My Invisible Illness

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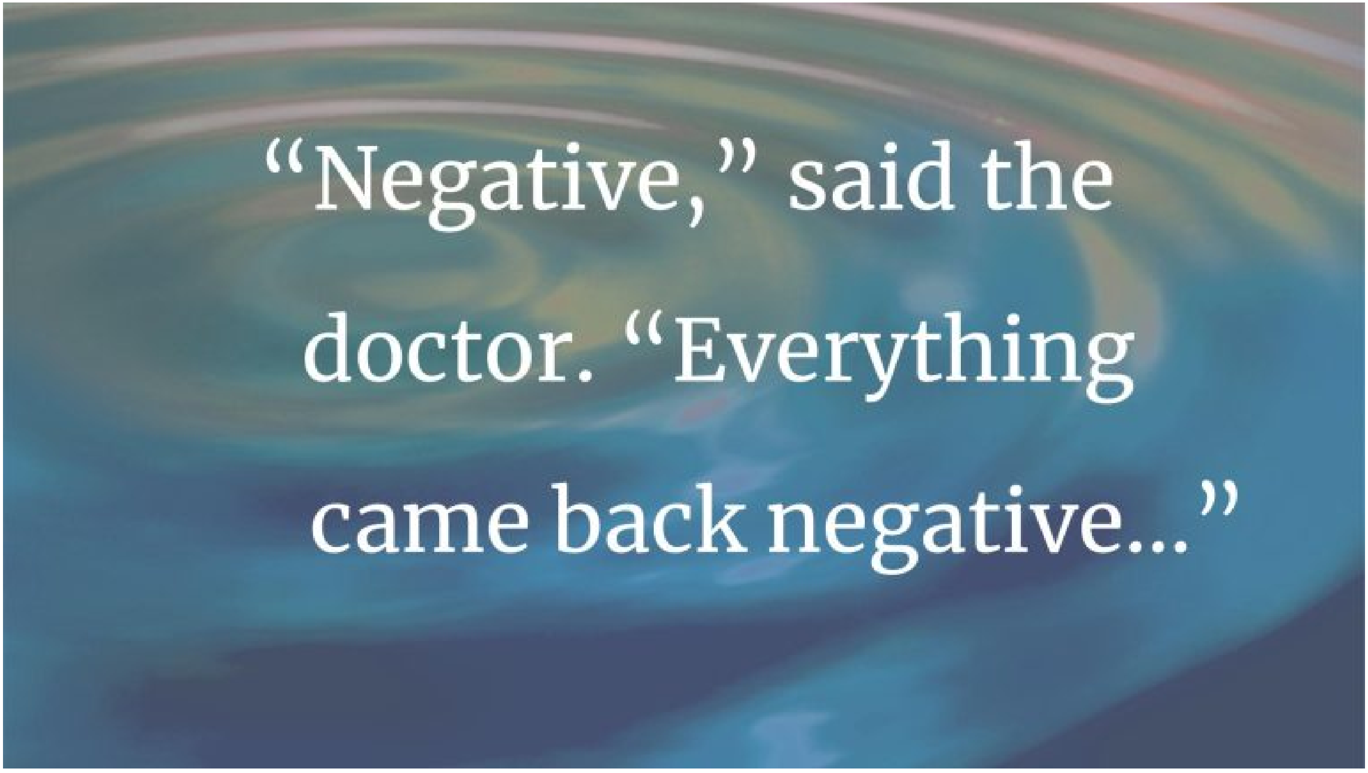

“Negative,” said the doctor. “Everything came back negative...”

Growing up, I was a healthy child. I only went to the doctor for check-ups, vaccinations and school forms.

So when, at age fourteen, I woke in the middle of the night in excruciating pain and crawled into my parents’ bedroom to wake them to take me to the emergency room, I wasn’t prepared for what awaited on the other side of those sliding glass doors.

My experience was like a medical TV-show montage—bright lights, beeping monitors, medical professionals hovering over me and talking incomprehensible jargon, soft cries from patients in surrounding rooms, concerned looks on my parents’ faces.

There was the bitter chill in the air, the sterile smell, the scratchy blanket on my body, the metallic taste in my mouth from the saline IV, and the feeling of immobility as I was carted from one machine to the next, being told to remain still for imaging while every ounce of me wanted to curl up in a ball and hide.

Looking back, the medical testing was only half the battle. The other half was the waiting—the what-ifs, the Google searches, the doomsday prepping.

Then the results came back.

“Negative,” said the doctor, sounding optimistic. “Everything came back negative.”

This should be good news, right? I wondered, hearing the word and knowing that I should feel good, but feeling—well—negative.

On one hand, “negative” meant no life-threatening illness, but on the other, it meant no answers, which made me question what was meant by “life-threatening.” Was I at risk that my heart would quit beating or my lungs stop breathing? No. But I *was* at risk for questioning my own sanity and losing the ability to function day to day, to feel meaning and joy. My life *was* threatened, just not in the ways we’re conditioned to believe are urgent.

I was set on a new path, with the hope and expectation of a cure, a treatment or simply an answer.

Seeking these, my doctors engaged in trial, error and a never-ending routine of testing and re-testing. For my part, I had to track how I felt and when I felt it, to help them figure out possible causes.

I lived through a year of this before I finally heard: “It is this. You have endometriosis.”

Endometriosis is the presence of endometrial-like tissue elsewhere in the body. It latches onto organs, creating adhesions and scar tissue that can cause pain and infertility. A sneaky, invisible disease, it doesn’t show up on tests or imaging and can only be properly diagnosed through surgery.

That diagnosis felt like a giant embrace, a breath of fresh air and a warm chocolate-chip cookie all in one.

I didn’t make this up! My pain is valid! My pain has a source! I exulted—then came down to earth, realizing: *My pain cannot be cured.*

In that moment, I earned my “chronic” badge of honor. I was suffering from an illness that impacts so many, yet is widely misunderstood and mistreated.

I received hormonal therapy—believed at the time to diminish the disease, reduce symptoms and allow the patient to resume normal life. When my pain continued, my doctors threw up their hands and placed the blame on me.

The following is from my medical records, written by the lead doctor managing my pain.

“I noted that a large behavioral component to her complaints was reinforced today by yet again seeing that despite the fact that she feels so terrible, she is made up extremely nicely, has lots of energy and appears perfectly comfortable and moves very freely. If she is not willing to take the psychology course seriously, then she is wasting everyone’s time.”

This doctor, like many others, had trouble recognizing invisible illness. He fixated on what he *could* see (the makeup on my face), disregarding my verbal cues. He didn’t consider that I was a fifteen-year-old girl who’d lost control of her entire life and found comfort in controlling her appearance—or that I could “move freely” because when you’re living with pain, you simply don’t have a choice.

And what *I* didn’t realize until much later was that, in that moment, I didn’t stand a chance.

Medical records travel with you from doctor to doctor—a breadcrumb trail that makes it nearly impossible to visit a doctor who’ll have no preexisting bias. This situation continued until my senior year of high school, by which time I completely mistrusted both myself and medicine. In my mind, I had one option: to run.

I felt I had nothing to lose, and that I’d make my doctors’ lives easier by simply disappearing from their caseloads. I successfully tapered myself off of all twenty prescription medications I was on and did my best to fake wellness until graduation.

Heading off to college, I excitedly told my mom that this was my chance to start over. I was determined to hide every ounce of my illness from my new friends.

I’m not going to be the “sick kid,” I vowed. *If I’m supposedly capable of making up illness, then I can also make up wellness.*

I dabbled in every form of holistic care: acupuncture, chiropractic, energy work, supplements, reiki—anything that didn’t involve entering a doctor’s office or a hospital and that gave me a (false) sense that I was taking care of myself. This lasted ten years. Ten years of ignoring every signal my body sent, until the signals got too loud to ignore.

At that point, I went back into psychotherapy, fearing that there was something deeply wrong with me that I couldn’t simply be well. After a few sessions of reciting my history, I heard these words, spoken by my therapist, for the first time:

“What you experienced was traumatic.”

My eyes welled up.

“I’ve never heard it described that way,” I said.

That moment started me on a path that I never could have imagined—one that took me from a career in fashion to pursuing a master’s degree in clinical mental-health counseling, hoping to offer others the same validation that my therapist had given me. I began to take back ownership of my health and wellness.

Slowly but surely, I started seeking medical help and discussing my case with the specialists I found, who have surprised and delighted me with their bedside manner, deep understanding of the disease and unwavering empathy.

I can’t say the road has been easy, but it has offered continual reminders that I didn’t make any of this up, and that what I’m managing is *hard.* Admittedly, since that moment with my therapist I’ve had two surgeries, with one more on the horizon. Although that isn’t my ideal scenario, it shows my growing ability to manage my medical trauma and regain some trust in medical professionals.

And though I’m unsure that a cure will emerge anytime soon, I’m hopeful that it will eventually be found. So I’ll continue to put energy into research and advocacy—for myself and for every other person, now and in future, who might be plagued with this invisible illness.