

# “Patients deserve agency when it comes to their body”: a patient’s experience with endometriosis

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I’ve always had quite a bit of period pain, but I didn’t talk to people about it. In my early 20s, the pain around ovulation became unbearable. I also started having pelvic pain with exercise, bladder pain and frequent urination around the time of my period. That was when I was done keeping my symptoms to myself.

I tried birth control, but I got migraines, so I stopped taking it. Eventually, I told my doctor that I thought it was endometriosis. I found out people in my family had it but never talked about it. My gynecologist agreed that I sounded like a classic case

that I should be able to handle it. I don’t think I can fully encapsulate the loneliness, alienation and exhaustion I experienced. I discovered I couldn’t get pregnant naturally and I knew that I didn’t want in vitro fertilization. Before my gynecologist agreed to do my hysterectomy, I told him I didn’t think that I could go on with life if I continued to have such severe symptoms. I wasn’t very composed during that appointment, but he had seen me through a lot and he knew I was suffering. I was at a point where I needed more help. I asked to switch to a gynecologist who specialized in

things influence whether I feel that someone understands me.

I felt like people focused more on my fertility than on the pain I was in. When I was interested in trying to conceive, I was told to forget about endometriosis and focus on getting pregnant. That’s impossible — becoming pregnant does not cure endometriosis. I had to fight to have my hysterectomy. I understand that doctors have a certain responsibility in case someone regrets their decision later, but I didn’t come to that choice without a lot of thought. I wish I had been treated as someone responsible and mature enough to decide it was okay if I never got pregnant. Patients deserve agency when it comes to their body. — Ruby Stickney

## I wish I had been treated as someone responsible and mature enough to decide it was okay if I never got pregnant.

and did laparoscopic surgery. For about 5 years, my symptoms were manageable. Unfortunately, that didn’t last forever and I started experiencing pelvic pain most days. I’ve since had 3 laparoscopic surgeries, including a hysterectomy. My symptoms are better these days — I rely less on daily pain medication and require fewer trips to the doctor and emergency department.

Before my hysterectomy, endometriosis greatly affected my mental health. My daily symptoms, combined with society’s expectation to keep these parts of myself private, became unbearable. I felt pressure to accept that my pain was normal and

endometriosis after that. My new gynecologist is 2.5 hours away, but it’s worth the drive.

Something that was missing for me was that I wasn’t often treated like I knew what I wanted for my body and for my life. Each person’s path is valid. I identify as gender fluid. I was never asked what my pronouns are, but I was referred to as a “lady,” a “girl” and as having “very pretty and pink reproductive organs.” It’s traumatizing to have this disease to start with, and having assumptions made about my gender and sexual identity only makes it worse. A lot of old-fashioned language and thinking is used, and that bleeds into care. These

### As told to Victoria Saigle MSc

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This article has not been peer reviewed.

Consent has been given for these perspectives to be shared.

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