Encounters

Living with ALS

Courtesy of Ben Parfitt

The author, Alicia Priest.

In my dreams I kiss, speak and spit. I cook, eat and drink. I dress myself and bathe myself, drive my car, hike forest trails, practise yoga, garden and walk my dog. My husband and I, having raised our daughter and set her up for independence, have our home to ourselves. In a few years, retirement beckons. We gather with friends to solve the world's problems, travel, volunteer and dine out.

Then I wake and stumble through the nightmare that is amyotrophic lateral sclerosis (ALS).

It's been three years now, and because I have the top-down as opposed to bottom-up variety of ALS, I still awkwardly get myself out of bed and walk like a flat-footed robot. I type with one finger — a left-hand finger, mind you, because my right hand is almost useless. And that's about it. My daily caregiver prepares my breakfast in the blender. The puréed green slush will be pushed through the six-inch plastic tube protruding from my stomach. My last eaten meal was roasted tomato soup followed by small chunks of dark chocolate. My last drink was a Guinness. Able to smell aromas, I crave the taste and textures of foods despite having no appetite. Every meal underscores the artificiality of my existence. But more than fried eggs and bacon, I miss my voice and ability to converse.

As a former registered nurse and long-time medical journalist, I prided myself on my health habits. What cometh after pride? In my case, a fall down a snakepit. Never seriously ill a day in my life, I was fit, trim and slim. Which made me a perfect candidate for ALS, the only terminal illness that also bears the name of a professional athlete: New York Yankees baseball player Lou Gehrig. Add to that list Jim "Catfish" Hunter (baseball player), Ezzard Charles (heavyweight boxing champion), David Niven (competitive sailor) and former New Orleans Saints footballer Steve Gleason, to name a few. And the most famous thin man with ALS: Stephen Hawking. This disease is a good reason to be fat and lazy.

Three years ago, when a neurologist nervously suggested my cold, weak right hand might be due to ALS, I didn't believe him. It just could not be. Known as an orphan disease, ALS is relatively rare, affecting roughly 2 in 100 000 people. Aside from my right hand, I felt strong and normal. The doctor kept looking in my mouth and asking if I had trouble eating or swallowing. No, no, no. True, I had sudden bursts of tears, but I had good reasons to cry. My 86-year-old mother had died two months previously, and three weeks later we had had to put our eight-year-old chocolate lab down. As for the mysterious withering of my right hand, surely it was something else.

In January 2012, I received the official diagnosis of sporadic ALS by another neurologist at the ALS Clinic in Vancouver's GF Strong Rehabilitation Centre. After an hour of tests, including tortuous electromyography, my husband and I were ushered to her office, where the only word I heard was "unfortunately." We drove home to Victoria in silence. My diagnosis is a death sentence; for more than 100 years, ALS has evaded science's attempt to find a treatment, cure and cause. Once home, there was nothing to do but weep, which I did daily, accompanied by the occasional bout of inappropriate giggles. To counter the emotional labiality — a symptom of bulbar ALS — my family doctor prescribed a combination of dextromethorphan and quinidine, the two active ingredients in a product not available in Canada.

Within a month, I quit all work. I was 59. Within two months, friends told my husband my speech was slightly slurred. He hadn't noticed. Two more months, and even I noticed I sounded like I had had one too many. One merchant asked if I'd just had my teeth done and the freezing hadn't worn off. Of course, I said yes. A dog walker asked what my accent was. I said Russian and was shocked to hear him respond in fluent Russian. I replied with one of the few Russian words I know — *do svidaniya* (goodbye).

Although I was still fully mobile — except for waning dexterity in my right hand — and ate and drank almost anything, the shock paralyzed me emotionally for about six months. Then muscle twitches, fasciculations, invaded my hands, arms, torso and face. Almost constant, they feel like worms writhing under my skin. My whole body chemistry began to change: oilier skin and hair, more earwax, and faster-growing fingernails and toenails. Medical science was not interested though, and after the diagnosis my days of seeing a neurologist were done. I flirted with discreet ways to kill myself: drive off a cliff; walk into the woods with a bottle of Scotch and a

vial of sedatives; step in front of a bus. Then I had my epiphany: each day I am worse than I was but better than I'll be.

There was only one thing on my bucket list: to write the book I'd been blathering about for decades, an investigation into how my father, back in the 1960s, masterminded the theft of 70 tons of super-rich silver ore from under the nose of one of the world's most productive and profitable mining company's in the world. United Keno Hill Mines was based in a remote hamlet in the middle of the Yukon Territory where I spent my first 10 years. The book would also be a memoir of how his crime affected our family. I'd done a good chunk of the research before my diagnosis: interviews, archival sleuthing, a trip to the Yukon, reading and more reading. Now it was time for the hard part, the writing. For the next 14 months, I wrote at least four hours a day. As my ability to speak and swallow deteriorated, I wrote. And rewrote. I had great organizational help from my husband, who moved his office home early in 2013. I had a manuscript ready by November and sent it to Harbour Publishing.

In January 2014, a gastroenterologist inserted a feeding tube in me despite my initial vow to avoid all medical intervention. The following week, I heard from Harbour that they would publish my book, titled *A Rock Fell on the Moon: Dad and the Great Yukon Silver Ore Heist*. I jumped up and down and squealed with joy. At that point, I could swallow a sip or three of champagne. Editing, picture selection and book promotion ensued. So did increased muscle atrophy, twitches, overwhelming fatigue, weight loss, and the waning of my voice and ability to swallow. Through community care (bless you, Canada), we hired three part-time caregivers, seven days a week. Goodbye privacy and independence, and hello humility. My biggest humility lessons are, one, I'm not the only one suffering and, two, ditch "Why me?" in favour of "Why not me?"

A third lesson this disease has taught me is that love truly is a medicine. Not a cure, but a salve of gratitude, comfort and peace. From acquaintances to close friends and family, I'm being carried out on a river of love. Who could ask for more?

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Editor's note: Alicia Priest died on Jan. 13, 2015, at the age of 61.

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Poetry

St. Vitus' dance

Pieter Brueghel the Younger

A jig. Pray to god and little basal ganglia bugs that stand at attention and command *March*. Your face flails according to order: *choreathetoid, choreathetoid*, your jerky-sinuous lips pulled and pushed to command the martial music of a possessed two-year-old who can't sleep because his heart bugs have autoimmuned. *Sleep Child* a mother says, and the great Syndenham asks *what's in a name* and the febrile child is coursing, his mother applies cold cloths to the forehead, but the child hits invisible targets. Group A *Streptococcus* insists on mad ballet, of buck-sinister crump, the waking hours of the child devoted to marionette tugs. Yet the prognosis is good, the gyrating at St. Vitus' altar proves transient. Look at the child, the body wracked, the face ticked, the parents afflicted, praying to patrons.

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