

## A Struggle to Forgive: My Long Battle With Dystonia

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Although I knew that the Americans with Disabilities Act protects employees from discrimination for their disability in the workplace, I worked for two years at my last job before disclosing the nature of my ailment to my supervisor. I waited that long out of fear not of discrimination, but of stigmatization. I was also concerned that my coworkers could be making erroneous assumptions on the basis of my symptoms. I blink and wince frequently and occasionally lose my balance. In 1991, I'd been diagnosed by the director of the Movement Disorders Clinic at McLean Hospital as having a blepharospasm.

When I disclosed my condition to my supervisor, I handed her an issue of the Benign Essential Blepharospasm Research Foundation's monthly newsletter along with a brochure titled *Blind, but With Perfect Vision*. That title accurately describes the first five years of my affliction: my vision remained normal, but I couldn't lift my eyelids to see. After meeting with my supervisor, we came up with a few minor accommodations for me, including lowering the blinds when meeting in her office, for my eyes had become extremely sensitive to light.

The blepharospasm began suddenly during a class I was attending at the University of Massachusetts in Boston. My eyes began to painfully sting and water. Soon, the muscles around my eyes began to spasm, causing my eyelids to snap shut in very painful contractions. I could not lift my eyelids except by temporarily prying them open with a fingertip. The condition forced me to withdraw from college, resign from my residential case management position, give up my apartment, and move home with my aging parents.

What prompted this condition? From 1983 to 1990, in the process of seeking psychiatric care, I was prescribed a medication that belongs to a class of medications called phenothiazines, which have the potential to cause tardive dystonia. My understanding is that, although a blepharospasm can arise under natural circumstances, it also can be a medication side effect, such as in my case. I've also heard that the chances of occurrence increase the longer the patient uses the medication.

I recollect early in my treatment, when I was the most vulnerable, asking my psychiatrist some questions concerning the safety and necessity of taking the medication he had prescribed. I remember his replying in a stentorian tone, "With all my experience and advanced degrees you dare to question me?" And, when I raised similar concerns in a later session, he retorted, "What—do you think you're special, or something?" I felt very scarred by those responses.

During the 1980s, I spent most of an entire, precious year locked in psychiatric wards by that aforementioned psychiatrist,

basically for refusing to take the drug that eventually nearly ruined my life. During that period, I also languished in a day treatment program where medication compliance was strictly enforced. In one instance, the day treatment program director urged fellow consumers to gang up during group therapy and pressure me into taking medication.

I lived with the blepharospasm in my parents' home for several years, and then I stopped taking my medications. By then I had been prescribed a different antipsychotic, but one with potentially the same side effects. I felt I was in a Catch 22 situation: If I complied, I risked more side effects, but if I didn't, I risked a return to a locked ward (1). My mother was terminally ill, and my father and siblings were determined to get me out of the house if I didn't comply soon. After several angry confrontations and with my increasingly delusional and paranoid state of mind, I wound up in a local homeless shelter. I lived there for about a month, during which time my mother died and our parents' home was cleaned up and sold. I was offered a supervised apartment by the local area Department of Mental Health on the condition that I resume taking medication. Given my predicament, I readily agreed.

In the Summer 2011 issue of *Psychiatric Rehabilitation Journal*, Swarbrick and Roe (2) stated, "A handful of recent studies have suggested that nonadherence, rather than simply reflecting 'poor insight,' 'poor judgment,' or 'lack of competency' may often signify a personal choice directed to protect one's participation in valued activities which they perceive medication will interfere with." The article further states, "Decisions to stop taking medication which often held personal meaning of making and carrying out personal choice, were reported to be vital milestones in their recovery process."

During three decades of treatment, I can't recall a single mental health professional who has affirmed my concerns about medication side effects. Even my current psychiatrist calls the data in black box warnings sometimes misleading. When I was released from a state hospital in 2001, my social worker wrote on my discharge summary that I lacked insight.

Year 2001 was my last, and hopefully final, psychiatric hospitalization. I continue to have chronically dry eyes, extreme photosensitivity, and painful, though less frequent, eye muscle spasms. I struggle to forgive the individuals and institutions that coerced me into taking what for me was a harmful medication. I realize that their intentions were mainly good and that it was their job to keep me safe and free of psychiatric symptoms. But this unrelenting irritation that is quite literally "in my face" serves as a constant reminder of what they've

done to me. I'd like to forgive them, so they could see firsthand the fully recovered person I've become.

Since first afflicted with a blepharospasm, I have tried a variety of treatments for it. The most recommended treatment, the one the blepharospasm foundation endorses, is botulinum toxin, which is essentially the same substance that is used to remove facial wrinkles. With a blepharospasm, the purpose of the substance is to paralyze the muscles around the eyes and prevent spasms. The effect of each treatment typically lasts three months, and then the patient must have another series of injections. I found the procedure to be extremely uncomfortable and experienced no significant improvement, so I stopped after a few years. I tried over-the-counter eye drops and gels, but they didn't last long and left my vision blurred. About two years ago, after seeing a commercial for a medication for chronic dry eye disease, I asked my optometrist if I could try it. She wrote me a prescription, and I had almost instant, long-lasting relief. My eyes feel much better, and I'm now able to engage in more activities.

Looking back, I just wish my clinicians had affirmed my concerns about the possible side effects of what they were prescribing. That would have been informative, not coercive, and I would have felt I had made an informed choice (3,4). Every patient now has the right to be fully informed by the prescribing clinician and pharmacist about known side effects. When it comes to many products, including medications, an educated consumer is a safer consumer. I don't wish for anyone to suffer the way I have.

Anyone exposed to direct-to-consumer commercials for new drugs has heard those long lists of possible side effects mentioned while a seductive, bucolic scene plays in the background. Then there is a statement similar to "If any of these symptoms arise, go see your doctor immediately." Those of us who take psychiatric medications need to be more proactive than that. We need to exercise our right to make an informed choice prior to even starting a new medication and not wait for side effects to arise because they might be permanent.

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