

Life Lesson I WISH I HAD MY HYSTERECTOMY DECADES AGO

BY JOHANNA READ ● Last year, at age 52, I finally had a hysterectomy, after three decades of incrementally increasing pain for two weeks of every month. For the most part, removing my uterus rid me of the severe pain I was having (both when ovulating and during my period). And while it was a relief, it's still hard for me to process that there were options all along—I just didn't know it. I didn't even believe I had an issue worthy of medical intervention.

In my 20s, I first asked my GP about the weird, sudden-onset bloating I would get. "I wake up with a flat stomach but within a few minutes, without even eating anything, I look like I'm four months pregnant," I told the doctor. "I don't know anyone else who has this."

She asked a couple of questions: "Does it only happen around your period?" No; always before my period, but at other times too—I didn't notice a pattern. "Is it painful?" At the time, I categorized it more as discomfort than pain, though it was a rare month when I didn't use any painkillers. She dismissed it as normal. The bloating was inconvenient, sometimes embarrassing, but the pain would rarely last more than a few days, so I started dismissing it, too.

Other symptoms—which, I now know, were all related to my troublesome uterus—started to creep in over time. I needed to pee frequently, and I had difficulty fully emptying my bladder (which led to chronic UTIs). I also experienced discomfort during sex, as well as heavier periods and continuously increasing pain and bloating. The worsening of these symptoms was steady but slow, so I waved it away as just one of those things most women have to deal with. And because period pain comes and goes, it was possible to forget about it once it subsided.

Here and there over the years I would ask my doctors about solutions, but each time I was told "there's nothing to be done," or that I should focus on managing my stress. Even the urologist who was advising me on my chronic UTIs quickly moved on to the next routine question. I didn't want to be labelled as a "problem patient," so I stopped pushing it. Even as the pain got more debilitating, I avoided talking about it with friends, my husband, even my mum and sister. I just relied on ibuprofen, acetaminophen, a heating pad and the knowledge that it would get better in a few days.

Of course, when my period pain first began—as a teen in the 1980s—there was no Dr. Google to consult. And it was



ILLUSTRATION BY SALINI PERERA

only a few years ago, thanks to a cycle tracking app, that I even realized my symptoms were arriving and ramping up like clockwork. That's when I noticed it wasn't just before and during my period, but also when I was ovulating, mid-month. Knowing that the pattern was mostly predictable helped me cope.

What wasn't predictable was a half dozen episodes of additional, intense pain that was so excruciating I would writhe on the floor for an hour or two. This was likely the rupturing of ovarian cysts, I have since learned, and it feels as agonizing as appendicitis (or so I'm told). I was about 16 the first time it happened; the last was while I was waiting for my hysterectomy date.

For reasons that don't make any sense to me now, I had always rationalized that it was just terrible cramps combined with a bad reaction to taking ibuprofen and acetaminophen together. After about an hour, the meds would start to work and the pain would begin to ease. The next few days would always be difficult, but then it would be another five years or so before another episode. So, I would forget about it and go back to my life.

We're all conditioned to downplay symptoms related to uteruses—both period-havers and our doctors, whether they're male or female. When I would mention my pain, people close to me would be sympathetic. But they couldn't do anything, and doctors didn't seem to think it was an issue. (I wonder, though: If I'd wanted children and was having problems getting pregnant, might they have listened to me a little more?)

What was the point of talking about it? *Periods are painful. Suck it up, buttercup.*

According to many studies, women's pain is not treated as seriously as men's and is very often attributed to psychological rather than physical causes. This dismissing of female pain is especially true for racialized and marginalized groups, including queer, trans, Black, brown and Indigenous women. When women suffer heart attacks, for example, it's often missed, or downplayed as stress. A 2019 study by the BC Women's Health Foundation found that 51 percent of women "felt a doctor or physician had diminished or overlooked their symptoms." We also know that women's health issues have also been chronically underfunded for years. Should we be surprised that the word "hysterical" comes from the Greek for "suffering in the womb?"

The dismissal of women's pain can also be internalized. Now that I know

I had a legitimate medical problem all along, one that's worthy of attention and resolution, I wonder what it might have taken for me to honour my own symptoms, instead of discounting and dismissing them just as my doctors had. How bad would the pain and bleeding have had to get before I insisted on more treatment, or at least demanded some tests? Would I have pushed harder if "periods are painful" didn't apply? Or if the pain was emanating from a body part that men have, too?

Things changed for me only with the discovery of something physical and measurable—fibroids—during a routine pelvic exam at age 50. (Canadian provinces transitioned what used to be annual pelvic exams to every three years in 2013. I believe that had I been checked yearly, my diagnosis would likely have come sooner.)

This was when I was finally sent for some diagnostic tests and referred to a gynecologist—the first time any doctor, even the urologist, had ever mentioned seeing this specialist. She suspected both fibroids and adenomyosis, a condition where endometrial tissue grows on the outside of the uterine wall instead of staying inside, where it's supposed to be. I'd only heard of endometriosis before, which is when uterine tissue grows on organs elsewhere in the abdomen.

Not only did I now have validation and recognition of my symptoms, I also had a cornucopia of options: medications, an IUD, uterine artery embolization (cutting off the blood supply to temporarily shrink the fibroids), myomectomy (removal of the fibroids) or a hysterectomy. Each had varying degrees of side effects and effectiveness, and some were faster to schedule than others.

The only cure for fibroids and adenomyosis is to remove the organ they grow on—the uterus. This is why my decision to have a hysterectomy was easy, even though it meant the longest wait: If I needed an invasive procedure, I wanted only one. And I wanted it to work.

The pandemic delayed my hysterectomy, but I finally had it in May 2022. Once the surgery began, it turned out to be more complicated than expected. Not only did I have several fibroids and adenomyosis, they also found ovarian cysts and endometriosis that had fused my uterus to my bowel. The uterus is normally plum-sized and squishy, but my uterus was so large and rigid that I needed a 10-centimetre incision up to my belly button to remove it. They initially

planned to operate through my cervix, then switched to laparoscopic mid-surgery, and then ended up having to do the vertical abdominal incision. Even the typical "bikini cut" C-section wouldn't have worked.

I felt vindicated when, explaining everything she'd found, my surgeon commented, "You must have incredible pain tolerance!" I guess I'd gotten good at sucking it up.

More than a year post-surgery now, I feel pretty great. I still get minor bloating and cramping twice a month, when I'm ovulating and during the week when I would have gotten my period. I still have my ovaries and, as far as I can tell, I haven't gone through menopause yet.

I do worry whether the endometrial tissue that had to be left on my intestine is still growing, and I hope that if I have another painful ovarian cyst rupture, it will pass quickly, like the others. And as I approach menopause, all of this should diminish. Though I realize I may be in for a whole other set of notorious symptoms that are often minimized.

Hindsight is 20/20, of course, but I have to wonder what could have happened if my doctors had looked into my symptoms when they first started, or when they worsened. What if I hadn't accepted "it's normal" for an answer, time and time again? Would they have found the fibroids, cysts, adenomyosis and endometriosis then? Would that have prevented decades of discomfort and pain? Would I have known at an early age that I was infertile anyway? Maybe I could have avoided the side effects and expense of birth control pills. Would an early hysterectomy have been simpler, without all the complications? Or would I have been outright denied a hysterectomy when I was still of child-bearing age?

I'll never know. I wish I'd taken my symptoms more seriously decades ago, and had better advocated for myself to get the help I needed.

Women's pain is valid, and it matters: It's telling us something is wrong. We shouldn't hesitate to demand more attention and to ask all of the questions until we get answers. Knowing our own bodies and wanting our medical concerns addressed doesn't mean we're problem patients. I've learned that toughing it out and living with pain for decades is neither acceptable nor something to be proud of. We have to speak up, and keep speaking up, until we get the care we deserve.

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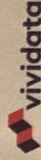
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PRINTED AND PUBLISHED SIX TIMES A YEAR BY THE READER'S DIGEST MAGAZINES CANADA LIMITED.

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Best Health publishes 6 issues per year and may occasionally publish special issues (special issues count as two), subject to change without notice. Subscriptions, \$27.97 a year, plus \$7.99 postage, processing and handling. Please add applicable taxes. Outside Canada, \$48.96 yearly, including postage, processing and handling. (Prices and postage subject to change without notice.) ISSN 1919-0387

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We acknowledge with gratitude the financial support of the Government of Canada.
Nous remercions le Gouvernement du Canada pour son appui financier.

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