

Personal Experiences with Lewy Body Dementia

by Jean Rough, July 2018

Knowing that I have both Alzheimer's and Lewy Body disease, I found myself interested in what I could learn. In my search, I discovered Dave Itzkoff who wrote a book *Inside the Final Days of Robin Williams*. Robin Williams, the actor, had Lewy body dementia (LBD) but it was not discovered until an autopsy after his death. Itzkoff learned about Robin's symptoms mostly from Robin's wife Susan. I learned from Dave. Itzkoff's book was a BIG breakthrough for me. As I read about how much Robin suffered, I felt my own suffering. I no longer was alone. For instance, he and I had the frustration of not knowing if a LBD symptom is leaving, arriving, or returning. No way to prepare. And no way for caregivers to prepare. Robin's wife and others tried everything to stop a symptom but nothing would work. His body had its own time. And so does mine.

Here is the "endless parade of symptoms" that Robin went through, mostly in his last year of life. It shocked me that his symptoms were so similar to my own symptoms.

** anesthesia	** constipation	** moments of quiet; moments of crying
** severe loss of weight	** trouble seeing	** motor impairments
** loss of sense of smell	** cogwheel rigidity (limb stops itself)	** difficulty remembering
** heartburn	** stooped posture	** indigestion
** tremor in left hand	** "freeze" current motion	** Hallucinations are not mentioned in Robin's list, but they have been important for me
** less voice	** anxiety (off the chart)	
** stomach cramps	** thinner and frail	

For each symptom there is a story. I have been keeping a journal for my stories. For example, four years ago, I was changing my niece's diaper. In cleaning it up, I noticed that I was not smelling it. That night at dinner with my husband and my 90 year old father I asked them to smell with eyes closed. They could smell. I could not. At the moment Lewy body Dementia was not a part of my life. But last year I realized that it was most likely due to Lewy. And I still can't smell.

Another all time experience is that my weight was around 124 lbs in 2014 and now is about 97. No matter what and when I eat, my body is not responding. Of course there are many Lewy symptoms that appear and then disappear. This was true with my rheumatoid arthritis. It lasted for a couple of years and then disappeared. Please note that RA does not usually disappear!

How did this begin for me? Four years ago, at least, I began noticing that I was being different, such as trouble with words. I took one of those tests and did fairly well making a clock, knowing where I lived, and remembering the three animals proposed to me when I arrived. A doctor did an X-ray and said it was fine with slight mild cognitive impairment (MCI).

Two years later those small mistakes and thoughts on the tests had shifted. My husband Jim and I decided to attend an event in Seattle focused on Alzheimer's disease with Dr. Thomas Grabowski who is Director of UW Medicine Memory and Brain Wellness Center. After attending one of his private sessions and taking a MRI, we were ready to hear the news. Later Dr. Grabowski suggested that I bring someone who could be a caregiver. I decided to bring Jim my husband and our son Dan and his wife Bonnie.

As we were preparing to leave our home in Port Townsend for our session, I remembered that I had that X-ray from the years before. But where would it be in our home after all of these years? I gave it one possibility, in my husband's closet pushed way back. I went into the closet and there it was! We took the X-ray with us to Seattle. It was a good choice because it gave Tom enough to measure and see a few differences.

At the UW Memory and Brain Wellness Center, Dr. Grabowski asked lots of questions. He also shared what he saw on the MRI. It was hard for me to see what clearly was OK and what was not. It was very important to include our caregivers. They asked good questions and now I have better knowledge of what I can expect.

Another UW Memory and Brain Wellness Center event was held a month ago with the focus on Lewy body dementia: Lewy Body Education Day. I was impressed how well the organizers allowed time to share and for us to hear other stories that professionals shared. And two of my caregivers attended by taking off of work (and picking me up at the ferry!). They had the chance to learn more about Lewy. We hope that the Center will offer more events.

What It's Like to have LBD

A friend asked me what is it like to "have" LBD. The image that comes to my mind is a ferris wheel except you don't know when it will start or stop. What helps me is to be conscious about how I feel each day. If it is something a bit unusual, then see if it is in the LBD list or maybe something new for the list appears. And give yourself a moment to relax or take a walk knowing that this event will pass. In the meantime, check to see if you need to inform your caregivers in preparation for the ups and downs.

I'm Cleaning!

Recently, I cleaned our dishwasher. Then I brought my cleaning stuff to the bathroom. I noticed that there was lots of dust on the floor behind the toilet. Obviously, it had not been cleaned for a while. I got down on my knees and cleaned. Then I noticed the wall had some spots, and another wall to clean. I cleaned them. I was in the midst of the next wall when I suddenly realized something. I stopped and screamed with a huge smile: "I'm cleaning! I'm cleaning!" Something was released that had been locked up along with LBD. The "locked up" had been keeping me safe. I could only face so much at the time of my life. But the "doing the cleaning" released me. That is how great I feel!

Driving my car

Something else I notice. If I share with someone about a problem, such as forgetting where they put things or getting lost when driving their car, their response often is: "I know what you mean. That happens to me all the time." Yes, that is true as how she/he experienced it. However, there is this different kind of loss. My car loss situation shortens my thinking. For instance I might not think to call "Siri." My friend with getting lost with a car has the choice to think and perhaps check with Siri.

Recently I was driving my car and pulled out from our hospital to a larger street. My destination was to turn left to a grocery store. It looked clear. When I looked to the right, two cars were coming. Knowing the left was clear I moved out, but the left was not clear. I had to make a quick choice. In the moment, turning a bit fast to the left seemed the best choice. I gave the car a quick move and made it. But it only worked because the car to the right slowed down. As I drove away, I hoped the driver would follow me so I could apologize. He did pull in right next to me. I walked over and apologized. He happened to be someone I knew and was mayor of our town for years. We talked about the almost crash. We knew that all of us were over 72. I shared that I had Alzheimer's and Lewy. And that Dr. Grabowski had mentioned that I should consider not driving. Now I know why.

Two weeks later I was driving to pick up my great niece and take her to a friend's house. An easy task. However, I made a wrong turn and had no idea where to drive. It was like being in a swirl from street to street, with little thinking. Finally I found a way to get out of the swirl and finish my task with the car.

That night Jim and I talked about our choices. It hit us hard. How could we manage without my driving? It would be far more difficult for both of us. But as we talked, we remembered Tom's words. And we remembered two other events in Seattle that would follow in as Lewy. And we talked about our grandchildren. This is our first week with Jim driving me to someplace. I am riding my bike more often.

Hallucinations

I saw Jim walk by with morning light under the doorway while I was lying on my bed. I called out to have him join me. But he doesn't hear me. As I am watching the door, I now see these crazy looking creatures, very small, parade under the door going in a perfect line, the opposite than what Jim was doing. I smile and speak to the creatures. Soon I realize that I have been in a visual hallucination, once again.

Finding Help

We have someone who helps with cleaning, gardens, and paying bills. But there is no one who helps with our daily living. As simple as keeping our calendar up to date. It can no longer be me. Small tears come. We begin to consider our options, such as having someone who stays during the day. Or how later could sleep where. There is some laughter as to how we could sleep. But mostly we are caught in a maze that has no way out. As if we have hit ground. The reality is that we have a long way to go. Maybe it is closer than we think. The thought is scary, sometimes more so for Jim than me. •