

Dialysis at HOME: On My Terms

By Peter C. Savage, PAC Chair Suffolk County

The Loss

One of the first things that I became aware of when I started dialysis was the losses: I lost six hours every other day. I lost the ability to schedule activities at my discretion. I lost control over what I ate and how much I could drink as my diet dos and don'ts were explained to me. I lost my sense of freedom by having to be tethered to a machine at a dialysis center for life sustaining treatments. I lost some of my dignity and self esteem while enduring first the neck catheter and then the access disfigurement of my arms. I lost my sense of self-determination— as every thing was taken out of my control.

These losses were magnified by the Hemodialysis waiting game. Wait for your chair to become available, wait for a nurse to put you on, wait for a nurse to take you off, wait to clot after treatment and wait for your ride home.



Peter Savage has been living with ESRD since 1996 and has been has been the PAC Chairman for Suffolk County since 2006.

After two years of traditional in-center dialysis then in-center self-care, Peter was transplanted with a deceased donor kidney. Unfortunately he rejected that kidney after four years. He has had two additional transplants which also failed.

Peter presents at patient meetings on Home Dialysis and is a member of the ESRD National Coordinating Center's Patient and Family Engagement Learning and Action Network

The Silver Lining

I was angry and depressed at the losses I've listed above, but there was a silver lining to my situation.

I had the good fortune of having to dialyze at the Good Samaritan Dialysis Center (GSDC) in Bay Shore, Long Island. My center is staffed by skilled, knowledgeable and caring nurses that believe in empowering patients through support and education. I quickly learned to self cannulate which greatly reduced the incidents of infiltration. I was educated in how to optimize my blood chemistries by being diet conscious and medication compliant. (Remembering to take binders with meals & snacks helped to control my phosphorus).

This education helped me understand and participate more in the treatment of my renal failure but did little to compensate for all of my losses. I still had to go to the center every other day and play the waiting game.

An Attractive Alternative

Making thrice weekly visits to the center for treatment was a burden because I am the primary care giver to

my wife who suffers with Chronic Progressive Multiple Sclerosis and is wheel chair bound.

Knowing my situation and genuinely caring for my wellbeing, my head nurse suggested I could be

a candidate for “Home Hemo” (using the NxStage dialysis machine). I educated myself about the requirements for Home Hemodialysis and immediately saw the many benefits of this treatment modality.

Home Hemodialysis offered me the ability to dialyze on my schedule. My fluid restrictions were eased because I dialyzed five days a week. Most importantly I did not have to play the waiting game any longer.

Home Hemodialysis Requirements

Candidates for home hemodialysis must be medically compliant and able to self cannulate or have a partner cannulate them. They should have a partner that will assist in monitoring the treatment. The candidate and partner must complete the Home Hemodialysis training program (typically 3-4 weeks). Additionally, the NxStage machine requires nearby water and drainage source - most connect their machines to their existing water and drain in either the bathroom or kitchen.

The candidate will be required to submit monthly blood samples to monitor blood chemistries and meet with the medical team to discuss results.

All things considered, Home Hemodialysis has afforded me an opportunity to have “Dialysis on My Terms”.

Home Hemodialysis Resources

For more information

Home Dialysis Central: www.homedialysis.org

Find a clinic that provides

Home Dialysis: Dialysis Facility Compare
www.medicare.gov/dialysis

Life@Home articles about

Home Dialysis:

www.homedialysis.org/types/life_at_home

Types of Home Dialysis Equipment:

<http://homedialysis.org/types/equipment/C60>

On-line Patient Forums:

Home Dialysis Central
<http://forums.homedialysis.org>

I Hate Dialysis Forums

www.ihatedialysis.com/forum/

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