



Gain Control of Your Seizures: Strategies for Coping

by Susan Brown

Edited by Robin Owen, Managing Editor

Like some people with seizures, I used to get a warning (some call it an aura) before my seizures occurred. Over time, I learned how to use the warning to help ease the impact and keep myself safer during the seizure.

My epilepsy is controlled by medication now, but for most of my life I had absence seizures and nocturnal (night-time) convulsive seizures (known as grand mal by us oldies and as tonic-clonic by younger generations). Over the years, I gradually developed relaxation and focusing techniques that lessened the embarrassment, severity and trauma of my seizures. For those of you who may be able to apply these techniques, I share my story here.

My absence seizures were very frightening; a bit like suddenly being drunk, with my mind not controlling my body properly, although without the “benefit” of actually being drunk and thus not caring! If you are a driver, the experience could be compared to going up a steep hill in a queue of traffic with an automatic transmission and suddenly finding yourself in a manual car needing clutch control, handbrake and gear changes! It was alarming and disorienting to feel such a lack of control.

For many years, I struggled with absence seizures and became aware of particular warning signs; first, a huge adrenaline rush, followed by a sense of foreboding, and then by a gradual or sudden disconnection of my mind from my body. I had no idea when they would occur and it felt like a lot of time passed before they wore off. Because I am somewhat deaf, my parents simply thought I was daydreaming and thus, could not hear them. I did not communicate what I was experiencing because I could not explain what was happening. It was easier to ignore these events and carry on.

I accepted and expected these mysterious occurrences as a part of my life for a long period.

But, eventually, I learned to fear them, as other students looked at me oddly after such times and teachers shouted at me for being inattentive. Due to the escalating fear, the adrenaline rushes became stronger, which, in turn made the absence seizures worse. Every bit of my consciousness was focused on just hanging in there and trying to get a grip on what was happening. It really felt as if my mind was caught within an alien body that it had absolutely no control over. I did not know how to work this apparatus—my body.

When I was about seven years old, I was getting ready for Sunday school, on the floor tying my shoe laces. As I grabbed the laces of one shoe, a sudden absence seizure hit me. I didn't want my parents to notice and scold me for daydreaming. I observed my hands moving and wondered if I could make them do what I wanted. For the first time, I became interested in trying to do something instead of being consumed by my fear. I tried to focus on how to make my hands move. It was an intense and complex effort; I have since developed a sense of awe about all the complex activities we do routinely and automatically. I could sort out that I was trying to tie my laces and although I did not succeed, I found myself engrossed with attempting to control my thoughts and movements “manually,” and the absence seizure seemed shorter than normal.

It took many years of practice to overcome that initial jolt of fear that always occurred before and during absence seizures, and to train myself to focus and continue what I had been doing before the seizure began. Walking is one of those things that we take for granted, we do it automatically, often while doing or thinking about other things. Yet it requires a great deal of mental and physical coordination of actions. During an absence seizure, while standing baffled as to why I couldn't make the muscles in my legs walk, I realized that if I shifted my weight onto one foot, it was possible to move. This I achieved by

leaning slightly to one side, then, using a swinging action I was able to make my other leg move. Since the seizures were brief, I could resume walking. Once begun, it was easy, but I still had some difficulty around corners!

I found that by learning how to focus during an absence seizure, they seemed shorter in duration and frequency. I was able to continue without other people being aware I was having one. Eventually, the absence seizures became a minor inconvenience, with only the occasional seizure being strong enough to really slow me down. After a change of medication, I found that my absence auras now included a tingling sensation in my right hand. Firm pressure and rubbing my hand helped ease this and sometimes prevented the absence seizure altogether.

I was fortunate that my tonic-clonic seizures were always at night, although this did cause a few problems initially. I would wake up abruptly with a huge adrenaline rush, next a sense of foreboding, and then my body would start to convulse. It was incredibly painful and I would try to shout for help. I experienced increasing ringing in my ears and the pain would reach such a point that I eventually passed out. While few people with convulsive seizures are conscious during the seizure, I tended to remain conscious and thus, aware of the pain. Again, I could not explain what had happened, and so was reprimanded for wetting the bed. I was utterly terrified of these occurrences and dreaded going to bed. When I was young, the effects often wore off before I got up in the morning, but as I grew older, I found I had a terrible headache for a few days afterwards, along with sore and aching muscles due to the intense contractions.

My seizures were not diagnosed until I was thirteen. The anticonvulsants prescribed caused an allergy to metals and my schoolwork suffered. I learned to log my seizures and found that they were seasonal, spring and autumn to be precise. I grew to dread those times of the year.

As my sense of control over my absence seizures improved, I began wondering what, if anything, I could do about the tonic-clonic seizures. I knew I could not stop them and trying to get out of bed was not feasible. Was there anything about my techniques for coping with absence seizures that could be applied to coping with my tonic-clonic seizures? Finally, it sunk in that the things they had in common were the

apprehensive feeling and the adrenaline rush. Having found that controlling the fear worked in reducing the impact of the absence seizures, I wondered if I could do the same in a convulsive seizure. The problem was that mine were so infrequent, so when they did occur it was a shock and I had difficulty responding in time.

The answer came in a roundabout way. I had very bad headaches and the doctors tried changing my medication. Sodium valproate triggered four seizures in two months combined with chronic sickness. Carbamazepine caused indigestion, but one big bonus was that I did not lose control of my bladder—wonderful! Then I was put on Epanutin (phenytoin). I was not informed that there could be any major change in my seizures and after twenty-two years of nocturnal seizures, it was a huge surprise to finally have a seizure during the day.

The only positive aspect while trying all these different medications was, ironically, an increase in seizures! It took many years, but I gradually retrained my thinking. When a seizure started, I learned to relax my mind, despite the seizure. Although I could not prevent them, they became much easier to deal with and were not quite as painful because I deliberately stopped myself from tensing—despite the shaking and pain, which still caused me to pass out at some point. I became able to be aware, grasp what was happening, and remember to try my method. It was incredibly challenging to try and relax my mind and body. At these moments, I would lie shaking, and try to imagine a blue sky. Then, I would “cut and paste” different shaped clouds into it. The only thing that seemed wrong was that my clouds, for some weird reason, were always pink bunnies!

After the first daytime seizure, my medication was revised again at my insistence. I lost my driver’s license, but fortunately not my job. It was four years before I was able to drive again. Thankfully, I have now been seizure free for seven years. Living with epilepsy has been a struggle, but I can’t help but think that the coping strategies I’ve worked to develop will be assets to me in the other struggles I encounter.

Susan Brown jointly ran a self-help group for people with epilepsy and set up a free newsletter service for a hearing organization while she was working and caring for infirm relatives. Currently, she supports students with disabilities and is training for proofreading and editorial work.

From the Editor of Epilepsy.com

What are the lessons for others? First, pay attention to whether you have a warning (aura) prior to your seizures. It could be an adrenaline rush, a strange feeling, a loss of control or a variety of other sensations. According to the doctors of epilepsy.com, the table below lists some common auras.

Table 1: Common warnings (auras) of seizures

Deja vu (a strange sense of familiar surroundings)
Body heat or flushing
Hair standing on end
Sudden sweating for no clear reason
Tingling rising through the body
Sudden stomach upset
Unexplained fear or panic
Inability to speak or understand
Ringing in the ears
Visions of colors or shapes
Bad smells or tastes, like something burning
Spinning/tilting sensation
Brief loss and return of awareness
Uncontrolled twitching of the face or limbs
Sudden numbness of face or limbs
Sudden rubbery legs

Not everybody with seizures has an aura, but if you do, try to use it as a cue to do something. Sit down and get yourself in a safe position. Try to control your fear, distract yourself or change your emotional state. If your seizures happen when you are mentally drifting or drowsy, try to wake up, perhaps by doing mental activity or pinching yourself. Experiment to find something that might work for you.

Lessons Continued

By Sandra Cushman-Weinstein

Many children and adults that live with epilepsy learn to fear their seizures and worry about their loss of control. When we become afraid, it is natural to become tense, hyperventilate, and feel our heart rate increase. Once fear takes over, it is easier to lose control and even begin to panic. Yet, there are strategies that can help reduce our fears and increase our sense of control. The first step is to know your seizure type and recognize the signs or behaviors related to your seizure(s). Once you know your seizure type, begin to pay attention to your experience. Over time you can learn to recognize the changes you feel before, during, and after your seizures. If you have auras, acknowledge your auras as a warning sign. When the aura occurs, as with any warning sign, you have a choice. You can choose to prepare yourself and take control of your fear or allow your fear to take over. One approach for gaining control of your fear is to learn to relax and focus. Learning to relax can involve training yourself to use diaphragmatic breathing and visualization. Sometimes meditation or biofeedback can be effective approaches for learning to relax. When seeking help, look for someone you are comfortable working with, who is experienced with relaxation techniques and understands seizures. Resources are available in your community. If you have questions, let us know at epilepsy.com.

Sandra Cushman-Weinstein, a licensed physical therapist and clinical social worker, is the Director of Camps and Services, in the Division of Neuroscience and Behavioral Medicine at Children's Hospital, where she develops programs and runs camps for children with epilepsy and other chronic neurological disorders and their families. As a psychotherapist, Sandra has spent years training peer counselors and parent advocates and maintains a clinical practice specializing in children, teens, and adults diagnosed with epilepsy. Her research focuses on adaptive coping, parenting stress, resiliency and quality of life.