

My Experience with Parkinson's Disease

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“There's a fine line between genius and insanity.”

~ Oscar Levant (1906-1972)

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This narrative is written out of sequence—it just happened that way. Because of the recent chemical and electrical imbalance in my brain, I am now experiencing some really strange neurological, psychological and spiritual phenomena. One positive side effect is that my innate ability to express myself through writing has been amplified. I have developed my writing ability through academic study of the English language, which is primarily left-brain oriented—but there is a right-brain abstract attribute that defies explanation and today, March 30, 2012—I am being obsessively driven to write by some force that I do not comprehend. I worked so long and so hard on my Master's thesis that by the time I finished it, I was sick of it. There were moments, however, that I was truly passionate about what I was writing, and I found myself “in the zone”—which ironically is where my damaged brain has placed me today. (I started this narrative on March 30, but have been working on it for about six months).

For those who have entered this drama “in medias res”—in November 2008, in the third semester of the Master's degree program that I just successfully completed, I was diagnosed with Parkinson's Disease, a neurological impairment that affects body movement, which is the result of a deficiency of dopamine, a neurotransmitter that is necessary for the brain to send electrical signals to muscles throughout the body to initiate movement—which can be as obvious as walking, or using a fork to eat spaghetti, or as subtle as facial expressions that depict emotion. The cells that produce dopamine naturally—have died, for reasons both known and unknown—and without dopamine in the brain, the muscles “don't work right.” Those of us afflicted with Parkinson's experience a variety of problems with motor skills, especially with our hands, and many of us have problems with walking caused by balance issues. Sometimes muscles don't move when you want them to, known as freezing—and sometimes muscles move when you *don't* want them to, which is manifested as involuntary movements such as *Parkinsonian tremors* and *dyskinesia*. Tremors are caused by a deficiency of dopamine in the brain—conversely dyskinesia is caused by too much dopamine. It is difficult to maintain the appropriate balance of dopamine by taking oral medication. The most common oral form of dopamine is carbidopa-levodopa (brand name *Sinemet*) which is a combination of dopamine compounds that are chemically modified to be able to cross the blood-brain barrier.

Parkinson's affects everyone differently. I typically experience Parkinsonian tremors in my right hand, left foot, and in my lips, and tongue. Sometimes my lips and tongue are stiff and tingly—and feel like pins and needles are poking them. While suffering tremors in my mouth, I frequently experience hypersalivation—drooling. With me, dyskinesia is manifested by “rocking” of my head and body and a general inability to be still—when I experience dyskinesia while lying in bed at night, especially when my legs twitch and kick—my wife is not amused. To

me, tremors are much more unpleasant than dyskinesia—which I experience as a type of “nervous energy” that can be neutralized with exercise.

Parkinson’s Disease is very difficult to treat because it is what I call “a moving target”—it is different every single day. Some days I wake up feeling great with no tremors or other symptoms—other days I wake up in what I call “full-tremor mode” and I have to use both hands to lift my coffee cup, and I have to eat my cereal with my left hand. My speech is also different from day to day. Sometimes, my speech is “loud and clear” and my pronunciation is crisp and clean—and other times I have significant problems with speaking. I perceive two reasons for speech difficulty—if my lips and tongue are trembling or experiencing paralysis, of course it will adversely affect speech. However, sometimes I have a neurological problem and I simply can’t think of the word I want to say, when that happens I frequently stutter.

The first symptoms that I encountered, in the summer of 2006, were difficulty swallowing and coordination issues involving the use of keys—specifically flipping the correct key into position, with one hand, to open a lock. I also noticed that I was having trouble with my guitar playing, particularly with right-hand strumming. I slowly became aware that something was “wrong with me” as new symptoms appeared and the execution of simple tasks was becoming increasingly more difficult. I went to a neurologist, who incorrectly surmised that I had suffered a brain stem stroke. He sent me to get a MRI (Magnetic Resonance Image) of my brain. While attempting this procedure, the technician scolded me because I did not remain motionless during the test. I now realize that although I was trying not to move, I was already experiencing involuntary movement because of an impairment that I did not yet know that I had—Parkinson’s Disease. While I was crammed into that horrible tubular coffin thing, I discovered that I suffered from another previously undiscovered impairment—claustrophobia. Like many people, submitting to an MRI causes me to experience extreme debilitating anxiety. I have discovered that the only way it is possible for me to submit to an MRI is to be unconscious. The MRI that was recently administered prior to my last surgery required me to be under general anesthesia.

Today, medical science research has produced some astonishingly remarkable technological advancements. Technology that previously only existed in science fiction is now a reality. There is an extraordinary technology that is now being used to treat the debilitating symptoms of Parkinson’s Disease—DBS—Deep Brain Stimulation. Electrodes are surgically inserted deep into the human brain that create an interface between a biological organism and an artificial intelligence entity—creating a symbiotic relationship between them.

The science actually involved is way too complex for me to comprehend. My limited understanding from my own rudimentary research is that in some cases, electrical signals from the brain become corrupted, and no longer perform their intended function of sending messages to the muscles. In the most obvious scenario, the intended movement is uncoordinated or does not happen at all. Sometimes, however, the brain sends messages that are so corrupted that the muscle movements they produce are horribly deformed involuntary movements, such as tremors and dyskinesia. The electromagnetic field created by the DBS blocks these corrupted signals. One medical professional explained it to me this way—and I still don’t really understand the concept—that DBS “fools” the brain into working right—so it does.

I had my first DBS installed in August 2010 by a neurosurgeon in Austin. I was seeing a neurologist in New Braunfels. I gradually became aware that this neurologist was not providing the quality care that I deserved, and did not have the knowledge or skill to program my DBS. Upon the recommendation of several of my friends at the *Austin Young Onset Parkinson Support Group*—I contacted Dr. Robert Izor.

Dr. Izor became my neurologist and after attempting several times to program my DBS, and after getting a new low-resolution MRI, he came to the conclusion that it had been installed incorrectly, that the leads were not in the optimal position, that they were a few millimeters off-target. The reason that a low-resolution MRI was necessary was that a standard high-resolution MRI cannot be administered to a patient with metal anywhere in his or her body—it would be sort of like putting aluminum foil in the microwave!

The new plan was to remove the existing DBS equipment, and install a new unit in the correct position. On March 27th, Dr. Patel, my neurosurgeon, removed my DBS unit. On April 4th and 10th he installed the new unit, and on April 12, Dr. Izor turned it on and began the process of programming it.

After having my first DBS for almost two years, even though it was not properly installed, I felt like I had developed some kind of symbiotic relationship with it and that I was experiencing some weird kind of withdrawal. I felt that part of my soul has been taken away, and that I no longer was me. After the removal of my first deep brain stimulator on March 27th, I felt really strange. I now believe that the weird sensations, and thoughts, were nothing more or less than the result of someone poking around in my brain.

I have experienced strange, vivid dreams and even waking hallucinations in variable degrees of severity almost from the beginning of my experience with Parkinson's. Sometimes they were the result of the imbalance of my brain chemistry caused by Parkinson's—other times they were caused by drugs they were giving me. When I was first diagnosed, I was given Mirapex, a drug known as a dopamine agonist, which helps some people, but with me caused severe negative side effects, including paranoia, anxiety, vivid dreams—and even hallucinations. I experienced hallucinations even before I was taking Mirapex, but they were much more intense while I was taking the drug. Since I have discontinued taking this drug, the hallucinations have decreased significantly, but I still experience them from time to time.

What are hallucinations? Wikipedia.org offers the following:

*A hallucination*, in the broadest sense of the word, is a *perception* in the absence of a *stimulus*. In a stricter sense, hallucinations are defined as perceptions in a conscious and awake state in the absence of external stimuli which have qualities of real perception, in that they are vivid, substantial, and located in external objective space.

While experiencing hallucinations, which were usually visual hallucinations, I was always aware that I was hallucinating. When I saw an iguana on the kitchen table, or a giant tarantula in the bathroom, I just looked at them and said, “whoa... cool...”—but I knew that they weren't really

there. I was rarely frightened by these manifestations; a notable exception was the time I saw a huge rat, bearing his teeth at me, sitting on my pillow.

I believe that hallucinations are *usually* just illusions created by our imagination, but *sometimes* are the result of perceiving (seeing, hearing, smelling, tasting, tactile feeling) things that other people do not—but that does not necessarily mean that they are not there. I believe that there are alternate planes of existence that we usually cannot perceive but drugs and certain physiological conditions make perception possible.

While I was living in San Marcos, I frequently saw *shadow people* in my bedroom at night. Typically, I would see them when I woke up after sleeping. The only light source in our bedroom at night was my alarm clock, which very faintly illuminated the room. I saw three-dimensional dark humanlike figures walking around in the room; sometimes they floated around in the air. Usually they seemed to be wearing some type of hooded cloak that totally obscured their features. Occasionally, I would see them wearing hats.

When we are asleep and dreaming, we accept the events we dream about as being possible—despite how fantastic or unlikely they may be. I believe that when I saw the shadow people, I was in a state of consciousness somewhere between being awake and asleep. I was “awake” in that I was cognizant of the fact that I was in my bedroom and I could glance at my alarm clock at therefore be aware of the correct time, and observe other things in the room that I knew was really there, such as my wife sleeping in the bed (I never saw the shadow people when my wife was awake—I assumed that they did not want anyone else to see them, or *not* see them when I saw them—so that I could neither prove nor disprove their existence). When I saw them, I did not doubt that I saw them; however, I was not afraid of them—only astonished. I got out of bed, walked around the room and tried to communicate with them. If I was got too close to them, they ran from me, and would even go through the wall to escape. Sometimes, I amused myself by yelling, “boo” and lurching toward them and watching them scatter and disappear.

For a long time, I thought that the shadow people were my personal hallucination. Then one night I was listening to *Coast to Coast with George Noory* on the radio and the topic for the night was—shadow people. I discovered that other people all over the world for hundreds of years have seen them and described them exactly as I saw them. I have since spoken to other people with Parkinson’s Disease who admit that they have seen them.

I was hesitant to discuss my hallucinations in this reasonable rational treatise about “My Experience with Parkinson’s Disease”—but hallucinations are part of the Parkinson’s experience.

I warned you in the first sentence that this narrative is written out of sequence, so you’ll have to forgive me if the ending is—anticlimactic.