

Dialysis patient advocates for home treatment

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Somewhere along the way, Rich Berkowitz of Skokie decided that he needed to advocate for his own medical care.

"I came to the conclusion that I had to do that to survive," said the Skokie resident, a dialysis patient who suffered from kidney failure years ago.

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Richard Berkowitz sets up his dialysis machine at the Wellbound Dialysis Center. (Curtis Lehmkuhl/Staff Photographer)

But Berkowitz has moved well beyond just advocating on his own behalf. Changing from in-center dialysis to home dialysis treatment has saved his life, he said. And he believes it should be saving many more people's lives, too.

"I want to save lives," Berkowitz said. "I want to spread the word to as many people as possible."

Downward spiral

Berkowitz, 63, suffered from hypertension and high blood pressure since early adulthood. In 1998, he was diagnosed with kidney cancer that resulted in the loss of one of his kidneys.

But for Berkowitz, the medical problems didn't end there; in some ways, they were just beginning.

"I had another kidney that was probably compromised because of the hypertension," he said. "In another four-and-a-half years, I lost the use of that kidney as well."

Like many people in the same difficult situation, Berkowitz began in-center dialysis treatment. He still remembers the date -- February, 2003 -- because it began to change his life in significant ways.

He became seriously ill on dialysis. Dr. Stuart Sprague, chief of nephrology and hypertension at Northshore University Healthcare and University of Chicago professor of medicine, said that many people are reluctant to even begin dialysis.

The treatment provides an artificial replacement for lost kidney function (renal replacement therapy) due to renal failure. Dialysis is used for very sick patients or for stable patients who lose kidney function.

Berkowitz underwent dialysis three days a week, waking up at 5 a.m. to head to his center in Evanston for four hours of treatment.

During dialysis, patients often lose the ability to urinate between treatments. Dialysis removes toxins from the body and excess fluids that accumulate between visits.

"It's very hard on the body," Berkowitz said. "I was really beginning to fade."

His condition worsened when he suffered a heart attack in 2004 while driving home from dialysis.

Heart attacks for those undergoing in-center dialysis are fairly frequent, Sprague said. The mortality rate for dialysis patients is about 20 percent, and half of those deaths are caused by heart problems. In fact, a heart attack (followed by infection) is the biggest cause of death for dialysis, he said.

"I was on in-center dialysis for three years, and I am convinced that if I did not go home for my dialysis, I would have died a couple of years ago," Berkowitz said.

Sprague, who has been Berkowitz's doctor for years, said that there is no hyperbole in that assessment. Berkowitz had difficulty tolerating the removal of fluid three days a week. He said the stress was overwhelming for his patient.

"He had a hard time making it from one treatment to another," he said.

"I was crashing," Berkowitz said. "Many people in-center crash after their treatment and they sleep the rest of the day."

In-center dialysis impacted almost every aspect of Berkowitz's life including his ability to work as a computer consulting business owner or to enjoy his life. He grew depressed toward the end of his treatment, regularly sapped of energy, he said.

"At first, dialysis made me feel better," Berkowitz said. "Then it was something I had to do to stay alive." He now calls in-center dialysis "a slow death."

Sprague said that his description is too harsh since some patients can't undergo mobile dialysis and do well with in-center treatment. But doctor and patient agree that mobile dialysis can have dramatic results and should be available to more people.

"I've been an advocate for mobile dialysis for a long time," Sprague said.

Home treatment

Unfortunately, the doctor has also been frustrated for a long time because home dialysis is not regularly made available to patients who could benefit from it. Even in Berkowitz's case, his home dialysis kept being delayed, which he said contributed to his depression.

Sprague said he knew his patient was an ideal candidate for home patient dialysis early on, but there were no established clinics. Today, Wellbound Of Evanston in Skokie, where Sprague works, trains 57 patients in home dialysis care, a major step forward from when Berkowitz first suffered from chronic kidney disease.

Berkowitz couldn't begin his home dialysis care until February, 2006. But when he did, his life immediately changed -- this time for the better. He said he noticed a difference after only a week, a dramatic turnaround that Sprague calls "pretty typical."

"I wasn't washed out, my blood pressure went down. I just felt alive again," Berkowitz said.

Doctors have been reluctant to steer patients toward home dialysis. Insurance and financial issues also play a role. According to Sprague, it takes more work for the medical staff to oversee mobile dialysis.

For a myriad of reasons then, Sprague said, the United States lags behind other countries in home dialysis care. Only 7 percent of all dialysis patients are on home dialysis and fewer than 1 percent undergoes home hemodialysis, which can be more beneficial than peritoneal dialysis.

Berkowitz is one of the 1 percent using the NxStage System One dialysis machine.

NxStage describes the device as relatively small compared to other hemodialysis equipment, standard electrical connections, and bagged solutions. Berkowitz said that he also undergoes home dialysis while he is sleeping (nocturnal home dialysis) although not everyone is a candidate for the treatment.

The home solutions for Berkowitz have allowed him to be much more mobile and enjoy his life with more energy. His medications have been cut in half and his diet is less restricted, he said.

Cruise control

His changed treatment also made it possible for him to celebrate his 63rd birthday in a way he never thought possible.

In January, Berkowitz and 10 other dialysis patients enjoyed a Caribbean cruise, a vacation Berkowitz helped to organize. The dialysis patients all brought their NxStage

System One machines on board to participate in a one-week vacation that was unthinkable not so long ago.

"Cruises like this were only possible with a dialysis medical team onboard," Berkowitz said. "We are excited to show other dialysis patients that we, too, can enjoy the freedom and flexibility that others have by traveling with our System Ones. Dialysis doesn't have to be the end of 'normal' living, but rather a new beginning."

NxStage Medical Chief Executive Officer Jeffrey H. Burbank said the cruise underscored the company's mission to help dialysis patients lead full and vibrant lives. "We hope that this is just one of many trips in the future," he said.

If Berkowitz has anything to say about it, and he certainly intends to, the cruise of 2010 is just the start.

An advocate for home dialysis treatment, he continues to lobby officials, form online patient education groups and serve as a dialysis patient voice in government and media forums. He wants the availability of home dialysis care to change in this country, to become an available option for so many who could benefit.

"Rich to me is a perfect advocate," Sprague said. "He actually pushed me along. The truth is change has got to come from patients like Rich. It's also important to dissuade that having kidney disease is a death sentence, and Rich is all about that."

Berkowitz smiled when he heard his doctor's description.

"Living with a chronic disease does not mean you cannot live a quality life," he said. "I'm proving that every day."