

Still Standing

Will the insurance industry finish what neuropathy started?

BY CATHY CRENSHAW DOHENY

ou've been fighting this for a long time, so I understand if you feel it's time," Dr. Rao said. "But consider waiting as long as possible. Once you begin using a wheelchair, it's difficult to go back."

Dr. Rao's words haunted me the rest of the afternoon. He had been the ideal neurologist, compassionate but never patronizing. I could always count on him to tell me the truth in a nonjudgmental manner. This occasion was no different. Dr. Rao had given me permission to use mobility assistance while gently nudging me away

from it. It was only when I was granted permission that I gained the courage to hold off.

At the time, I had been living with chronic inflammatory demyelinating polyneuropathy (CIDP) for over six years. Though I had been treated with intravenous immunoglobulin (IVIG) since diagnosis, I had still experienced a slow decline.

At only 37 years of age, I knew I wasn't ready to give up my mobility. Still, keeping up with the young child my husband and I had adopted was becoming daunting.

"Mommy, what's wrong?" Jade asked, as I struggled to lift myself from the ground several months prior to my conversation with Dr. Rao.

"Honey, go get Daddy please," I said with urgency. I had crouched down in the yard to play with my daughter, and now my legs had totally given out. I hated for Jade or my husband to see me this way. What if they began to panic, the same way I was panicking inside? I tried again to get up, but my legs collapsed each time I tried to put weight on them. Was this it then? Was it finally time for CIDP to truly disable me?

By the time Kevin reached me, I was in tears. He quickly helped me up and got me to a nearby chair to recover. Though I resumed walking later that day, I suspected that this was not just a passing lapse in muscle strength. Soon, I began to experience diffi-

culty getting into the bathtub and climbing stairs.

Several months later, I suffered an "insufficiency fracture" of my tibia—a stress fracture caused by normal stress on weakened bone—that forced me to wear a walking boot for six weeks. That's when I started to think about a wheelchair. The boot was heavy and cumbersome, especially given my dwindling muscle strength. I was exhausted much of the time—just accomplishing simple tasks around the house had become difficult. Why shouldn't I request a wheelchair?

But I knew Dr. Rao was right. What about the good days? I still had those once in a while. How would I even know I was having a good day if I didn't give my legs a chance to communicate with me? And I feared losing the small amount of muscle strength I still had if I didn't force my legs to exercise. I returned the wheelchair to the back of my mind, comforted that I could recall it when needed.

Now, two years later, I am still putting one foot in front of the other. Unfortunately, after nearly nine years of receiving

IVIG treatments, my longtime health insurance company has decided they no longer agree with my CIDP diagnosis and will deny me the care that has kept me on my feet. Nameless administrators have determined what is best for my health without ever meeting me. Somehow, I think their decision might be different if they could just look into my daughter's eyes and hear her ask, "When will my mommy feel better again?"

Perhaps the health insurance industry will learn to work in partnership with doctors. I just hope I am still standing when that day comes.

Cathy Crenshaw Doheny lives with her husband Kevin and their 6-year-old daughter Jade in Charlotte, NC. Cathy was diagnosed with chronic inflammatory demyelinating polyneuropathy in 2002.

