Breathless

Category: Stories
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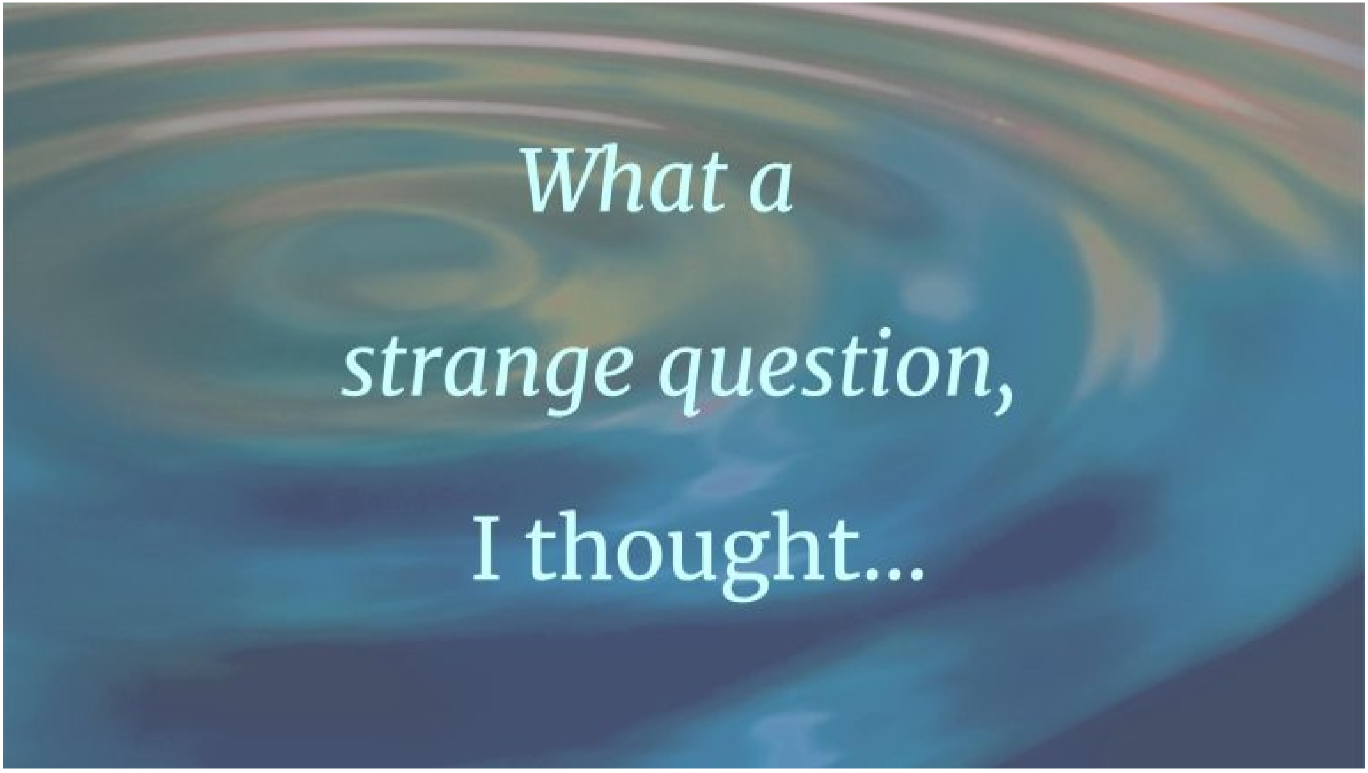

Editor's Note: This piece was a finalist in the Pulse *writing contest, "On Being Different."*

I was a disaster in fourth grade—too chubby for my Girl Scout uniform, which gapped where it should not have gapped. I dragged my right foot, so I wore orthopedic shoes. My horn-rimmed glasses made me look like a sixtysomething church lady. My jet-black hair with five cowlicks had been partially tamed with a beauty-shop permanent. I was the last chosen for red rover and other recess favorites.

Ten-year-olds know when they are different from their peers. I didn't want to be different and felt self-conscious. Then came the *coup de grâce.*

My orthodontist prescribed a facebow—a metal frame locked on my upper teeth and hooked around my head with a broad black strap. I wore it while sleeping and for a few hours every evening. I felt as conspicuous as if I were from another planet.

I'm now a sixtysomething church lady with fashionable horn-rims—and I feel different from my peers because I carry an oxygen tank due to my life-threatening lung disease.

In 2016, after being hospitalized for a bad asthma flare-up, I began seeing a pulmonologist, who put me on supplemental oxygen. Over the following years, baffled by my case, he doggedly kept studying my shortness of breath on exertion, chest pain, gravelly voice, wild coughing fits and fatigue.

In 2021, his office unexpectedly asked me to get another CT scan. This request seemed odd, but I went for the test and the follow-up visit.

After greeting me, the doctor asked, “Did you grow up in a rural area?”

What a strange question, I thought.

“Yes,” I responded. “I lived out in the country in Indiana and spent time at my grandparents’ farm.”

He said, “Well, I think you have fibrosing mediastinitis. It comes from histoplasmosis, a fungal disease that’s prevalent in rural areas.” It comes from breathing in fungus spores from bird or bat droppings, he explained, and it’s rife in the Midwest.

Fibrosing mediastinitis enlarges the lymph nodes between the lungs and nearby organs. As a result, the airways and vascular system become obstructed, leading to difficulty breathing. Unfortunately, the disease has no cure.

In childhood, as a member of 4-H, I dug in the soil to plant gladiola bulbs for my flower project, and that’s likely where I contracted histoplasmosis. Even now, I’m sometimes amazed at how something that seemed so ordinary more than fifty years ago continues to wreak such harm on me today.

My doctor, having stewed about my case, had ordered the extra scan to confirm his suspicions. Seeing the results, he’d attended a case conference, where other physicians supported his diagnosis.

After wearing oxygen for breathing since 2016, it was a relief to finally have a definite diagnosis. On the other hand, wearing an oxygen tank 24/7 undeniably separates me from the world. I need two tanks (or compressors): a ten-pound portable that provides pulsed puffs of air, and a forty-pound compressor for home and sleeping. I call them Li’l Tanko and Big Tanko.

Wearing Li’l Tanko, I feel like I’m sporting a giant ten-pound facebow on my shoulder. At events that run longer than two to three hours—family gatherings, weddings or funerals—I must depend on access to an electrical outlet to keep it charged.

When I travel anywhere overnight, I have to take both tanks, because I need continuous air at night. Flying is not an option, because placing a rented machine worth thousands of dollars in checked baggage is asking for damage. And the battery life required for a long flight doesn’t exist on any portable tank.

Television commercials give a false impression about people who need supplemental oxygen; Li’l Tanko always runs out during church services, for instance. Carrying extra batteries is cumbersome (they weigh several pounds each), and of the three systems I’ve had, not one has worked well. I always bring an electric cord, which adds another four pounds, then scramble to find an outlet. Add up the compressor, the cords, the extra batteries and my giant purse, and it’s all too awkward and laborious to hoist around. It’s no wonder that I’ve had to forego ziplining since my corded life began.

In addition to wrestling with the logistical issues of a tethered life, I struggle with other people's lack of empathy. This emotional burden weighs just as heavily on me as my portable compressor and three batteries.

People tend to be skeptical, sometimes even after I explain my situation. I'm guessing that their skepticism persists because I don't look ill, except during extreme coughing fits or severe breathlessness. Also, over the course of my retirement, thanks to having fewer lunches out, I've lost about thirty pounds, so I look perfectly healthy, which confuses some people.

Years ago, when visiting my aunt, my husband and I stayed at the bed-and-breakfast down the hill from her apartment. Having no car, and knowing that I couldn't walk up, I asked someone to drive me.

"Oh, it's not so far," the person said. So we set off on foot.

Yes, it was too far. Going to the mailbox is too far, and taking a shower requires accommodation.

At the time, I said inwardly, *What do you not understand about shortness of breath?* Nowadays I would speak up and explain my need for a ride—but back then, I didn't.

I recovered outside, making a grand (late) entrance. Even on oxygen, it took me twenty minutes to breathe normally again.

More recently, during the pandemic, I masked if I had to go out, and I stayed home more than before my retirement in 2017. I still often do wear a mask; I don't want to risk my life in a crowded theatre.

I sometimes feel uneasy asking for what I need. I compare myself to others who have it so much worse—I don't experience constant pain, I'm not on a ventilator, I'm not in a wheelchair—and feel guilty about speaking up.

But dismissing my needs is ridiculous. Or, as my dad used to say, "Hogwash." I need what I need, and ignoring my real health concerns doesn't help anyone who's worse off.

Often, even when I explain my choices, I still don't feel heard—because my disease is rare and relatively unknown to people.

The key to bridging this gap, I've found, is to share information. As I share more facts with others, their greater understanding often translates into empathy. Feeling understood reduces my feelings of isolation. The cautionary tale, for me, is that I must do the same for others by doing my best to recognize *their* invisible struggles.

I'm not asking for pity—I don't need that. But I am asking for support. I don't want to be different, to stand aside from life, but be a part of the main current. That's what the fourth-grade Amy wanted—and what sixty-something Amy wants, too.