explained to me that yes, we could in fact do home dialysis. She explained that there were several home dialysis options, and if we chose to go that route – the choice of which therapy would be ours.

We trained for peritoneal dialysis (PD). John's last day at the in-center dialysis unit was a joyful one. Two days after completing PD training, we flew to Vegas! The airlines are not allowed to charge you for medical supplies, so I carried several boxes of fluid, and a rolling suitcase of supplies. While on PD, we've been camping, stayed at hotels in many different states, took our daughter to college in New York City, and on a few cruises. All it took was some educating, and some pre-planning. Satellite WellBound's phone number is programmed into my phone because it's happened that we've arrived at our destination only to realize we forgot something vital that we can't replace at the local CVS. (It'll happen to you too! Breathe and relax.) The center is good at directing me to another helpful dialysis unit who happily supplies me with the missing items.

We made the switch to short daily home hemodialysis when PD was no longer the optimum therapy for us. During the training for home hemodialysis, we again started to worry about whether or not we would be able to continue to travel. Our social worker, Julie, assured us there was no need to worry. We named our NxStage dialysis machine Vlad. We've taken Vlad with us while camping in the Smokey Mountains, cruising, and several road trips. It was easy to fit the treatment into our daily lives.

Recently we switched to nocturnal home hemodialysis. We currently run every other night, approximately 8 hours, while we sleep. Nocturnal dialysis has not only made my husband feel better, it gave us back the entirety of our lives. Our days are no longer marred by figuring out when we want to do treatment, setting up, running treatment, and tearing down. The longer, slower dialysis is easier on his body, and leaves him feeling healthier and happier during his waking hours. Mentally, and emotionally, we both simply feel free.

These are our top tips for traveling while on home dialysis:

1. Knowledge. I carry a book with all of my husband's medical information should we need medical care when we are away from home. This can save a lot of time if dealing with health care professionals who don't know you. My book contains information on my husband's medical history, medications, lab work and health care team. With this knowledge, you always have to remember to 'Use Your Voice'. As a home dialysis patient, you are a knowledgeable, active member in your health care, and you often have to make that very clear when dealing with medical professionals who don't know you. Calm, rational, knowledgeable conversation almost always gets them on your side.

2. Plan. Are you driving or flying? Your supplies can be shipped to your arrival destination, but this requires pre-planning and getting your clinic involved. Call the hotel and alert them to a medical shipment. Call them after it's to be delivered and verify it's there. If you are taking a cruise, make sure to call the cruise line to verify your medical supplies have arrived. Verify, verify some more and verify again.

3. Speak up! The only person responsible for your travel with dialysis is you. You will come into constant contact with those who have no idea what dialysis is, nor how important it is to your health. It's your job to educate individuals about what you need from them. The service industry wants to make you happy, but dialysis may be foreign to some workers. Speak clearly about exactly what you need. Tipping in some instances where it is warranted is a good way to get help!

4. Realize that traveling this way will be a big change. Recognize that even if you are on the vacation of a lifetime, you will still probably have days you just don't feel good. Prepare yourself for a bit more stress with regards to arrangements and plans. And then, be fluid. Roll with the punches.

I spend a good deal of time reading posts on dialysis patient support group website pages, and it saddens me when patients are forced to fight their health care team to be allowed to do a home dialysis therapy. I advocate as loudly and often as possible for those who are within a few hours of a Satellite WellBound to consider switching. I have found them to be incredibly progressive in their approach to treating patients, and more importantly, empowering. They are our sources for knowledge, help, and advice, but they allow us latitude to handle my husband's medical care in the way that is best for us. They are

willing to hear us out if we disagree with a proposed change, and more importantly, willing to explain to me why the proposed change might be for the best. We have the luxury of making educated choices in care.

We are not experts, but we've traveled a fair bit while being dialysis users and I'm always happy to share whatever we've learned with others who would like to travel but aren't sure where to start. I can be reached at justjen321@gmail.com. If you are able, take your life back. Go home.

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- **Written:** September 02, 2013

- **Posted in:** Patient Stories, Renal Dialysis
- **Item Tag:** care partner, caregiver, dialysis, health care team, home hemodialysis