

## 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.

