

# home AT last



Spring 2011

A Quarterly Newsletter for the NxStage® Home HD Community

## In this issue

Carmen's Story . . . . .	1
Seven Years Later: At Home with NxStage . . . . .	3
Important Considerations . . . . .	4
NxStage News . . . . .	5

## Alligators, Lizards, and NxStage – Oh, My!

### Carmen's story.

Looking back over the last 30 years, Carmen C. of Athens, Michigan feels blessed. At 53, she's a happily married grandmother who runs a small gift shop and loves life more than ever.

The road to this point was not always smooth for Carmen. She was diagnosed with kidney disease in 1981 and began in-center hemodialysis in 1983. With a four-year old son and a newborn daughter to care for, she was devastated. "I didn't want to leave my children motherless."

After less than a year on dialysis, her younger brother donated a kidney. Unfortunately, Carmen's body kept trying to reject the kidney, putting her in the hospital frequently for the next 10 years. She says,

"I felt like the most pathetic weakling...sorry for myself and blaming the world." Sleeping all the time with bills mounting and her children growing up without her, Carmen sunk into depression.

In 1994, the kidney failed completely. Carmen went back to dialysis and tried to cope with another disappointment. In less than a year a new kidney was available. Carmen received her second transplant and was healthy enough to get a job to help pay the medical bills. But in 1995, this kidney also rejected. *(Continued on page 2)*





## Carmen's story: A call from her sister.

For Carmen, sadness and despair took over again. "My wake-up call came in the form of a call from my sister. I was crying and whining about my life. She just 'lit into me' like she has never done before. She told me to stop feeling sorry for myself. She reminded me that my kids and husband needed me, and I was not the only one going through this. My family was hurting too but I was too selfish to see it."

"She didn't know what I was going through," Carmen remembers. "But the more I thought about it, the more I knew she was right. I decided to never again let despair and depression take over my life." She hasn't. In 1997, Carmen started peritoneal dialysis (PD) and took control of her own

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treatments. With a more positive outlook, she was able to become a mentor for the National Kidney Foundation, a volunteer for the Gift of Life Agency, and even started a support group for her dialysis center. Helping others became a great remedy for coping with her own illness. Even when Carmen's PD catheter had to be removed and she returned to in-center hemodialysis, she did not let the depression overtake her.

In fact, she decided to finish a book she had started and in 2001, *The Courage To Live: My Journey With God. A Kidney Patient's Story* was published. A second book, *Panama Crossroads Of The World: My Reflections Of Childhood* was published in 2005.

## Carmen's story: Bringing it all home.

As soon as daily home hemodialysis with the NxStage System One™ was offered at her center in 2007, Carmen signed up, wanting to take charge of her life once again. Shortly after beginning daily home hemo, she felt better than she had in very long time. "I thank God for the NxStage cycler. It's given me and my family a new lease on life. I have energy."

"I am so grateful...I didn't think I would live to watch my children grow up, marry, and have children of their own. Today, I can enjoy my grandchildren. I am content."

(Continued on page 5)



# Seven Years Later: At Home with NxStage



“Much better  
and it’s made

## Seven years is a long time.

For Carl M., Craig B., and Everette R. – all of northern California – it has also been a rewarding time. As pioneering NxStagers, their commitment to taking control of their lives and their care has paid off.

All three started daily hemodialysis treatments on December 8, 2003, as part of NxStage’s clinical IDE study for FDA clearance of the home indication for the System One. By being among the first to embrace this therapy, they’ve moved the ball forward for themselves and for all dialyzors.

We recently caught up with all three to check on their progress.

### What thoughts, moments, or memories come to mind when you think about your initial training on the System One?

**Carl:** “The training went smoothly... in fact, the only problem we had was fixed by a suggestion my wife and I made: Because it was a bit confusing at first to keep all the connections straight, we suggested color-coding them to make the process easier as well as faster.”

**Craig:** “I enjoyed the camaraderie a lot...hanging out with the patients and team, helping fine tune things. I remember feeling great right away.”

**Everette:** “I didn’t think I could do it. I was deathly afraid at first...but it was fear mixed with excitement. I wanted to do it so bad.”



### What changes have you noticed from NxStage since you began home treatment 7 years ago?

**Carl:** “It’s even better now. They never seem to stop improving on it.”

**Craig:** “To me, it’s been very consistent.”

**Everette:** “I think they spoiled us a bit more in the beginning. But as it’s become more successful, we’ve benefitted from PureFlow, cartridge improvements and other product upgrades.”

### How has your life been affected by doing daily home hemodialysis with NxStage?

**Carl:** “Life has improved...I used to have to wait 20 minutes in my car after treatment at the center just to have enough energy to drive. Now I eat more...I can even smell food better! My doctor is ok with me eating a big old potato occasionally – I could never do that with in-center treatment. More food, more energy. I even do yard work now. And the things you can do, you can do better.”

**Craig:** “It helps me be more productive...I have more time available. I feel fortunate for me and for my family.”

**Everette:** “Much better quality of life. I feel better, look better, and it’s made me feel more like I’m not on dialysis.”



“It helps me be more productive... I have more time available. I feel fortunate for me and for my family.”

~ Craig

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~ **Everette**



### Are you currently working?

**Carl:** “I used to be a truck driver, but I’m retired.”

**Craig:** “I work part-time selling products for home remodeling.”

**Everette:** “I retired three years ago, after working for the cities of Oakland and Concord. Now I sell clothing and accessories through an online store, [urbandesire.net](http://urbandesire.net). We are getting ready to open a retail store as well.”

### What activities or hobbies do you enjoy?

**Carl:** “I still hunt and fish just like I used to... in-center, I didn’t feel like doing anything.”

**Craig:** “I enjoy cycling and car audio.”

**Everette:** “I like basketball, and I’m glad I can play again. Before, I barely had enough energy for a half-court game. Now I play full court no problem.”

### What is one thing that you would tell a prospective in-center hemodialysis patient about home hemodialysis?

**Carl:** “They need to switch! It’s like really living, like being born again.”

**Craig:** “You enjoy the freedom to set your own schedule. I feel like I got control back.”

**Everette:** “Anyone who’s capable of doing it should be doing it. It turned my life around.”

### How do feel about the seven-year milestone?

**Carl:** “Seven more years coming up! I didn’t realize it was already seven years. I feel great about it...anybody else would feel great about it, too.”

**Craig:** “Very proud to be part of it at the beginning and help improve it. It’s real progress. Keep the fire lit.”

**Everette:** “The years went by fast. It chokes me up a bit, what we made possible, what we did together. But it’s a great release...a feeling I didn’t have before.”

### Our thanks and best wishes to Carl, Craig, and Everette!

Editor’s Note: Just before the publishing of this issue, we learned that Craig received a successful kidney transplant – all of us at NxStage wish Craig and his family all the best!



## Important Considerations

Home and daily therapies are not for everyone. They require a patient and partner who are both committed to being trained on and following the guidelines for proper system operation. While the patient’s doctor, clinic staff, and NxStage customer service and technical support are available to provide support, home and/or daily therapy require a patient and partner who are committed to taking on the responsibilities of self-care.

Patients on NxStage typically treat 5-6 days per week at 2½ to 3 hours per treatment. Daily home hemodialysis patients experience many of the same risks associated with three-times-weekly in-center hemodialysis. In addition, there are certain risks unique to the home environment. Treatments at home are done without the presence of medical personnel and on-site technical support. Patients and their partners must be trained on what to do and how to get medical or technical help if needed. Talk to your doctor to understand the risks and responsibilities associated with home and/or daily hemodialysis, and to see if daily home hemodialysis with NxStage is right for you.

The patients in this newsletter have given NxStage permission to share their experiences with daily home therapy using the NxStage System One. The experiences reported by these patients will not necessarily be experienced by another patient. All patients differ and their experiences will vary.



## Carmen's story: A beautiful sanctuary.

During the first ten years of her initial transplant, Carmen's husband David built a small back yard pond with fish and turtles to distract the kids from the stress of their mother's illness. Over the years, new animals showed up and pretty soon the back yard turned into a small reptile zoo. The kids brought their friends by for entertainment.

David always loved reptiles, and decided he would begin rescuing them. After his first alligator, word got around and more alligators started showing up. "I was not keen on living with reptiles", Carmen states, "but how could I crush my husband's dream after he stood by me 'in sickness and in health'? I told him that if I could have a gift shop to sell my crafts, I didn't care what animals he rescued."

David helped her build a craft hut. That backyard hut is now a gift shop at what became, by 2007, a full-fledged zoo called Critchlow Alligator Sanctuary and Zoological Gardens. The zoo, which rescues reptiles people outgrow or no longer want and works with animal control departments, is now home to nearly seventy rescued alligators, lizards and other reptiles. Amazingly, alligators can be trained, and some alligators at the Sanctuary respond to word and color commands. The Sanctuary sponsors educational programs, school visits, parties, field trips, and even a college internship program.

Carmen, her family, and the Sanctuary are thriving. In addition to selling alligator teeth jewelry, Carmen gives tours and serves as webmaster for the zoo's website, [www.alligatorsanctuary.com](http://www.alligatorsanctuary.com). She is also finalizing her third book, *Life On The Balance: Surviving Home Hemo Among Reptiles*, which will be available soon.

“Thanks to my husband and care partner, my doctor, my home nurse, and NxStage, I am smiling today.”

## NxStage News

### UPS delivery service enhancement

NxStage's Logistics Department is happy to announce an upcoming service enhancement. Within the next few weeks, all NxStage users receiving UPS deliveries will have the opportunity to receive email notifications that will provide information on when the packages from NxStage have shipped and when they will arrive. If you haven't already, now is a good time to provide your email address to NxStage so you can receive this important information when your shipments travel via UPS. Contact your Customer Support Specialist with your email address.

### The first 5K was just a warm-up.

In February, NxStage announced that more than 5,000 patients are using the NxStage System One™ for home hemodialysis. "This new milestone demonstrates growing support of home hemodialysis within the renal community", said NxStage Founder and CEO Jeff Burbank. "Many of these patients and providers have become enthusiastic advocates of our therapy and should be credited with growing patient access to the clinical and quality of life benefits possible with more frequent hemodialysis." Thank you for your support and we look forward to continuing this growth, together.



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## NxStageUsers Next Big Adventure!

NxStageUsers, a patient advocacy organization independent of NxStage Medical, is planning its 2nd Annual Meet-Up and Conference. The meeting will be held in New Orleans from October 2-5, and provides a great opportunity to network with other users and care partners, hear from prominent nephrologists and renal professionals, and participate in a service event to help rebuild New Orleans. Read their press release for more information: [www.nxstageusers.com/neworleans/NOLAPressRelease.pdf](http://www.nxstageusers.com/neworleans/NOLAPressRelease.pdf).



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**WE WANT TO HEAR FROM YOU!**

Please send us your feedback!  
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