JEWISH WORLD REVIEW
The Intersection of faith, culture, and politics

Monday
May 14th, 2018

It Could Happen To You

Following doctors' ever-changing orders only made me -- a former runner, swimmer and hiker -- sicker. Then I found out why

By Melissa Banigan The Washington Post
Published April 3, 2017

Twenty years ago, I started experiencing what turned into a long list of seemingly unrelated health issues. Headaches, depression, insomnia, peripheral neuropathy, fatigue, joint pain, chest pain, shortness of breath, a lesion on my spine and a variety of uncomfortable gastrointestinal ailments.

Over the past five years, things went from bad to worse as I also became lactose-intolerant, developed mild vitiligo (a condition that leads to loss of skin pigmentation) and major vertigo, experienced a series of low-grade fevers and started to have some memory loss that I referred to as brain fogs.

Doctors told me that as an overworked single mother of 40, I might just need to figure out ways to get more sleep and relax. Some of what was happening, they said, might be attributed to the normal processes of aging.

What was happening, however, didn't feel normal. Always a voracious reader and a writer by profession, I could no longer focus on work, read even a page of a book or grip a pen long enough to write a grocery list. I often felt too exhausted to keep plans with friends. When I did pull myself off my couch to see them, I couldn't concentrate on conversations, so I sequestered myself in my apartment and let my friendships fade. I had been a runner, a swimmer and a hiker, but just walking up a flight of stairs made me lose my breath so completely that I succumbed to inactivity.

I did everything the doctors asked me to do. I changed my diet and sleep schedule, went to a physical therapist and saw specialists in neurology and rheumatology and even a mental-health therapist. I then also turned to massage therapists, herbalists and an acupuncturist.

Despite all of this, my symptoms worsened. The pins-and-needles sensations of the peripheral neuropathy in my arms and legs became so uncomfortable that it was difficult to sleep, and feelings of dread and severe joint pain roused me with a jolt most mornings at 3 or 4 o'clock. I tried to maintain a normal work schedule, but it was cut short when I went into an intensive care unit after a common cold turned into pneumonia and I developed sepsis. My brain fogs, which previously had amounted to forgetting a few words or leaving my keys in odd places, worsened. I forgot my Social Security number, important deadlines and, once, even the date of my daughter's birth.

One afternoon, I stood in a room and had no idea where I was. Confused and panicked, my world feeling black, I finally realized that I was in the kitchen of my apartment in Brooklyn. The myriad of symptoms I had been dealing with for 20 years was no longer manageable. Feeling sound in neither mind nor body, I was terrified.

The next day, I went to a neurologist (the third over the past many years), mostly concerned with my memory loss. Early-onset Alzheimer's felt like the elephant in the room, but I was assured that I was too young. After giving me a short memory test - during which I couldn't remember even the name of the mayor of New York - he scheduled a second appointment to conduct a longer cognition battery. As usual, one of his nurses drew blood during the first appointment. I thought nothing of it until I received a phone call the next morning: "You have a B12 deficiency," I was told.

A vitamin found naturally only in animal-sourced foods such as red meat and dairy products, B12 has a key role in the functioning of the brain and nervous system and is necessary for making healthy red blood cells. I had been taking the vitamin daily for more than a year as an oral supplement while I explored a vegan diet, so I was more than a little surprised to find out that I had a deficiency.

"It's treatable," my doctor continued, easing some of my concern. The only catch? My deficiency might be caused by an autoimmune disease called pernicious anemia.

A chronic disease, pernicious anemia occurs when the immune system attacks the parietal cells in the gastric glands and the lining of the stomach. These cells secrete a protein called intrinsic factor, which bonds with B12 before being absorbed through the gut. Without intrinsic factor, the body absorbs very little B12, which in my case had led to a deficiency despite the oral supplements I had been taking.

Symptoms of the disease vary, but I had many of them, and it was worrisome to learn that without treatment, final stages can lead to congestive heart failure, degeneration of the spinal column, neurological complications such as dementia and - until a medical therapy was discovered in 1926 - a long, slow death.

In the early 1920s, biological researcher and physician George Whipple found through experiments with dogs that raw liver offset the effects of anemia. A few years later, George Richards Minot and William Parry Murphy discovered that their human patients' anemic symptoms were alleviated after eating a half-pound of raw or lightly cooked calf liver per day. Whipple, Minot and Murphy received a Nobel Prize in Physiology or Medicine in 1934 for their groundbreaking discoveries.

Because pernicious anemia appears most often in people of Scandinavian or northern European descent, it may be a hereditary disease. I already knew of my family's strong Irish roots, and a simple DNA test revealed a genetic connection to long-forgotten Scandinavian ancestors. The final piece of my familial puzzle fit into place after I described my symptoms to relatives.

"When I was a child," my aunt told me, "your Nana took what she called 'liver shots.'" B12 had been synthesized as cyanocobalamin in 1948, meaning that by the time my tiny Irish American grandmother was my age, she was able to forgo what I imagine were unsavory daily doses of undercooked liver and instead take injections prescribed by a doctor for pernicious anemia.

My first "liver shot" eased my symptoms to such a degree that I felt like a new person: For the first time in my adult life, the pain I had been living with washed away, and my brain fog lifted overnight. I wonder whether my grandmother had a similar experience.

Despite how easy it is to treat B12 deficiencies, millions of people remain affected. In poorer countries, this is because they lack the vitamin in their diets. In the United States, close to 40 percent of people may have deficiencies, although only 0.1 percent of the general population and 1.9 percent of people older than 60 have pernicious anemia.

It took about 20 years for me to receive the pernicious anemia diagnosis that led to my first B12 injection. Research shows that the disease can take 20 years or more to progress, with symptoms worsening slowly over time.

I still am lactose-intolerant and have symptoms such as vitiligo and the pins and needles of peripheral neuropathy. The injections stave off the worst of my brain fogs, vertigo and other symptoms. My symptoms return slowly about two weeks after an injection and quickly by the third week. My insurance covers only one injection of B12 a month, however, which means my health and mental state fluctuate greatly depending on the week.

If I had diabetes, my insurer probably wouldn't restrict my access to insulin. My condition shouldn't be treated differently. I hope that over time, as more people learn about pernicious anemia, there will be fewer limits on treatment.

Except for a handful of online support groups, there aren't many resources in the United States for people living with pernicious anemia. On the other side of the Atlantic, in Wales, Martyn Hooper founded the Pernicious Anaemia Society in 2005 to raise awareness of the disease.

When he was diagnosed in 2002, Hooper said, "there was no 'plain English' explanation of the disease available. I resorted to looking up the word 'pernicious' in the dictionary and discovered it meant 'ruinous, destructive and fatal.' It was obvious that nothing was available to newly diagnosed patients."

The Pernicious Anaemia Society has more than 6,000 members, and I wish that there were such a group in the United States to raise awareness. I often feel frustrated with my insurer for not reimbursing me for all of the injections I need, and when I'm feeling my worst, I sometimes lament the loss of ruined romantic relationships or income from jobs I couldn't complete because of my disease. I could have received a diagnosis much sooner.

Yet a 20-year fog is lifting, and I'm hopeful that regular B12 injections will continue to make me feel better.