How Getting a Vagus Nerve Stimulator — and a Refocus on Helping Others — Turned My Life Around

by Deirdre P. Floyd

Editor's Notes by Robert S. Fisher, M.D., Ph.D., Editor-in-Chief of epilepsy.com

Edited by Robin Owen, Managing Editor

Nineteen years ago, I lost my job because I was having about forty-five seizures a month. I was devastated, and needed something to fill the place left by not going to work each day. My doctor suggested I volunteer for The Epilepsy Association of Nova Scotia (EANS). Through various projects with EANS, I began helping others to cope with their epilepsy—and discovered a whole new purpose to living. Then, twelve years ago, I became the first female patient in Nova Scotia to receive a vagus nerve stimulator (VNS), and this has helped me gain control over my seizures and my life.

I was diagnosed approximately thirty-three years ago with partial seizures, and for many years my seizures were relatively controlled. In my early thirties, however, my condition worsened significantly and so did my quality of life. The seizure frequency became intolerable, and various medications I tried either didn't work or had side effects that were too sedating and made

me feel miserable all day. Like many others with epilepsy, I had a difficult time trying to find a balance between reasonable control of seizures and keeping side effects at a tolerable level.

There were times I chose to accept having more seizures rather than feel the discomfort of the side effects of the drug I was taking. I call epilepsy a "designer condition" since the treatments for epilepsy must really be tailored to your seizure frequency and overall lifestyle. Each person has to decide upon acceptable (or as acceptable as possible) trade-offs between the limitations and effects imposed by medications and those caused by seizures. Working with your doctor as a team can really make a difference. I always kept an accurate daily record of my seizures—a seizure diary—and reviewed it with my doctor at all appointments. For me, it really helped determine which changes of medications seemed to help and which didn't. You can find out more about epilepsy.com's seizure diary at http://www.epilepsy.com/seizurediary.

In 1991, I was assessed for epilepsy surgery, but I was not a surgical candidate.

Editor's Note: Surgery here refers to the type of an operation to remove the portion of the brain (called the seizure focus) that gives rise to a person's seizures. To be a candidate for this type of surgery: 1. seizures have to always or almost always come from one location in the brain; 2. that location has to be identified by medical tests; 3. the seizure focus cannot be in a critical area of the brain where removal would cause major impairment; 4. the patient has to be physically and psychologically in shape for major surgery. Not everyone with uncontrolled seizures meets these criteria. VNS surgery is of course also a type of epilepsy surgery, but much less intense. On the other hand, brain surgery sometimes can cure epilepsy; VNS implantation does not cure, but just improves epilepsy.

My condition was not evaluated as one that would benefit from neurosurgery. I lost my job as a ward clerk in a local hospital in Halifax when the seizure frequency was at its worst. I was having about twenty-one simple-partial and about twenty-five complex seizures a month. For me, as for most people, having a job is more than just get-

For me, my seizure diary really helped determine which changes of medications seemed to help and which didn't.

ting a paycheck; it's a fundamental component of who you are within your community. When I was eventually able to transition to my role as a volunteer at the Epilepsy Association of Nova Scotia, it gave me the satisfaction of helping others that share a common purpose.

Approximately twelve years ago, I was one of eight patients selected in Nova Scotia, Canada for a pilot project of the vagus nerve stimulator (VNS). I was the fourth patient and first female in Nova Scotia to get one. This was one of the projects implemented for the Epilepsy Program with funding provided by the Foundation of the QEII Health Sciences Centre in Nova Scotia. After the pilot project was completed, the plan was that five devices per year would be purchased, so the VNS treatment would be available for patients who had tried many other options without success.

Editor's Note: Good candidates for VNS are those who do not respond adequately to seizure medicines or have intolerable side effects from the medicines. They have to be willing to undergo a minor, but still surgical, procedure with some risks. Frequent visits are required to turn up the stimulation current.

In Canada, access to health care is mandated at the Federal level, and medications and devices for treatment are approved by Health Canada but the funding to provide the services comes from each individual province, with some support provided by transfer payments from the Federal government. My surgery and all follow-ups with specialists are covered by the Nova Scotia Department of Health. I did not pay anything directly since Canada's tax system covers the cost of health care, including surgeries like this one.

Editor's Note: In the United States, Medicare, Medical Assistance and many private insurance companies will pay for VNS implantation, provided that the payor is convinced that their customer is a suitable candidate. There can be co-pay charges.

The surgical procedure for implanting the device began with the creation of a small pocket under the skin above the left side of my chest. The device, which looks much like a pocket watch, was placed in this pocket. The surgeon then used a tunneling tool to feed the device's wire under the skin up to the neck area, where he made a small horizontal incision to wrap the delicate wire

with a coil on the end of it around my vagus nerve.

Editor's Note: You are asleep with general anesthesia while this is being done. At the end, everything is under the skin, with no loose wires or devices protruding through the skin. There is a small bulge and scar on the chest under the collarbone and a small scar on the neck.

The signal of the device piggybacks along the vagus nerve to the brain to change the brain's electrical activity in a way that makes it harder for a seizure to get going. In addition to these implanted parts of the VNS, there is also a magnet that comes with the device. The magnet is used when you have an aura—a warning signaling the possible onset of a seizure—and wish to activate the device by swiping it with the magnet.

Editor's Note: Using the magnet is an extra bonus for people who find it helpful to turn stimulation on right at the start of a seizure. But it is not necessary, because the device turns on and off automatically on a programmable clock cycle, typically thirty seconds on and five minutes off. That usually is enough to benefit the seizures. Many people cannot use the magnet, because they are not that functional at the start of a seizure.

After the initial implantation, the device was turned on. I had to wait three weeks for the incision to heal before my doctors began to turn up the settings. They gradually adjust the settings for the device—in the same way you would increase the dosage of a medication—by using a device that looks a lot like a Palm Pilot now, although for the first implant it was a laptop computer with a programming wand that was placed over the area above the chest where the VNS device was implanted.

Editor's Note: Starting stimulation usually is with 0.25 mA (milli-Amperes, a measure of electrical current). Every few weeks the device is turned up by 0.25 - 0.5 mA until seizures are better or irritation in the throat or to breathing is a limiting factor. Rarely is the current turned higher than 3.5 mA.

It is turned up very gradually since one possible side effect—if it's turned up too quickly—is throat pain or a slight cough. I experienced a loss of volume in my voice when the VNS would begin stimulation. It would only last a minute, and my understanding is that because the wire on the vagus nerve is close to the vocal cords, loss of volume is a normal side effect. Gradually, I adjusted to this and it wasn't a problem for me. The implant was set initially to come on every five minutes. The handheld magnet was set to change the activation to one-minute intervals. The doctors adjusted my VNS device for rapid cycling, based on feedback I submitted once the device reached its optimal setting. Rapid cycling means that the VNS device is set to come on more frequently. It can be every twenty seconds, like my setting, or any interval the doctors believe will disrupt the seizure activity.

As a person with epilepsy, having a positive attitude and focusing on what you can do really makes a difference.

Editor's Note: Of course, faster cycling means shorter battery life, maybe dropping it from, say, five years to two years (see below). The device has readouts to tell when the battery is getting low. When the battery is low, the stimulator in the chest has to be replaced, since it is all in a sealed unit. But the wire around the vagus nerve and the connecting wire can stay in place to be plugged into the new stimulator.

I noticed after the first implant that I was dreaming more. Prior to the implant, I would wake up feeling really tired, as if I had not rested. When I started to dream more, I contacted my doctor who in turn contacted the company. I found out that since the device is on all the time, it alters a person's sleep pattern, especially REM sleep (the term used for the dream state—rapid eye movement). It's not unusual for people to feel more energetic and refreshed in the mornings.

Prior to the surgery, I had been given materials and videos to review that outlined the procedure. I was interested to know whether the device would interfere with airport security systems, since my husband and I like to travel. I do carry a doctor's letter in case an explanation is required, but it has not been an issue thus far. As for dental cleaning, a sonic cleaning tool for scaling my teeth cannot be used because it's on the same frequency as the VNS device and would cause damage to it. As for MRI scans, only a scanner with a transmit and receive head coil can be used and the VNS device must be turned off since it will damage the device, and then turned back on after taking the MRI. I cannot have a body MRI, even if the device is turned off. I realized quickly that it was important to keep the magnet away from my credit cards since it's powerful and can erase data on any cards that have a magnetic strip. On the positive side, if it's in my pocket I don't seem to lose my change since all the coins stick to it. I was advised always to have my epilepsy specialist speak with any other doctors I consult with or receive treatment from. Generally speaking, it's been a learning experience, but when in doubt it's essential to check with your doctor.

I went to follow-up appointments every three months, and I submitted seizure calendar records monthly. The number of simple-partial seizures I experienced was still high—sixteen or so per month. However, it made a difference for me that I did not have to use Ativan to stop the clusters of com-

plex-partial seizures. The magnet replaced the Ativan without side effects. The number of complex-partial seizures was reduced to around ten or so per month. This meant that I wasn't nearly as tired as I had been before the implant, and I didn't have to take breaks from carrying out my regular activities. I felt that I finally had some control over my seizures with the VNS device as my safety net.

The first device's battery lasted for approximately three years, and then I was reassessed for implantation. I was not worried about the cosmetic aspect of the implant because the scar is not very noticeable.

Editor's Note: Some people form bigger scars than do others.

The surgeon agreed, based on the data, to do a second implant. This was done as an outpatient procedure. They just open up the pocket in the chest area, unplug the old device, and replace it with a new one. Even though the battery life has increased for me each time, my doctors always change the battery two years prior to the expected expiration date of the device. This is mostly due to the rapid cycling pattern that is used. Every time I visit my doctor, the device is checked to monitor the battery life.

Editor's Note: About half of people using a VNS for at least a year believe that it has significantly improved their seizures. Some studies find even higher rates. VNS also is FDA-approved for treating depression, which is common in people with epilepsy. If the device does not work, it can be removed in a minor surgical procedure. Usually, the wire wrapped around the vagus nerve is left in place and just clipped, to avoid tugging on the nerve. The extension wire and stimulator are removed.

I am on my third battery and I take only one medication now. I have approximately twelve simple-partial seizures a month and about five complex-partial seizures. I submit monthly reports to my specialist, but I now see him only once a year. He reviews my reports and although it has not been necessary for me, additional appointments would be booked if need be. I know the VNS device doesn't work for everyone, but for me it has helped me to have control of my seizures rather than my seizures having control over me. I am not afraid of tasks that previously troubled me, and since the magnet helps me stop the seizures, my lifestyle is close to what it once was.

Editor's Note: Complications can occur with the implant procedure or with stimulation. Some people have had infections, breathing problems or heart irregularities: the relation to the stimulation is sometimes uncertain. Ultrasound and diathermy (used to relax muscles) can be dangerous with a VNS in place.

As a person with epilepsy, having a positive attitude and focusing on what you can do really makes a difference. I am now Presi-

dent of Epilepsy Nova Scotia, which is the Global Partner/ founding Agency of March 26 Purple Day for Epilepsy Campaign. As President of EANS and Global Partner for the Campaign, I find the volunteer work, along with the people I meet, very rewarding. I work closely with Debbie Josephs, Executive Director, of the Anita Kaufmann Foundation/ Global Partner for Purple Day in the United States to develop more initiatives world-wide to encourage others with epilepsy to be open about their seizures. We all share a common purpose: to educate the public about epilepsy and help each other in any way we can.

Deirdre Floyd lives in Halifax, Nova Scotia, Canada with her husband and two cats. She loves participating in different roles that include media relations, volunteer coordination and as a member of production crew for televised shows, festivals, and events for charities including epilepsy. She is President of The Epilepsy Association of Nova Scotia and serves on the Board of Directors for the Canadian Epilepsy Alliance which consists of a Canada-wide network of epilepsy agencies that promote education and awareness. She is a freelance make-up artist and sometimes works as a background performer in movies that are filmed in Nova Scotia. She is co-chair of the Purple Day for Epilepsy Global Campaign and during the twenty years of her volunteer service she has met some wonderful people who have taught her lots of new skills.

In Previous Issues

Issue 1

- International Travel with Epilepsy
- Video-EEG Monitoring: In Preparation for Possible Epilepsy Surgery
- Choosing Epilepsy Surgery: Undergoing a Temporal Lobectomy
- The Moment of Empowerment: Thoughts from a Parent
- The Americans with Disabilities Act Amendments Act…
- Gain Control of Your Seizures: Strategies for Coping
- How Patients and Health-Care Providers Can Improve the Epilepsy Clinic Visit Experience

Issue 2

- How to Get Pills into a Patient Who Can't Swallow Them
- Managing Your Antiepileptic Medications for Cost Effectiveness
- Surviving a New Diagnosis of Epilepsy
- Eight Years on the Ketogenic Diet: How a Grown-Up Took the Keto Plunge
- Understanding Your Health Insurance Options: A Practical Overview…
- Getting and Keeping a Job in a Recession

Issue 3

- When an Epilepsy Doctor has an Epileptic Seizure
- Seizures Triggered by Video Games: Underestimated and Undiagnosed
- Learning to Use Humor as an Epilepsy Coping Skill
- General Principles of Pharmacology for Epilepsy Patients and Their Caregivers
- Exercising and Playing Sports Safely: Guidance for People with Epilepsy
- Epilepsy and Self-Confidence