

The Gift Shop

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The rain blew sideways this cold, dark evening; nothing like the misty droplets that, as a resident of Seattle, I knew well. I had just returned from a foray out into the icy sheeting rain to pick up a few items from the nearby drugstore. I stopped in the hotel bar to order a steak and Caesar salad, sipping a glass of chardonnay while I waited. When my meal arrived, the kind bartender mentioned that I could take the glass of wine with me to my room upstairs.

It had been a long, stimulating but tiring day; I had pushed through it. When I do this, I find I often become dyskenetic. It's as though the adrenaline kick-starts my brain's processing of the dopamine in my blood that I take by alarm, on my phone every three hours. I had DBS in 2008 at the age of 51, 6 years after my diagnosis of Parkinson's disease. I chose DBS mostly because I loved my job and wanted to get back to work as a speech-language pathologist for the local school system, I needed to keep co-parenting two daughters, and because of my brain's sensitivity to medications. Being tired, I began to stagger and lurch, becoming off balance and tripping on my toes. I took a deep breath, brought my shoulders back, stabilized myself, and walked into the hotel lobby. I spotted the gift store, and thinking of my daughters, dropped in to find a souvenir or two.



The proprietor of the gift shop did not greet me when I walked in. My speech was dysarthric, or slurred, my voice flattened as it will when I'm tired or later in the evening. I find my issues with word retrieval worsen when I am in a dyskenetic episode. I asked her about a lanyard as I picked up a shot glass with the presidential seal on it, turned it over to see the price, and put it back on the shelf. But in my clumsy way, I dropped it and it broke. The woman turned to me, pointed to the glass of chardonnay, her disapproval evident in her "tsk, tsk", and the frown on her face.

"Five dollar," she said as she rang it up on the cash register. My cheeks burned in shame. I paid the fine and left the store to head up to my bedroom. I realized she thought I was inebriated just like the guests at my brother's wedding assumed, in October, 2012.

I wasn't. I am learning to advocate for myself, wearing my tulip pin and letting people know about Parkinson's but that interaction troubled me, and troubles me still.

I am younger than the average person with Parkinson's disease. But this is changing. And I have been able to hide the progression (or so I tell myself). But I had to retire in 2010 from a job I loved, not for the motor symptoms of Parkinson's but because I could not cognitively "shift" quickly enough to work with young, behaviorally disturbed children, and because the increasingly demanding paperwork required me to put in extra hours after school. I have worked with many special needs children, their families, and their classroom teachers, so have a toolbox of tricks to help them accommodate their lives to their needs. I knew enough about voice, articulation, swallowing, word retrieval, memory, executive functioning, and nonverbal skills to recognize that I was becoming more like my students than I ever thought I would be.

Parkinson's disease is a disease of the brain, which means it's more than a "movement disorder"; it affects all motor and non-motor functioning. Some of these systems involve large and small motor skills. Others are actions our bodies take that we don't usually have much conscious control over, such as our digestive systems, breathing, and swallowing. Vocalization for speech involves many muscles, such as the diaphragm, lungs, and vocal chords. If any one of these is affected by the neurodegenerative effects of Parkinson's disease, it will impact speech production.



If I don't control my posture (shoulders back), breathing from my diaphragm then my volume is decreased. If I don't very carefully move my mouth; jaw, tongue, lips, then my speech becomes "slurry". I have little control over the perception of my voice sounding "strangled" nor the episodes of pitch breaks (like an adolescent male voice) and I miss my formerly sweet, but deeper voice. I find I am more dysfluent, which I cannot seem to control, but as I hear my voice flattening I work on putting more melody in my voice. As always, I use a gentle laryngeal onset of my vowels to decrease hoarseness and stridency (commonly heard in people who over-use their voices.)

So what can we do as patients to improve our speech? Not all of us have access to adequate resources, for a variety of reasons. First, ask for a

prescription for speech therapy from your neurologist. The American Speech-Language Hearing Association's website is a good reference for information related to speech-language pathologists certified in LSVT, "LOUD" methods. LOUD, or "LSVT" is a specially designed program to enhance the voice and articulation skills of people with Parkinson's disease. It has been well-researched, is quite intensive, and there are follow up groups to help with carryover of new skills to other settings. ASHA (www.asha.org) is also a good source of information for those therapists who provide tele-therapy services, for those of us who may not have access to local speech therapy.

I personally believe that singing is excellent for improving or maintaining vocal skills. Most religious institutions have opportunities for singing in the choir. There are local "Tremble Clef" groups in my area; Google or Bing for your area singing opportunities. Check out Wii "RockBand" for software to karaoke to, if you are homebound. Investigate groups on Facebook to gather more information regarding patient ideas for keeping your quality of life the best it can be.

Keep up the fight! I will cover other strategies I find helpful for language, articulation, swallowing, memory, multitasking, and most importantly, nonverbal communication in subsequent articles.



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