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Silent Suffering: Living with an Invisible Disease

“Just keep resting, and things will get better.”

These were the comments Emma Smith heard at her first doctor’s visit in the fall of 2021. Smith, a once-energetic, active, athletic 23-year-old, had been out of work for the past five days, dealing with severe muscle fatigue, brain fog and a tingling sensation throughout her body.

Smith graduated from the University of Montana Journalism School in May 2021, and she worked as a photojournalism intern in Bozeman, Montana, during the summer of 2021. Eventually, she returned to Missoula, home of the University of Montana, and continued perfecting her craft as a rock climber while simultaneously working more than 30 hours a week at the climbing gym.

Following her initial appointment, Smith’s symptoms began to fluctuate. Her days consisted of working and climbing when she could manage it, but every so often, she would wake up in an energy-less fog that persisted for days, no matter how long she rested. These mysterious symptoms started after her COVID-

19 infection in November of 2020. In the months following her infection, Smith said the “endless supply of energy I once had was gone.”

On Oct. 29, 2021, Smith woke up in the same mysterious fog. She went into the Providence Urgent Care at Grant Creek in Missoula, where they immediately tested her for COVID-19. The test was negative, leaving the doctors with no answers for her.

As the months passed, her symptoms became more frequent. In late March 2022, Smith realized things were not improving, and she needed to make a change.

“Climbing was becoming harder; I would get dizzy on the wall and had multiple experiences of vertigo. My fatigue was getting worse daily,” she said.

The following month, Smith had an appointment at Providence Women’s Care and Family Wellness in Missoula. The doctors told her that she was fatigued because she was depressed. Smith told the doctors that the reasoning behind this “depression” was because she felt physically horrible and nobody was giving her any answers.

On May 1, 2022, Smith started experiencing significant vertigo and sensations going up and down her spine and around her brain. A panic attack ensued, overwhelming Smith. The four ER doctors told Smith that she needed to go on anti-anxiety medication and that she may have a drinking problem. Smith, who refrained from drinking in most instances, shared that she had only consumed one single beer on that day.

At this point, Smith had either been misdiagnosed or given no answers regarding her consistent symptoms, and she was growing increasingly impatient and discouraged as time went on. “I wasn’t getting any answers and didn't know what to do anymore. As an independent 23-year-old, I picked up the phone and desperately called my mom for help,” Smith said.

Two weeks later, Smith followed up with her doctor at Providence Women’s Care, this time with her mother, Nancy Smith. After hearing the doctor push Lexapro, an antidepressant, as a solution for her daughter, Nancy spoke up. “This is NOT her normal. Emma is active, a go-getter, independent and lively. She can’t even go into work for a two-hour shift. There is something wrong with her. We’ve already lost a child to leukemia. This is the family where weird medical stuff happens. You need to test her for everything. Epstein-Barr, mono, everything.”

After the appointment, the two had an emotionally-charged conversation, and they decided that the best thing for Smith was to move home.

Breaking Point

Upon returning home to Oregon in May of 2022, Smith visited another doctor, and immediately tested positive for cytomegalovirus, which, according to the Center for Disease Control and Prevention (CDC), is an infection that causes fatigue, sore throat, fever and swollen glands.

“Moving home and uprooting my life wasn’t an easy decision for me. It felt like I had failed,” Smith said.

This same appointment led to the discovery of Smith’s severely low vitamin B12 levels. Deficiency levels fall into the range of 200-300, and Smith’s level was 168. The doctor prescribed B12 vitamin shots.

The following week, Smith discovered she had been exposed to COVID-19 at a small gathering. On the fifth day following the exposure, when she woke up feeling off, she tested for COVID-19. The test was positive.

Over the course of the next couple of weeks, things began to get worse. Smith began experiencing vision problems, numbness in her feet and hands, severe aching after any form of exertion and painful migraines.

Smith visited several doctors after returning home, but none of them could help her. A neurologist suggested that most of her symptoms were related to her B12 deficiency. A naturopath suggested donating blood to help with the heart palpitations. A psychiatrist suggested anti-anxiety medication. A trauma-based nurse suggested that this was all happening due to trauma. At the start of February 2023, Smith ended up in a mental health crisis center for a couple of hours.

Finding Clarity

“A few weeks later I sat in the kitchen, legs draped over a chair and opened an article from the Washington Post discussing long COVID and chronic fatigue syndrome; little did I know at the time, that this would provide more answers about what was going on with me and change the course of my medical journey.”

Smith meticulously scoured the internet for a few weeks, researching every single symptom of long COVID. She looked into old internet archives and newer medical studies and found out that every single symptom she had was being reported by long COVID patients. Not only did Smith learn that there were many people suffering from this illness, but it was so new that many health care providers had been overlooking long COVID.

“When I read about long COVID in the Washington Post, I formed a timeline and connected the dots to understand that this was what I had been dealing with for years. I was upset. I had seen numerous doctors across several channels of medicine, and not one of them had proposed that this was what I was dealing with. Had they never believed me? Instead, they just left me to suffer,” Smith said.

According to the CDC, long COVID is a serious illness that can last various amounts of time, up to years. The illness has an extensive range of symptoms that can require thorough care, sometimes leading to disability.

In early March, Smith and her mom took a trip to visit a new neurologist, this time arriving with new findings of their own. As they frantically told the neurologist about their discovery, he immediately

agreed. Despite going so long without any answers, Smith's symptoms did align with those of long COVID. It was the source of her suffering, and her symptoms had worsened after her second infection. Smith recalls her mother, Nancy, asking the doctor, "What can I give her? She's 24." Smith already knew the answer: there was no prescribed medication, no FDA-approved treatment, and, worst of all, no proven cure.

The Smiths knew, once again, they had to take matters into their own hands. This started with revisiting a previous doctor and requesting a referral to Oregon Health Science University (OHSU) Long COVID clinic. This clinic would provide the proper care for her illness and guide her along the rest of her medical journey with long COVID.

After submitting her referral, Smith waited. The unfortunate reality was that clinics of this type were overwhelmed by the pandemic and experienced lengthy waitlists, causing months of waiting.

Smith suffered a similar experience: growing impatient while waiting months for an appointment before hearing anything from the clinic. After weeks, Smith called the clinic. They told her that they had no record of her referral. Smith, frustrated, picked herself up, ordered another referral for the clinic from her doctor, and waited once again.

Finally, after nearly six months of waiting and dealing with a lost referral, Smith was accepted into the Long COVID Clinic at OHSU in August 2023. This allowed Smith to work with a speech therapist, a physical therapist, and another doctor who was able to diagnose her with postural orthostatic tachycardia syndrome.

The OHSU Long COVID Clinic validated Smith and provided her with proper health care and the diagnostic tests they had, including the ability to start taking low-dose naltrexone (LDN), the only medication that has alleviated fatigue, brain fog and pain for patients living with long COVID.

Embracing the Struggle

Although Smith is not cured and still battles the symptoms of this seemingly never-ending disease daily, she is slowly getting better. "I realized there was no moving away from this disease; there was only moving forward with it," Smith said. "This is hard and unfair, but I either isolate myself in anger, or I find ways to participate in daily life. I must be accommodating and move forward with the skill set I have developed from this situation."

The downtime helped Smith discover more about herself. "I like being alone at times, but I need to be stimulated creatively and intellectually to maintain happiness. I learned how to stand up for myself and self-advocate. I also learned that it's okay to demand kind and empathetic treatment." Smith's over four-year-long sickness pushed her into writing about science and health, eventually leading to future areas of study.

Graduating with a journalism degree and never fully getting to explore the wonderful world of journalism due to illness was challenging for her. Smith credits much of her development as a writer and reader to

this harrowing period in her life. “Even when I feel awful, I can write, I can research and I can help other people who can't even do that,” Smith said. Smith began posting articles on Long COVID Connection (LCC) Medium, an online place to share writing. Her stories gained attention and helped other long COVID patients. This allowed her to find comfort within the isolation, especially with people who knew exactly what she was experiencing.

Currently

After slowly improving daily, Smith decided it was time for a change. She moved out of the room where she had spent almost three years battling this illness. She applied and was accepted into both the New York University Science Health and Environmental Reporting Program (NYU SHERP) and University College London’s (UCL) Science Communications Masters Program to further develop her writing and research skills and to advocate for patients who can't necessarily do so for themselves. Both these programs are considered some of the most competitive and exclusive in the world for health and science journalism.

“When I learned I received an interview with Dan Fagin, the director at NYU SHERP, my head started spinning. I couldn’t focus on work or anything that day. It was affirming to know that my writing was good enough to be noticed by a Pulitzer Prize-winning journalist and that this whole experience hadn’t all been negative. Once I learned I was accepted, I knew I could carry that with me forever. Then, I was also accepted into UCL.”

“It still feels unreal. But it shows that even when terrible things happen, you cannot shut down; you have to keep going because there is still so much beauty left in the world.”