

My epilepsy story

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Epilepsia, 55(5):642–643, 2014
doi: 10.1111/epi.12501



I've wanted to be a physician for as long as I can remember.

So I didn't let epilepsy stand in my way. Not when I started having complex partial seizures at age fourteen, nor when I was diagnosed with temporal lobe epilepsy at age 18, or even when the drunken pull of carbamazepine tried to lure me to sleep every day during my senior year of high school.

Throughout college and medical school I enjoyed various periods of seizure control and lack of control, medication adjustments, and a slurry of medication cocktails. The first time I met my new adult neurologist at the University of Wisconsin, he mentioned that I was a surgical candidate. I had right hippocampal sclerosis on magnetic resonance imaging (MRI) and had failed to respond to at least one medication. Too scared to pursue surgery immediately, I opted to continue trying medications while we slowly completed the workup for surgery.

Over the next 12 months, I learned the meaning of new medical words first-hand as I experienced them: diplopia, ataxia, anorexia, vertigo, and fatigue. The harsh side effects of medications made me anxious to find a better solution for my seizures. As a first-year pediatric resident, my struggle with epilepsy was increasingly apparent in the small resident community. A complex partial seizure forced me to stop discussing a patient in the middle of morning rounds

and left the rest of the group uncomfortable and confused. The diplopia that appeared on my first day of taking oxcarbazepine forced me to go home until the side effect wore off. My constant auras were a recurrent reminder that a seizure could appear at any moment.

Although my resident colleagues were supportive and caring during the time leading up to my temporal lobectomy, I could also sense their unease. As physicians, we are trained to care for the sick and support families in need, but we are not trained how to react when one of our own is unwell. This is especially true when the illness involves a neurologic disorder. The common personality traits of physicians have been described in a handbook published by the American Psychiatric Association.¹ Physicians tend to be perfectionists, prefer to be in control, and frequently seek approval.² None of these traits are consistent with the unpredictable life of a patient with epilepsy. The stigma associated with epilepsy is slowly crumbling in the halls of school cafeterias, shopping malls, and everyday life, but still much exists in the medical field. As I fought for seizure control, little did I know that I would struggle most with my future colleagues.

In the spring of 2003, during the second year of my pediatric residency, I had a right temporal lobectomy. The histopathologic evaluation of my hippocampus was favorable, showing "95% sclerosis with surrounding gliosis." Unfortunately, I was seizure-free for only 5 months.

Navigating life as an attending physician with epilepsy has brought both challenges and unexpected rewards. The hormonal changes with each of my three pregnancies have brought generalized seizures—most occurring in the night or evening hours. The continued search for the right medication combination has left me with a new combination of side

Accepted October 30, 2013; Early View publication December 20, 2013.

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effects that shake me to my academic core: a poor sense of direction, difficulty with word recall, and an unusual taste in foods. Still, I keep silent about my epilepsy for fear of being judged by others. A supervisor at a former job approached me after a missed day of work secondary to a generalized seizure. When I revealed the real reason for my absence, she admonished me that “this can never happen again.”

If only I had that much control.

As I have moved forward in my pediatric career, I have gained great respect for the breadth of knowledge that my pediatric colleagues have about children of all ages. From advocating for health care for all children in America to spearheading global immunization programs, the American Academy of Pediatrics has incredible power and fortitude to educate pediatricians and influence health care policy worldwide. One place where we continue to lag, however, is in the education of our patients and providers about epilepsy.

In a survey conducted on primary care physicians and presented at the American Epilepsy Society meeting in December 2012 focused on surgery practices for intractable epilepsy. Nearly two thirds of responding physicians (58% were pediatricians) were unsure if surgery should be considered for patients who fail to respond to anticonvulsant therapy.³ This position is directly contrary to evidence published by Wiebe et al.⁴ in the *The New England Journal of Medicine* in 2001, which demonstrated that surgery is preferable to prolonged medical therapy for patients with refractory temporal lobe epilepsy. Another survey done on pediatricians in Canada revealed that only 34% of respondents knew of sudden unexpected death in epilepsy (SUDEP). Fifty-seven percent of respondents to that same survey knew that children with epilepsy were at risk for sudden, unexplained death.⁵ This gap in knowledge is only part of what creates the stigma that remains.

For me, although epilepsy is often a source of frustration, anxiety, and near-despair, epilepsy in some ways has been my greatest teacher. As I have journeyed through my medical training and treatment, my experiences with vulnerability, humility, and uncertainty have taught me how to be a

better doctor. I have learned to accept the unknown, relish in my small successes, and step out of my comfort zone to touch patients' lives in the ways that soulful physicians have touched mine. I have learned that success as a physician or as a patient does not always come from textbooks or scholarly articles, but instead from looking beyond disease into a hurting soul. I have accepted that although epilepsy may plague all of my days, my distinction as the eternal patient may help balance my roles as doctor, patient, and mother.

And I continue to pray that through education, awareness, and advocacy, increased research dollars to fund projects like yours may one day lead to a cure.

DISCLOSURE

I declare no conflicts of interest. I confirm that I have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

DISCLAIMER

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