



The Personal Side of Parkinson's Disease

Personal Reflections on Parkinson's Disease Submitted by
Members and Friends of the Capital Area Parkinson's Society.

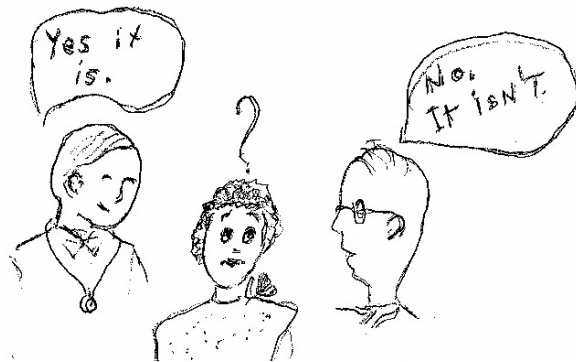
A Lighthearted Look at a Very Un-lighthearted Subject

Story and Artwork by Betty Pryor

In January 2002, I went to the doctor's office for a regular check-up, and after years of telling me that the tremor in my left hand was "Essential Tremor", this time he said that he thought it was Parkinson's Disease after all. He sent me to a local neurologist for confirmation and treatment.

The neurologist said it wasn't Parkinson's and gave me medication for something completely different. One says it is...one says it isn't, so I went to the top specialist on movement disorders at the University of Arkansas Medical Center. He voted with my first doctor.

So the tie was broken and I was officially a Parkinson's Patient.



I might say "Why me?", but just as logically, "Why not me?" I'm just lucky I have it when medicine has progressed as far as it has. It wasn't too many generations ago that a person with Parkinson's was pretty much left to live out his life just waiting to die.



There are so many well-known people with it now that everyone seems to keep up with what's going on in the way of medical advances. To name a few, there's Michael J. Fox, Billy Graham, a former Pope, Mohammed Ali, and former US Attorney General, Janet Reno. That's a pretty strong group to be a part of, no matter what your politics. Just to be fair, I'll name one more who historians now tell us had Parkinson's...Adolph Hitler!

As we learn more about the people who have it, we also learn more about the disease itself. There are many symptoms and no two people seem to have the same combination. I personally, seem to have escaped Rigidity, which is one of the four most common. Rigidity, along with Tremor, Postural Instability, and Bradykinesia are considered to be the Cardinal Symptoms of Parkinson's Disease.



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Since most people with Parkinson's are 'up in years' (the average age of onset is 60), a person who is stiff looks a lot like other seniors. Rigidity from Parkinson's or Rigidity from Arthritis at a glance looks pretty much the same.

The other symptom that one usually names first has to be Tremor, probably because it's the one that almost all have in one degree or another. Perhaps it comes to mind because it's so easy to demonstrate. After all, who hasn't been disgusted watching some comedienne doing her impression of Katherine Hepburn, complete with the exaggerated shaking of head and quivering voice! I have to admit my disgust increases along with my own symptoms.

Bradykinesthesia. When I first this heard this term mentioned, I assumed it was named for a Dr. Brady, who had observed some poor soul who suffered with it. I was surprised to find out that it comes from the Latin word meaning 'profound slow movement'. Since this is the symptom that has caused me the most trouble, I don't think 'profound' is near a strong enough term, but I can't think of one that's any better.

When I'm in this state, I can take up to 15 minutes getting across the room to answer the phone, which of course, has stopped ringing by the time I get there. And if I happen to wake during the night, I must assume it's an early warning that I need to go to the bathroom. If I don't, I may not make it.

I have plans for how to get to the bathroom from every part of the house. From my bedroom I go to the foot of the bed; from this point I steady myself 'til I feel secure enough to make a dive for the dresser. I don't know why I have to get up the courage, it's only four or five feet and I've never missed, but remember, it's usually dark when I'm making this trip.

Occasionally I get caught in the living room and must go to a different bathroom. If my body is almost completely out of medicine, I don't even try to walk. I crawl. There are times when one must throw dignity to the winds and do whatever works.



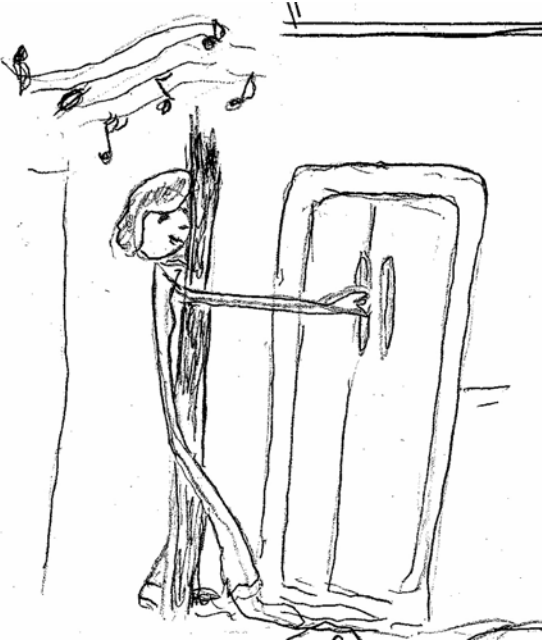
Normally, crawling is sure-fire, but there are times when even crawling needs to be improved upon. For instance, once I was on my way through the kitchen (no carpet) and my knees were begging for mercy. I was inspired. I turned over (from my crawling position) and sitting flat on the floor, began scooting backwards across the floor. I was



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amazed at how fast I could go and propelled myself across the room in no time. I'm also a pretty good housekeeper because my gown didn't get dirty in spite of being put to this new use.

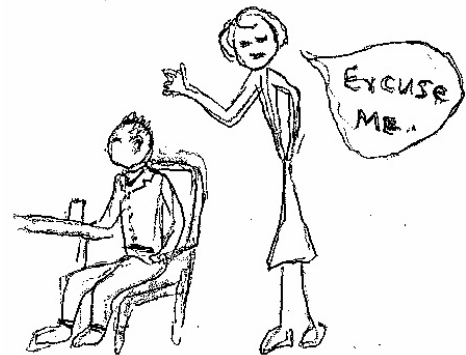


Now, reversing the trip brings me to one of the most humorous situations I've found myself in. Coming back to the kitchen and leaving the bathroom I have to maneuver through a short hall, after which I must make an immediate left turn. I can't describe it very well, but trying to reach something to hold on to, I find myself hugging the door jamb and reaching for the refrigerator handle. One night I got to this point and it suddenly dawned on me how funny I must look...posed like a stripper with her pole, just waiting for the music to begin.

I don't realize how much I depend on these various hand holds as I go from place to place through my house 'til I get away from familiar territory. That's when I really have to work at it.

Like last Sunday. We had gone out to eat (regular dining room...I've given up on buffets). I got along fine until it was time to go home. I stood up to leave and as I stood up, I realized that I was about to reach out and put my hand on a man's chair at the table next to us. I (mentally) practiced walking without holding on to his chair. I was really nervous, but I did alright and the man never noticed what a struggle had gone on right behind him (in my head).

Right now, I'm working on not dragging my fingers along the walls in the hallway. To think, I had handrails installed on both sides of the stairway just to keep this from happening.



I've have several nice things happen just because of my Parkinson's. One, my daughter got me the neatest walking stick. It's carved from top to bottom and at the top is a giraffe. I've always been fascinated by this awkward, yet beautiful animal, and I have a large giraffe collection at my house. My daughter said the when she saw it, knowing of



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my health problems and fondness for giraffes, she thought I just had to have it! I think she was right. It is so attractive; it gets attention wherever I go. But that's not all, when my Bradykinesthesia causes me to 'freeze' I use it like an oarsman on a gondola to start moving again.

The last of the four is Postural Instability, which means it's not easy keeping your balance. If first thought it meant "not having good posture" and I thought this won't be any problem for me. That's one thing my Mother was very strict about. She taught my sisters and me to walk like we had a wire attached to our chest with the other end attached to the ceiling so our bones would line up just right. (She used this, along with "if you slump, I'll get the back brace!")

I later learned that its actual meaning is "it's easy to lose your balance". Have you ever had a doctor stand behind you and try to pull you over backwards and then say "good" when he fails because you stepped back and caught yourself? That was your Postural Stability he was checking.

The first time this was tried on me, I misunderstood my directions and thought I was supposed to fall back and let him catch me, trying not to step back. Once I got my directions straight I did fine. On every visit to the doctor, he always asks, "How many times have you fallen?" I've always answered "None, because I'm so careful". Next time it will be different...I'll have to say "Once". I was coming into the house and was reaching for an inside opening door and missed it, but once I leaned over I couldn't stop. It was like watching myself in slow motion and having no control over what was happening.

One thing that I'm really enjoying that I never expected to, is my support group. In fact, I never intended to go to a meeting. I thought it would be extremely depressing to go to a meeting and see other people there who symptoms are more advanced than my own, and knowing that is what I have to look forward to. It's funny, but it doesn't work out that way because once you meet someone and are around them a bit, they stop being Parkinson's patients. They become just people...and more important, they become friends.

So I guess it's just like everything else – you do the best you can and just go on.

Mrs Pryor is a retired elementary school teacher, who lives with her husband in Northeast Arkansas. One of their three daughters lives in Austin and is an active CAPS member.