

Ellen Weisberg: In her own words Acupuncture helps medical researcher overcome disease and find her voice

By Alan Lecker



Ellen Weisberg, a medical researcher and author, is the subject of this edition's InnerView.

Ellen Weisberg had achieved an incredible balance in her life: An instructor at Harvard Medical School who also performs leukemia research at the Dan Farber Cancer Institute, she also enjoyed writing and illustrating, and even worked as a weather broadcaster for Hometown Forecast Services in Nashua, N.H., where she lives. But the onset of dystonia, an illness similar to Parkinson's disease, threatened to turn her world upside down.

As a result of dystonia, Weisberg lost the ability to conduct any kind of extended conversation, which brought her broadcasting work to a halt and interfered with her ability to work with other medical researchers. After seeking relief through conventional medicine, she turned to an unlikely source - acupuncture. Remarkably, it made progress in easing her symptoms, allowing her to begin her recovery and resume something closer to a normal life.

She has added to her writing credentials with the publication of her book, "Gathering Roses." It appeared first as an online book through Mountain Mist Productions, but is now available as a paperback through Chipmunkpublishing, which donates some of its proceeds to mental health causes. In addition, Weisberg is donating personal proceed toward the American Red Cross and American Heart Association in honor of a friend who died from heart disease. She has also released a geography book, "All About Canada," which she co-wrote with her husband, Ken Yoffe, a pediatrician; proceeds from that book will go toward Parkinson's and dystonia research.

Not only has Weisberg regained her balance; she says she's grown considerably from her experience with dystonia. I started off this InnerView by asking Ellen if she'd tried alternative medicine before the sudden onset of her illness, and how the experience influenced her view of traditional medicine.

Ellen: I didn't have any experience with alternative medicine before trying acupuncture. I had heard good things about it from people who were suffering from different ailments, like migraines and back pain, and the need to find something that would bring me relief - since western medicine was failing me - is what led me to it. It was more frustrating, even kind of scary, to admit that western medicine didn't hold any answers for me. I have a pretty open mind when it comes to things, and I don't feel like anyone can ever be too proud when it comes to quality-of-life-altering afflictions not to venture outside of the box.

I was on a low dose of the anticholinergic drug, Artane, for a while. However, after a brief honeymoon "fool's gold" kind of experience with it that lasted only a few days during which my speech seemed more effortless, the drug 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 my condition relapsed to the point where I could barely talk at all. I could no longer continue with broadcasting, which I loved. As for my other job in research, I had to schedule one-on-one meetings with my laboratory supervisor to go over data as opposed to giving formal lab presentations. I also had to go into the lab during off hours to avoid seeing people that I would otherwise have to talk to.

There currently is no cure for dystonia, only treatments. With adult onset dystonia, I've heard that it tends to stabilize over time, and can even go into remission for stretches. I still feel some discomfort at times on the left side of my mouth, and tend to have a little trouble doing anything that puts me into "broadcasting mode," like reading bedtime stories to my daughter. However, I'm continuing to get bimonthly acupuncture treatments that are more or less keeping the symptoms of the dystonia just enough at bay to make me forget I have the condition a lot of the time.

Alan: What was it like for you as the dystonia developed? Were there times when you despaired that you might never be able to have a normal conversation? How long did you suffer from dystonia before turning to acupuncture?

Ellen: I was in the middle of a 30-second broadcast, and halfway through it the left side of my mouth started twisting inward and making it difficult for me to talk. I wasn't sure what was happening or where it was coming from. I remember wondering if there was something with my delivery style that was 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? Was I having a stroke?

As time went on, the difficulties I was having with my broadcasting increased, and the job was becoming more and more of a struggle. My coworkers thought maybe I was having sudden "stage fright," or that it was "stress" that was causing this.

It was only when I saw a neurologist that I got the diagnosis of "task-specific oromandibular dystonia," brought on at least in part by repetitive movements. Dancers can get it in their arms and legs, trumpet players in their mouths, pianists in their fingers, etc. The condition is most likely genetic - at least 30 genes have been discovered associated with dystonia - and seems to be associated, like Parkinson's, with a lesion in the basal ganglia of the brain.

I tried to return to broadcasting several times when the symptoms of the dystonia would quiet down, only to have to quit it when I'd relapse. The condition eventually slipped over into my regular speech and, yes, there were times it was so bad that I thought I'd never be able to hold a normal conversation again.

I consulted a second neurologist who prescribed Artane, and it was shortly after starting the medication that I looked into acupuncture as another approach. I was on a Bell's Palsy acupuncture protocol for many months, since this was 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 relief, when I asked her if she had any protocols for Parkinson's, the closest disorder to dystonia that I could think of. She found an article that outlined a protocol that involves palpation and needling of areas around the temples that are reputed to be trouble zones - when tender - in Parkinson's patients. After several weeks of being on this protocol, twice a week, my speech problems cleared up. I'm able to talk normally now, after being speech-impaired for months. I still have occasional stiffness on the left side of my mouth, but am finding that acupuncture once or twice a month is helping to keep the symptoms at bay.

Alan: Writing and illustrating became a form of therapy for you. Do you feel they also aided in your physical recovery as well? Did they prompt, in their own ways, a form of inner healing?

Ellen: I've been told that stress can exacerbate a lot of physical conditions - the inflammatory bowel diseases come to mind. I know the same is true for dystonia, and so in this respect, there's a good chance that the writing and illustrating provided not just a creative outlet, but also an outlet for stress that helped the condition to heal over time.

Alan: Did you write "Gathering Roses" while you were suffering from dystonia, or was it written afterwards, and does it reflect in any way your experience?

Ellen: "Gathering Roses" was actually started many years prior to the onset of

Ellen: "Gathering Roses" was actually started many years prior to the onset of the dystonia. But it was after I gained extra hours in the day by losing the broadcasting that I was able to turn my attention back to the book, add to it and revise it, and search for a publisher.

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 does mirror how the - no pun intended here - sudden unexpected twists and turns life can take changed the way I look at life. It's made me a little more introspective, a lot more spiritual.

Alan: You've described Lori Solomon, the main character in "Gathering Roses," as the quintessential underdog. Is that how you view yourself?

Yes, I think this is how I have always viewed myself, and how I continue to view myself. I've been surrounded by people that are colorful and interesting - but difficult. I've found myself in situations that are exciting and challenging - but precarious. There isn't so much ebb and flow in my life as there is riptide and tsunami. While maybe this has made for some "gripping" reading material, it has also made for kind of a bumpy ride. It's my own ride, though, and I fully acknowledge that while some things are beyond my control, I still am the one at the steering wheel.

Alan: How did you become involved with chipmunkpublishing?

Ellen: "Gathering Roses" was first launched as an e-book by the Australian epubliher, Mountain Mist Productions, which I found while searching a watchdog Website for writers called "Preditors and Editors." Lynette King of Mountain Mist Productions acts as a sort of "guardian angel" for her group of artists and writers by showcasing their work and also making them aware of print publishing opportunities. I heard about the U.K.-based Chipmunkpublishing through Lynette, since one of her writers had been offered a publishing contract by them. "Gathering Roses" was picked up by Chipmunkpubishing and the e-book was taken off of the Mountain Mist site. I still, though, keep in touch with Lynette and do card illustrations for her site.

Alan: "Gathering Roses" opens with a quote from Albert Schweitzer, yet the story glides effortlessly into e-mails between various characters. Was this a conscious attempt to blend the old and new, and how would you describe it as a writing style?

Ellen: I did take active steps to blend the old and the new. There's a certain way today's youth are living, in a world colored by the Internet, and leave-nothing-to-the-imagination dress styles, mannerism and music. I tried to preserve the reality so that younger readers might be able to relate to the story. Yet like an old church left standing in between high rises in a city, I found myself interjecting between quips some famous quotes and proverbs, introspection and philosophy. I like the contrast, and I feel that it helps to make certain points and ideas stand out more.

Alan: How would you describe your spiritual beliefs, and were they affected by your illness and improvement through acupuncture?

Ellen: I've become much more spiritual over the past couple of years, after not just being diagnosed with my condition, but also experiencing the death of a young friend and watching

family members get sick. I read Catherine Marshall's "Beyond Ourselves," which described among other things how she was bedridden for several years due to illness, and how faith helped to pull her through. I believe that life throws out afflictions to help guide people to a better place, to make them more aware of the direction they've been taking, and if that direction needs to be changed. I think these afflictions test our faith, and force us to grow. I'd always been in touch with my dark side and thoughts about mortality, but I'm much more so in touch with it now after my experiences over the past couple of years.

© 2008 Many Hands

[ABOUT US](#) | [DIRECTORY](#) | [CALENDAR](#) | [REVIEWS](#) | [INNER VIEWS](#) | [ARTICLES](#) | [CLASSIFIEDS](#) | [POETRY](#) | [HOME](#)