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## Life With Dystonia (page 1 of 3)

By Ellen L. Weisberg, PhD

Dystonia is the third most common movement disorder, next to Parkinson's disease and Tremor, affecting at least 300,000 people in North America. It is a neurological condition that results in sustained and involuntary contractions of opposing muscles, which leads to spasmodic movements, twisting, and abnormal stances. Like Parkinson's disease, dystonia is believed to be due to an abnormality in the basal ganglia of the brain, where movement is controlled.

The symptoms of dystonia first surfaced when I was in the middle of a radio shift, getting ready to record what I thought would be another effortless 30-second broadcast in a string of reports. Halfway through it, the left side of my mouth started twisting inward, making it difficult for me to talk. At the time, I remember wondering if there was something with my delivery style that had-over time- become subtly different... Was my chair too high or too low and I was straining my neck to get to the microphone? Did it have to do with the amount of gesturing I was doing with my hands when I talked?

As time went on, though, the difficulties I was having with my broadcasting increased, and getting the job done comfortably and in a timely fashion was becoming more and more of a struggle. My coworkers thought that maybe I was having sudden "stage fright," or that it was simply stress that was causing this, since my conversational speech away from the microphone seemed normal. It was only when I saw a neurologist that the situation became clearer: I was diagnosed with a "focal dystonia," which targets a specific part of the body and usually afflicts people at mid-life. My condition, "task- specific oromandibular dystonia," causes the jaw to either be clamped shut or held open and is brought on at least in part by repetitive movements. I had been doing two and a half years of daily broadcasting for hours on end, repeating similar phrases and articulating in a way that was different from my regular, away-from-the-microphone speech. I tried to return to broadcasting several times when the symptoms of the dystonia had temporarily quieted down, only to have to quit again when the condition would relapse. The symptoms eventually slipped over into my conversational speech, and there were times they were so debilitating that I thought I'd never be able to hold a normal conversation again.

I had consulted a second neurologist who prescribed Artane, an anticholinergic agent that improves muscle control in Parkinson's patients. After a brief honeymoon, "fool's gold"-kind of experience with the drug that lasted only a few days during which my speech seemed more effortless, the Artane lost its effects. My neurologist also tried administering Botox injections on the side of my mouth where muscles were twisting in such a way as to make speaking difficult. However, it was shortly after the injections that the condition relapsed to the point where I could barely talk at all. Continuing with the broadcasting, on any level, eventually became impossible. At the time I had also been doing part-time research, and because of the difficulties with my speech, I had to schedule one-on-one meetings with my laboratory supervisor as opposed to giving formal presentations in front of my colleagues. I also had to go ... [continue to [next page](#)]



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into the laboratory during off hours to avoid seeing people that would otherwise try to engage me in conversation.

It was frustrating, as well as kind of scary, to admit that western medicine didn't seem to hold any answers. I was told when first diagnosed with dystonia that there currently is no cure, and the treatments that western medicine offer have the drawbacks of marginal effectiveness and patient desensitization with extended use. I had heard positive things about acupuncture from people who were suffering from different ailments, like migraines and back pain, and the need to find something that would bring me relief is what led me to it.

I had been placed on a Bell's Palsy acupuncture protocol for several months, since this was- at the time- the only neurological disorder my acupuncturist was familiar with, and unfortunately one that is characteristically very different from dystonia. I was about to quit the acupuncture since it wasn't bringing me any real benefit, when I asked her if she knew of any protocols used to treat Parkinson's disease- the closest disorder to dystonia that I knew of. Although researchers have not found a direct link between dystonia and Parkinson's disease, there is great interest in some of the symptom crossover, and research groups are actively trying to better understand the overlap between the two movement disorders. Since Parkinson's and Dystonia are both neurological and result in similar signs and symptoms, it was possible that a Parkinson's acupuncture protocol could be adapted to a dystonia patient.

My acupuncturist found a journal article that outlined a protocol that involves both body and scalp acupuncture, and which is used to treat Parkinson's patients.<sup>1</sup> Acupuncture can help relieve symptoms by altering blood hormone levels. In Traditional Chinese Medicine (TCM), Parkinson's and dystonia are believed to be caused by genetics, aging, damage from excessive emotions, faulty diet, and chronic disease. Parkinson's and Dystonia in TCM are seen as an inability of the blood and yin to nourish sinews and vessels, resulting in contraction, stiffness, and rigidity. The liver in TCM is what governs the sinews, and if the blood and yin become deficient, yang can become hyperactive, resulting in liver wind. These disorders mainly take root in the liver, but can lead to more complex presentations such as phlegm accumulation, qi and blood stagnation, and spleen and kidney deficiency. In TCM, you treat the root cause; in this case, treatment would involve settling the liver and extinguishing wind, and the manifestations, such as phlegm, stagnation, and/ or deficiency. One small study, An Acupuncture Protocol for Parkinson's Disease,<sup>2</sup> showed a total amelioration rate of 84.2 percent when scalp acupuncture was incorporated into an acupuncture treatment.

After several weeks of being treated with this protocol biweekly, my speech problems cleared up significantly. With adult-onset dystonia, I was informed that it often stabilizes over time. I do still occasionally feel some discomfort on the left side of my mouth, and tend to have some trouble when I have to project my voice over loud background noises, or when I am doing anything that

puts me into “broadcasting mode,” like reading bedtime stories out loud to my daughter. However, I’m continuing to get bimonthly acupuncture treatments that are more or less keeping the symptoms of the dystonia just ... [continue to [next page](#)]

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enough at bay to make me forget I have the condition much of the time.

Many months prior to finding relief for the symptoms of the dystonia, I struggled to try to keep my mind off of the physical discomfort of the condition, its social impact, and the uncertainty of not knowing if and when the affliction would eventually lift. It was while searching for a new creative outlet after the loss of broadcasting that I had begun channeling my energies into two old passions of mine: writing and illustrating. One outcome was my first published novel, “Gathering Roses.” The book focuses to a large extent on our awareness of life versus death, and how the level of this awareness can influence the way a person views and conducts his or her life. I suppose in this respect, the book mirrors how the (no pun intended) sudden unexpected twists and turns life can take changed the way I look at life and presently live it. It’s made me a little more introspective, and a great deal more spiritual.

I also, with the help of my husband, threw myself into two children’s book writing projects. The personal proceeds for the children’s books, which are now in press, will go toward Parkinson’s and dystonia research. Personal proceeds for the novel, “Gathering Roses,” are going toward the American Heart Association and the American Red Cross, in honor of a friend who passed away from heart disease.

People afflicted with quality-of-life-threatening physical conditions are often forced to give up things that they love. I’ve found that by trying to keep an open mind and an open heart, I can continue to enjoy life in a way that I never otherwise would have thought to. I believe that one can find some light in the darkness if one looks hard enough.

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