

Carpe Diem – Seize the Day Blog

Editor's Note: Content presented in the Carpe Diem – Seize the Day Blog is for awareness and informational purposes only, and it is not meant to be a diagnostic tool.

What is the most challenging thing about having epilepsy? That is a hard question to answer as it depends on who is responding to the question. If you said seizures, having seizures in public, around your friends and family, or the side effects of your medication your answer would be correct. Epilepsy is a very individualized disease. What is a challenge for one person may not necessarily be a challenge for another person. To be certain and to state the obvious, there is nothing easy about having epilepsy.

Seizures and the side effects to medication are visible to everyone. However, the one challenge that I want to talk about focuses on dealing with the stigma that is attached to having epilepsy. Each day as I review the numerous epilepsy support groups that I follow on social media, I see comments about how people must deal with and endure the stigma of epilepsy. The anguish that those with epilepsy must go through because of this stigma may hurt worse than the seizures or the side effects of their medications. The stigma attached to epilepsy can lead to a loss of status among their peers. When one is newly diagnosed, regardless of age, there are huge concerns about the stigma attached to epilepsy.

Stigmas that accompany epilepsy may come in many forms. There are people who still believe cruel and untrue myths about epilepsy that make it seem as if the condition is someone's fault or a punishment. Not being knowledgeable about epilepsy leads to the exacerbation of these myths. Some people still believe that epilepsy is a communicable disease and can be caught. Stigmas attached to having epilepsy can cause great unhappiness. The stigma surrounding epilepsy can isolate people with epilepsy from mainstream life. Epilepsy remains a formidable barrier to educational opportunities, employment, and personal fulfillment among older children and adults. Despite the advances in treatment and medications to control seizures, epilepsy continues to evoke negative stereotypes and fear. Many times, friends may avoid associating with a person with epilepsy because they are afraid the person may have a seizure, and they will not know what to do or how to administer seizure first aid. Most people have never seen anybody have a seizure, and they become frightened when witnessing someone having a seizure. To paraphrase Dr. Orrin Devinsky, director of the Epilepsy Center at New York University he said something to the effect that the feeling, for a lot of people, is that epilepsy does carry a lot worse stigma than cancer or H.I.V. At some level, society needs to wake up and realize it is just another neurologic disorder. As Tiffany Kairas once said, "You can put me down, but you can't take me down."

Stigmas come in all shapes and sizes. Words might be the most stigmatizing of all. Makaila Aarin once said about being called an Epileptic, "When I hear this word, right away, I feel judged. I feel stigmatized. I feel different. It stings, and it sounds wrong. Being called an

epileptic signifies that the speaker is separating me from him or herself. To me, the person is separating me from others he or she knows. I am no longer “one of them.” I am no longer an equal. I am someone with an invisible illness that keeps me out of the “normal” category in the eyes of peers. Once I am called an epileptic, I have a label. I am saddled with a name other than my own. I question my worth as a human. I am not an epileptic. I have epilepsy. I am a woman with epilepsy. I am more than my seizures. I am more than the side effects my medication causes. I am a sister and a daughter, I am an educator, I am a dog mom, I am a painter and a poet. I am more than an epileptic. While not everyone understands how much a label can hurt an individual, I know in my heart that I am not defined by my epilepsy.” Using a person-centered approach is one strategy that can be used to reduce the stigma attached to epilepsy. The correct protocol is **Person first, then the disability. Makaila has epilepsy.** She is not an epileptic. Makaila should be referred to as a “person with epilepsy.” A disability should not define the person.

The best weapon that Epilepsy Alliance Ohio has in fighting the stigma attached to epilepsy in our communities is through education and training. The mission of Epilepsy Alliance Ohio is one of dedication to supporting those impacted by epilepsy in local communities by confronting the spectrum of challenges created by seizures. Stigmas are certainly one of the challenges that those with epilepsy face. Through our education and awareness programs, we want to educate those in our communities to work against the stigma attached to those diagnosed with epilepsy. By providing awareness about the person centered approach and educating people in our community about epilepsy and seizure first aid, Epilepsy Alliance Ohio works to empower people impacted by epilepsy to seize hope every day and reduce the stigma connected with epilepsy. **Know Epilepsy – No Stigma.** Rest assured that Epilepsy Alliance Ohio will help those with epilepsy fight through this. We will fight through this together!

Editor’s Note: The Carpe Diem – Seize the Day Blog will be distributed and posted weekly.
Always remember – **CARPE DIEM – SEIZE THE DAY!**

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