Nora’s “Condition”

Nora was diagnosed in March of 2001.

Getting Nora to go to a Neurologist

In 1999 Nora retired from teaching after 32 years. In her last two years of teaching she said it was hard to get started in the morning. As she did, I thought this was simply that Nora was becoming burned-out.

Over the next year-and-a-half, I started to notice oddities in how she walked.

From time-to-time we would go to Sunken Meadow State Park on Long Island and walk on the boardwalk.

I started to notice that when Nora walked her arms didn’t swing. One day I said to her, “Your arms aren’t swinging!” She responding slightly sarcastically, “Do my arms have to swing?!” Eventually I mentioned it to our daughter Renée. And finally late in 2000 we started to try to get Nora to see a neurologist.

She finally agreed to go in March. The day arrived and we walked into a heavily-filled waiting room. After what seemed like a long time but was probably about 40 minutes to an hour. We were ushered into the doctor’s office. Before we even took a seat, he said, “I guess you want to know what’s wrong with you.” We agreed that was why we were there. He said, “You have Parkinson’s Disease.” He had seen Nora walk in and that was enough for him to diagnose her condition. As we later learned slightly stooped posture and arms not swinging are classic symptoms of the disease. Stupidly I said to her, “Well at least you have the best of the bad diseases.”

After some years Nora had still not come to grips with her having PD. I would refer to the “Disease” and she would say, “I don’t have a disease. I have a condition.”

Over the years her “condition” worsened and medications were changed and adjusted. She started to have painful cramps at night. The first time this occurred we called her doctor and got the answering service. We explained the situation and waited for a call back. It never came that night or ever. The next time she had severe leg cramps we again called and left a message with the service. Again there was never a call back.

On our next visit I complained to him about his lack of calling back. He said, “I have a life.” We immediately contacted another neurologist, Dr. David Kreitzman. He took Nora on as a patient; found that her meds were quite mis-prescribed. He adjusted her meds; over time put her on different meds; and things went along pretty well.

To step ahead a moment, these were Nora’s symptoms: stooped posture walking; and eventually indications of some mild Parkinson’s-related dementia. In 2011 our daughter Renée was getting married. We flew out to Seattle, had a great time—it was a memorable trip.

Late spring 2012 we flew out to Seattle to see our daughter’s newborn twins. We scheduled our return on a red-eye flight. We arrived home around 7am. Nora went to lie down and I went to our family room to rest. Some hours later Nora came into the family room saying, “I came to join the party.” I asked, “What party?” She responded, “All these people.” I said, “What people?”

Our Parkinson’s nightmare had begun.

Hallucinations – the hidden symptom

Over the next months Nora experienced hallucinations to the point she was always afraid to come home when we had been out. She would look at the house and see masses of people in it. One evening I had been working in the basement and when I came up I could not find Nora. I happened to open the front door and there was Nora in a nightgown, in the car, car door open, just sitting. I went out and asked what are you doing. I’m waiting for you to take these people home. Sigh. Of course there were no people.

Taking a step back about three years. Over a period of six weeks Nora had three or four car accidents. The last was speeding down our driveway head-on into a tree. Car totaled and Nora was no longer a driver which is why on this late fall night in 2012 Nora was in the car waiting for me to take the non-existent people home.

Things got worse. One night about 2am I awoke to find Nora racing around the bed and heading down the hall. I raced after her and caught her at the front door. She collapsed on the floor saying, “Are we dead yet?” I got her into a living room chair and had to talk her down from pure terror. It seems she had been having a nightmare in which there was a murderer with an axe trying to catch her. When she startled awake in her delirium she thought this was real and ran around the bed and down the hall.

Now people with PD really can’t normally run. But in the wee hours that day she did.

I called her neurologist in the morning and we went in for a visit. Eventually Nora became part of a trial study for a drug called Pimavanserin. Today that drug is available under the Nuplazid. The company, Acadia Pharmaceuticals has been a literal life-saver.

Immediately after taking the drug all hallucinations ceased as did her delirium.

That next year 2013 we (or at least I) recognized that I needed help with Nora. Eventually we found Sandy. Initially two times per week for three-hours at a time she would come over and be a companion for Nora. In 2013 Sandy was still in college in Delaware. But whenever she came home, after dropping her stuff at her house, she would drive down the street to our house. When Nora would see her she would start crying with joy. They became very close and I owe the last years of Nora's life to Sandy.

The Sandy Years

When we met her Nora had an immediate rapport with her. Sandy was still in college so her only availability was when she was home from college. Because of that we tried to find backup people. Some were actual aides and were concerned about Nora's physical wellbeing which was frustrating because they spent little time acting as a companion. Others failed to make a connection with Nora. Of course this was no one's fault. Sandy had made a connection and no one else came close.

At some point in 2013 (I believe) we were eating at the Venus Diner in Northport. Nora said she had to go to the bathroom. At this time Nora was mostly mobile but did rely somewhat on a cane. She got up wand went to make a step and for some reason her feet failed to move but because she was leaning forward she ended up doing a face plant. Her head hit the tiled floor hard. She had been unable to brace herself. I leaped up and started to check her when a gentleman at the next table knelt down to help. He was an EMT. We got her as cleaned up as possible and rejected an ambulance as too stressful for her. We headed home debating about stopping at the emergency room but did not.

She started to have more falls.

Some months later we started to notice that Nora was quite bent over when she walked. She said she could not straighten herself up. Also she began to have some difficulty swallowing pills.. Her neurologist was stuck in what I call Parkinson's mode and could find no reason for her stooped posture. Eventually at the urging of Dr. Friedling (her GP) we went to see another neurologist, Dr. Bruce Mayerson. He examined her and said he wanted to consult with Dr. Kreitzman. Some days later a test was ordered. She passed the test with flying colors… Nora also had Myasthenia-Gravis (a muscle-weakening disease).

Since Dr. Kreitzman only dealt with Parkinson's Disease we went back to Dr. Mayerson for treatment. He prescribed some medications and literally within and hour of taking the meds Nora could standup straight. Her swallowing also immediately improved. There is no known cure for Myasthenia-Gravis but as long as she took those meds the MG was only minimally a problem.

Christmas 2013 was a sad time for Nora. By this point Renée, her husband Joe, and their twins Hudson and Marcel had moved to the Glendale area of Los Angeles. Nora was terribly missing them. She started to get depressed and I looked for a way to get Nora out to see Renée and family. It was clear that flying was too stressful for Nora and driving across the country stopping every night in a different motel would also be too stressful.

My only solution was a motorhome. But motorhomes cost hundreds of thousands of dollars which we could never afford. Around March it occurred to me that we could buy a used motorhome and started looking. Nora was an enthusiastic partner in the hunt.

Eventually we found the beast.

We began planning our trip without telling Renée. We decided to leave on July 4th 2014 (a Friday).

Tuesday, July 1st proved to be an event-filled day. I was in the bathroom. When I came out I did not see Nora who I had left in the living room. But I noticed that the front door was open… not good.

Outside the front door is a cement porch. Then two-steps down to a cement walkway. There on the walkway was Nora's walker upside down. But that wasn't the concerning thing. By the walker was a huge pool of blood… but no Nora.

I raced back into the house and eventually found Nora in the hall bathroom covered in blood and she looking in the mirror babbling, "Its not bad." At that moment I had two thoughts. I'm embarrassed to admit my first thought was, "There goes our trip." My second thought was, "Shit, I've got to get Nora to the hospital." I bundled her into the car and off we went. After a long wait, stitches, and a catscan the verdict was in. No obvious damage and the doctors much to my surprise said there was no reason to postpone our trip. Really? Yep,

So Friday morning off we went. First to Washington, DC where we would spend the weekend with our friends the Weichers. Sunday, we spoke with Renée and told her we were coming cross-country in a motorhome and would see her in about 10 days.

You can read all about our successful trip of about 6 weeks in On the Road under travels. The only real damper on the trip was the day before we returned home we heard about the death of Robin Williams. It seems odd to think of that as the down point if you read the story and see that we did have some issues. But he was such an amazing force.

Back home and back into our routine with Sandy coming over two or three days a week when she was around we continued on.

Eventually Sandy was always around. Two, three, four, and even five days a week. For her it was much more than a job. She had formed an unbreakable bond with Nora which continued up until Nora's passing over night into the morning of January 30th 2019.

The "Condition"

Nora never developed tremor. She did however have trouble walking, developed profound dementia, and as indicated above, hallucinations and delirium. In addition she developed Myasthenia-Gravis—a muscle-weakening disease.

Her disease, as with all Parkinson's patients, was progressive.

In 2015 Nora spent about a week in the hospital with pneumonia followed by 6 weeks in a rehab facility.

In 2016 I had a surprise triple bypass and Nora spent a month with Renée and family in Alexandria, Virginia. Yes, her family now lives about seven hours away.

At the end of November 2018 into December, Nora spent about 10 days in the hospital again with pneumonia. By this point her condition was grave. Coming home from the hospital she started to receive outpatient care. While she recovered from the pneumonia her body and mind had taken a beating and she never was able to fully recover.

A little over a week before the end, Renée came up and spent time. It was difficult as Nora was mostly asleep and non-responsive. The night before she died she suddenly opened her eyes and was responsive to the point that we all had time with her. At one point Renée called Katja (Renée's pseudo-cousin) in Seattle and said, "Katja, speak German to Nora." She did and Nora smiled. That night I washed her for the last time, kissed her, laying her on her side and in the morning she was gone.

I sit here crying as I relive those days.

Treatments, Doctors, and Facilities

Drugs:

Sinemet, Asilect, Nuplazid, Ativan, Aricept, Lexapro, Lotrel, Mestinon, Cellcept, Namenda

Doctors:

David Kreitzman – PD
Bruce Mayerson – Myasthenia-Gravis
Aronson – Psychiatry
Steve Friedling – General (best doctor anyone could have) – a special thankyou
Dr Lisa Greco – Life Strength Physical Therapy

Facilities:

Saint Catherine of Sienna – Meh
Stony Brook hospital – terrific care
Smithtown Parkinsons Theraapy Center – three times per week for many years