

My name is Brian. Even though I have been diagnosed with epilepsy for over 65 years, I have been able to find a life filled with happiness. I had a successful career as an attorney doing a lot of interesting things and being involved in many important cases.

My first memory of epilepsy is remembering waking up as a young boy in the Chelsea Naval Hospital. Both my hands and feet were tied with pieces of cloth to the sides of a medical bed. It was scary! I had experienced a generalized tonic clonic seizure on New Year's Eve in 1961 in the setting of emotional distress. I was diagnosed with "grand mal" epilepsy, which was characterized by full body convulsions. I was placed on Dilantin and Phenobarbital. Several years later, Valium was substituted for the Phenobarbital. Back in the 60s, a lot less was known about epilepsy. Then there were only two types of epilepsy: grand mal seizures or petit mal seizures. Now there are over 30 types of seizure classifications.

When I was child I had many EEGs, which weren't pleasant and were scary. I had to take medicine three times a day. Part of my lunchtime recess was spent leaving my classmates to take my medicine. Besides sleepiness, another side effect of my drug regimen was severe bleeding of my gums. My seizures were grand mal or full body convulsions (now known as tonic-clonic seizures). In retrospect, I was fortunate in that I had relatively few convulsions.

I went through childhood experiencing a lot of stigma and misinformation. For many years, a number of classmates knew of my condition and so I felt very weird, especially since I probably experienced minor seizures in their presence. Also, due to widespread misinformation, I was not allowed to engage in a lot of boyhood activities, such as climbing trees, playing contact sports or even pickup football with neighborhood kids.

Myths about epilepsy abounded in my childhood years: "restrain him when he is convulsing", "don't let him swallow his tongue. . . put something in his mouth" (it's physically impossible to swallow one's tongue, which I did not learn until I was well into my adulthood), "something's wrong with his brain"; some people thought epilepsy was a mental illness.

Epilepsy became less stressful as I matured into adulthood and my tonic clonic seizures disappeared. As my brain developed, epilepsy became more medically, socially and emotionally manageable.

While many young people grow out of their seizures in late teenage years or twenties, I continue to experience "breakthrough " complex partial seizures from time to time. Several times over my 50+ years I was unable to drive while my medicine levels were adjusted.

Interestingly, my earliest contacts with EFDE came in 2005, not seeking information for myself, but for others. First, in my role as an attorney when I consulted Dr. Chuck Bean for assistance in helping a client. Later that year I consulted a former executive director for information about Women and Epilepsy when I was the Chairperson of the Health Committee of the Delaware Commission for Women. I am so glad that I crossed paths with EFDE twice in 2005!

Not only have I learned a lot about epilepsy, I have been able to be an advocate for those with epilepsy and their families. Since then I have been able to serve as an EFDE Board member, Board President and Vice President, as well as Advocacy Chair. Now I have the pleasure of serving on EFDE's Professional Advisory Board.

Epilepsy has been a lifelong challenge—but it has also shaped my resilience, my perspective, and my commitment to helping others.