

# How Doctors Ignored My Stage-Four Endometriosis

Abigail Anthony

Pharmaceutical suppression in the form of birth control was pushed on me as soon as I began menstruating. When I had the typical adolescent experience with unsightly acne, the drug was presented as a cure that would regulate my hormones and clear up my skin. Since I was a competitive dancer, doctors and coaches insisted that my period prevented optimal athleticism; supposedly, birth control would alleviate any monthly symptoms and improve my performance. Although I was not sexually active, doctors suggested that I strategically begin birth control so that I could eventually engage in casual sex without concerns about pregnancy. I repeatedly refused to take the drug.

My health began deteriorating in high school. I was moody and irritable, which everyone — including my parents — dismissed as standard teenage misery. Physical symptoms started hindering me and only worsened: I regularly felt as though my stomach was filled with barbed wire, I had very little appetite, and no amount of sleep or caffeine could energize me. In college, I had difficulty sitting for more than an hour because a pinching sensation would develop in my stomach. My weight fluctuated even though I maintained a consistent diet. But perhaps the most noticeable physical changes were apparent in my unpredictable menstrual cycle: I had my period for six months straight, or every two weeks, or not at all.

Yet, during every annual checkup, doctors concluded I was healthy. Indeed, my bloodwork always showed perfectly normal results. My academic success was cited as circumstantial

evidence that whatever I claimed to experience really wasn't that bad. Since no particular medical issue had been identified, everyone believed I was imagining the physical symptoms. As for my erratic menstrual cycle, doctors simply assumed that I had a hormonal imbalance that resulted from years of intense athletic training, and they suggested birth control as a treatment. The communal diagnosis was that I was debilitated by maintaining a perfectionist mindset at a demanding Ivy League university, so I was prescribed an antidepressant and Adderall. Yet even with those stimulants, I felt lethargic, unmotivated, and ultimately, severely depressed.

One morning, during my senior year at university, I woke up with a stabbing sensation near my right hip, so I swallowed some Advil and assumed I'd be back to normal in an hour. But the pain only intensified. I finally admitted myself to the university's healthcare center and was rushed to the nearby emergency room for appendicitis. After some tests, it was clear that I didn't have appendicitis. I insisted to the physicians that something must be wrong because I felt intense pain — even after I had been given morphine. But a doctor dismissed me and sent me back to campus. His explanation for the whole ordeal was that I was “maybe just having a bad menstrual cycle.”

I was willing to accept his explanation that I was experiencing particularly bad menstrual symptoms, but I knew that such debilitating symptoms — especially those that persisted after taking an opioid — were suggestive of something seriously wrong with my reproductive system.

I scheduled an appointment with a respected OBGYN in New York City, and he performed my first vaginal ultrasound. Nothing alarming appeared on the screen — no cysts, no tumors, no fibroids, no polyps. But I felt excruciating pain as if the probing device were a sharp sword. The doctor noticed my discomfort as I dug my nails into the exam table, and that was enough for him to diagnose me with endometriosis.

I had never heard of the condition. The doctor explained that endometriosis (sometimes called “endo”) is a disease where uterine tissue grows outside the uterus; it is commonly found in the ovaries, fallopian tubes, bladder, and bowel, although it can spread pretty much anywhere, including the breasts, nose, eyes, and even the brain. The disease is relatively common and affects roughly 10 percent of women, but it is particularly difficult to diagnose because there is no known cause, and the tissue rarely appears through imaging. Medications—including birth control—might alleviate the crippling symptoms of endometriosis, but the only effective treatment is to undergo excision surgery, during which the tissue is severed and removed. And so, I scheduled surgery for just a day after I submitted my last undergraduate exam.

Since endometriosis rarely appears on scans like ultrasounds or MRIs, I wasn’t even certain that I had the disease. As I waited for the anesthesia to knock me out on the day of my surgery, I was preoccupied with concerns: What if the surgeons don’t find any of the tissue, or what if there’s only a tiny bit? I worried that I wouldn’t feel much better after the procedure.

I woke up in a new room over five hours later, where my parents waited. Although I

had blurry vision and a foggy mind, I remember very clearly what my parents said: The doctors found endometriosis — *a lot of it*. The tissue had been on eight organs. (It had entirely covered my appendix, which probably explains the sudden pain that sent me to the emergency room earlier that year.) When I was visited by the surgeons, I was informed that my condition had been classified as stage four. One doctor said I had one of the worst cases that he had ever seen, and another was shocked that I had been able to manage daily activities. The lead surgeon—the man who had diagnosed me—looked at me with a smile and said, “You’re going to feel like a new person.” Now, I can say that he was right.

Sometimes, I wonder how dramatically different the past decade would have been if a doctor—just one doctor—had properly identified my condition. After all, it should have been an easy diagnosis: The disease is about as common as diabetes, and I had exhibited nearly every symptom. Instead of recommending the appropriate treatment, the medical industry presented birth control as a panacea for every reproduction-related issue. Perhaps I might have undergone surgery much earlier if I had just stumbled upon a single infographic on social media about endometriosis, or if I had met one other woman who endured the disease, or if my sex education classes in school had offered even a brief mention of common reproductive diseases. I’m deeply indebted to the doctors who finally listened to me and, more importantly, believed my accounts of seriously debilitating symptoms. I just wish it hadn’t taken eight years to find them.

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