

IBM patient number one my story:

I was never a very physical child. I remember in grade 7 we had a standardized test in physical education and I could not perform a single chin up. But I never really noticed anything specific until I was about 38 -- 40. I began to trip a lot and I noticed when I did a deep knee bend to look at something in a display counter in a store, I couldn't get up. Also, I noticed that I was having trouble pushing the button on a can of spray deodorant with my index finger. A key sign was when mowing the lawn and pulling the lawnmower back towards me, my legs gave out.

My brother was a general physician and suggested I was 40, overweight and out of shape. At the place where I worked, they had a full weight/exercise room for staff with a fitness instructor. He tested me and I started out at stage I on the chart for women. I went three times a week for 45 days. They had various machines and stations including a stationary bicycle with resistance. After 45 days I was still at stage I and the instructor said this was not normal. I continued trying to exercise.

Upon seeing my first neurologist and having my first "ambiguous" biopsy, I explained my story. He said that I had some sort of muscle disease and that it didn't matter which one because there was no treatment for any of them. I asked about exercise and he told me to stop, he dismissively said "run a marathon and get a wheelchair." He suggested I should try a year on Imuran and said, "it probably won't help but it wouldn't hurt you either." I declined treatment.

I slowly progressed, getting weaker in the legs and having more problems with balance and tripping. I was using a cane for stability. I progressed to a walker. My second biopsy with another neurologist was also ambiguous. The place where I was employed allowed me to go on half-time because I was finding myself pressed to do a full day.

I was able to go to California to see Dr. King Engel (2002) where I had my third biopsy and he gave me the diagnosis of inclusion body myositis. He did not recommend any treatment or exercise. Upon hearing my diagnosis, my employer immediately put me on long-term disability as they would not take the risk of me falling. I then began volunteering for the Muscular Dystrophy Association.

At one point someone suggested I try the saltwater pool at the hospital. The buoyancy of the water took the weight off my legs and I was able to walk. It felt great and I walked for about 20 minutes back and forth in the water. However, when I got home my legs were shaking and I could barely walk with assistance back to the house.

At another event, a conference, the group decided to walk quite some distance up a hill and I went with them. That also resulted in a severe weakening of my legs for a few days.

I was very lucky in my falls. I fell probably 60 times, breaking my ankle once and cutting my elbow for 70 stitches. I was lucky looking back on it that it wasn't worse.

It was a relief when I finally got my wheelchair because I was out of danger of falling. At that point, my arms were still fairly good and I could manipulate objects in my hands fairly well.

Would I have benefited from a supervised exercise program? That's hard to say. I did not experience any improvement in the roughly 3 months I was exercising regularly. I did not experience any pain exercising however, it's hard to speculate what would have happened if I had continued. Clearly for me, I didn't feel any improvement from the exercising I did.

The best advice I received was also the hardest to follow. A doctor told me now that I was in a

wheelchair I should be very careful about my diet and not overeat.

In terms of other symptoms, swallowing has not become a severe issue. I have choked four or five times and I'm always very careful. I had a bad bout of pneumonia in April 2008 and my doctor still was not happy with me in the fall, so I went to a respiratory doctor and had a spirometry test done. I also had a sleep study done. I was breathing about 30% of normal. I immediately went on a BiPAP which greatly improved my symptoms of feeling tired. Eventually my arms deteriorated and so did my daytime breathing. Today, I can use my thumb well enough to run the mouse on the computer and I'm using voice dictation. I have had to have a mouthpiece respirator on the back of my wheelchair to use during the day.