

KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

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THE ART OF LIVING

"The Tree That Reminds Me" by Rhonda Zimlich

"The Dissection of Joan Giles" by Kelsie Bennett

"Kathryn the Great" by Tim Campbell



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Kaleidoscope, beginning in 1979, pioneered the exploration of the experience of disability through the lens of literature and fine arts. Fiction, personal essays, poetry, articles, book reviews, and various artistic media including two-dimensional art, three-dimensional art, drama, theater, and dance are featured in the pages of various issues.

This award-winning publication expresses the experience of disability from a variety of perspectives including: individuals, families, friends, caregivers, healthcare professionals, and educators, among others. The material chosen for Kaleidoscope challenges stereotypical, patronizing, and sentimental attitudes about disabilities.



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GOOD VIBRATIONS

NANCY J. FAGAN

I wake at three in the morning, or thereabouts. I know the general time because my neck is vibrating. Every night, while I dream, my device fires during a randomized minute somewhere in those wee, predawn hours. If I sleep on my left side, the movement is startling and foreign, despite the many months the compact bullet of energy has rested deep against my vagal nerve, adjacent to my carotid artery. It does not wake me—that’s my busy mind instead. My device, a vagal nerve stimulator, has released me from the throes of pharmacology costing thousands of dollars in medication each month, millions over a lifetime. More importantly, it has relaxed the grip rheumatoid arthritis has held on my life for over thirty years.

* * *

Rheumatoid arthritis (RA) affects over one million people in the United States alone. RA is not the same as osteoarthritis which naturally occurs with age or after joint trauma. I get the confusion—they both cause joint pain and swelling. But RA brings a bonus: it is a disease that leaks from the joints through the body to the organs. It’s autoimmunity at its finest, a body attacking itself in a fit of rage, leaving erosion in its wake.

My husband’s friend gave him an article about using vagal nerve stimulators as an experimental treatment for rheumatoid arthritis. The preliminary results were hopeful. “Read this,” my husband urged, his voice filled with optimism. “Something new.”

I rolled my eyes and scoffed. “Everyone has the thing that will cure me.” I thought briefly about the pleas from well-meaning friends and family to try emu oil, gin-soaked raisins, or a line of natural products that would have cushioned my former dental hygienist’s pockets with profits from their sales. I received a recommendation from a nurse practitioner to switch to organic meats. She had no idea I had been a vegetarian for nearly fifty years. I had, long before my husband came to me with the heavily thumbed magazine, given up on miracles.

“Read it, please?” His tone was colored with the good, the bad, and the awfully ugly that over forty years of marriage to a person with a chronic illness had brought. He’d seen me at my worst and suffered alongside. The least I could do was read about the treatment.

The article drew me in immediately. It was printed in the magazine section of a well-known publication, with science to back it up. I reached out to the company that manufactured the stimulators and corresponded with them for nearly seven years, outlasting a variety of their staff members and physician leads who moved to other jobs or retirement. I decided to volunteer for their next clinical trial. But they needed funding and government approval, and I would have to qualify for the study, go off my effective biologic medication for months, and undergo neurosurgery. There was a fifty-fifty chance of sorting into the control group where I would not receive therapeutic stimulation for the first three-month phase of the trial. My mind tumbled with the decision.

When the invitation to apply to the official clinical trial appeared in my inbox one day, I accepted.

When you have a chronic disease that is hidden and you don't complain about it constantly, people assume you are fine. After thirty years of adjusting my life to suit the disease, people see the public me, not the patient. Not my early to bed days, afternoon naps, or the strain of folding laundry. They can't feel my ankles burning through the night despite medication and ice packs. No longer do I start the day at 5:00 a.m. in the gym for an hour on the stair-stepper before a twelve-hour nursing shift. Instead, I walk. I started slow. Five steps, then ten, and a few more each day until I got to one hundred. I consistently go one mile now, at least on weekdays. I had tried one drug after another and sometimes three at once for months, even years, until my team came up with an effective treatment that had tolerable side effects. One that allowed me to engage with the outside world. One that provided moderate relief and rest. The curated combination of drugs also gave me low platelets, dwindling white blood cells, and squamous cell skin cancer. And only the inner circle of someone with a forever illness sees the effect of its chronicity on a spouse, a dear friend, or a child. My body is hard to live with.

* * *

I saw my mother in the operating room. She sat in the corner with a quirky smile on her face, like she had a secret to share. I felt her around and within me, and I knew I was safe because she was there amidst the noise of the instruments clinking together, the masked faces above, and the straps that secured my arms. She'd been dead ten years, but death didn't stop my enhanced mind from imagining her. I wanted her there at my chance to rid myself of my pharmacy, and to take a gamble that I might feel mostly whole again. As I was attacked from both sides by mumbling doctors, she perched on a stool overseeing the procedure.

When I woke from the operation, my mother was gone, but her absence did not surprise me. The crisis of playing with my vagal nerve was over, with the device firmly stitched inside where it will stay for the rest of my life. I tuned into the recovery room, much like the one I used to work in before RA helped me leave my job. I understood the lingo, the procedures, the consciousness level of the patients. The normal buzz of conversation and its interruption by ringing phones and patient moans. I smelled the lick of anesthesia on my breath; I was certain I could taste it.

Over the months of summertime, my dosages, in the form of amperage instead of needles, were adjusted. Frequent four-hour round trips to the study center with my husband-chauffeur gave us time to discuss how I felt, though specifics were difficult to qualify and made me cranky. I told him, instead, how I wished to feel by the time the therapeutic dose

reached its ceiling. With each visit, the nurse raised her iPad and controlled me, entering mysterious numbers, testing my blood and my heart.

Pain resumed in small bursts and seared into my joints through June and July. My stiffness and fatigue threatened to overwhelm the way it had thirty years earlier when I begged my rheumatologist for relief. It was clear to me that I was sorted into the control group and was not receiving any stimulation.

At any point, I could have exited the trial, but I reminded myself of the reasons I had chosen to participate. I wanted to avoid the ill effects of drugs. The major pharmaceutical I took each week had been on the market for a mere twenty years—not enough time to predict its long-term effects on my body. What other not-yet-identified dangers would surface and threaten my future? In addition, as I neared Medicare age, my injectable drug cost out-of-pocket shifted astronomically. A change in drug regimen was planned, a pharmaceutical experiment that Medicare covered, thwarted when I signed the papers for the trial.

When you have a chronic disease that is hidden and you don't complain about it constantly, people assume you are fine.

Instead, my vagal nerve stimulator was gifted to me, endowed by generous benefactors who took a chance with their money instead of their bodies. The study paid my travel expenses and provided yarn money for my troubles. Above all, it carried a guarantee that after three months, when I entered Phase Two, the device would be fully activated to deliver its true therapeutic dosage, regulating my immune system through the vagal nerve, its manager. The fact of a fully functioning device, along with my study nurse's encouragement, came together as an acceptable risk and I plodded on through days peppered with long naps and sighs. The second phase approached: *The One Where Everyone Vibrates*.

* * *

Over a few weeks, the true therapeutic buzz from the stimulator dampened my RA symptoms. "It's remarkable, isn't it?" I watched my rheumatologist pore over my hands, wrists, feet, and ankles. "I have no swelling. No pain." He is cautious with praise. Six months after going off my injectable for the trial, we decided to stop my other RA medicines. Within a year after entering Phase Two, the bottles of pills

and capsules in my cupboard and the prefilled syringes from my fridge were banished. No more increased risk of skin cancers, lymphoma, or the need for medication to work through my tired liver to allow me a day free of pain.

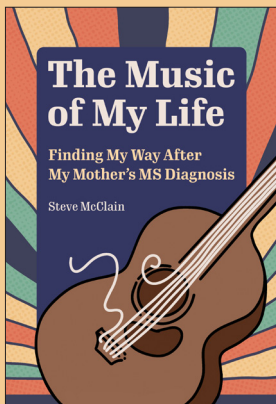
Weeks of continued improvement ensued, without the biweekly shots, pills, and steroid injections that I'd taken for decades. However, the damage that was done before persists in my wrists and hips. And on occasion, a finger joint will be tender or puffy. I'm realistic about the future. We're treading through territory that might have pitfalls, drawbacks, or a day when my stimulation is not enough to hold my disease in check.

* * *

Today, post implant, I work all day, full time at my hobby that is now my new profession as a writer. Though I take most of the credit, my device helped me complete graduate school and allowed the energy to publish essays and stories plus find an agent for my debut novel. But the vagal nerve stimulator did not fix every issue. Aside from random

joint tenderness, I also maintain a level of tiredness that supersedes the usual I-did-not-sleep-well-last-night. It is bone fatigue, felt inside out, like the sense of one's cells dying or reorganizing to mount a revolt. One of the study doctors says fatigue is indicative of my disease activity. Rheumatoid arthritis is still bubbling beneath the surface of my skin but it's no longer erupting. I also consider that my friends complain of tiredness too, so there is the possibility that something else comes along with being over sixty.

Last night when I woke at 3:00 a.m. and felt the buzz, I held a mix of appreciation with an eerie feeling. It was deep night, the windows were covered in blackout drapes, my husband snored lightly beside me. There was a lump of cat at the bottom of the bed echoing his rumbles while a piece of metal encased in plastic shuddered in my neck. In that moment, I wanted the device gone. Why couldn't I be well again without the extra metal inside? It's just too odd, too sci-fi. Then the vibration dissipated. It ebbed so quickly, I'm not sure I remembered what it felt like when it gave me a tune-up moments before. I stretched and wiggled my wrists, then my ankles, and slipped into a dream. ♦



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Dave Wisniewski, *Simple Folk*, 2009, oil on canvas, 48" x 36"



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