

Uterine Fibroids

Do you experience a heavy flow and pain during your period? It could be a sign of a common condition. Although uterine fibroids are common, women with extreme cases say they wish they knew more information sooner.

Soo Youn
August 2, 2021
The Lily magazine

Elisabeth Johnson found out that she had a fibroid in 2010.

Her periods were slightly heavier than usual, she said, so she went to the doctor and got a pelvic ultrasound. She was living in Dallas at the time. As she recalls, the doctor didn't give her answers about how she got the fibroid — a benign tumor in her uterus — or what she could do to remove it. What she was told, she said, was that it was something that happened to mostly Black women, like herself, or Hispanic women.

When she recounted the experience to her mother, she told Johnson that she and other women in their family also had them.

When Johnson saw a family doctor three years later in Houston, she found out she had not one, but three fibroids. After a visit to the OB/GYN, Johnson was put on birth control to try to shrink the masses, and told to skip the sugar pills to avoid her periods — which would last for more than 20 days.

“So entirely frustrating and draining,” the third-grade teacher, now 35, said.

But according to Johnson, the fibroids have gotten larger in response to the birth control, although she rarely menstruates now. She's waiting to have an abdominal myomectomy — a surgery to remove the fibroids but leave the uterus intact. Johnson has one that sits on top of her uterus and two others along the outside, but she's bracing for the news that more may be found during the surgery. The surgical removal of the fibroids should result in less heavy bleeding and pelvic pain, doctors have told her.

Johnson's experience is not rare. Twenty to 80 percent of women develop uterine fibroids, also called myomas, or leiomyomas — muscular tumors in the wall of the uterus — by the time they turn 50, according to the U.S. Department of Health and Human Services' Office on Women's Health. In the United States, about 26 million women between the ages of 15 and 50 have uterine fibroids, and more than 15 million will experience symptoms or health issues as a result.

For most women, fibroids are small and asymptomatic and may even shrink or go away on their own. But for others, they can grow or multiply, either on their own or in an

adverse reaction to hormonal treatments. As they increase, they can enlarge the uterus to a size similar to pregnancy, and cause extremely heavy bleeding, pain, bloating, discomfort, frequent urination or constipation or fatigue related to anemia from the blood loss. In severe cases, they may affect fertility.

The Lily heard from 28 women and one nonbinary person about their experience with uterine fibroids. Many described periods that lasted weeks, if not months, including one woman who bled constantly for nearly 10 months, she said. Others described uteruses so extended they looked several months pregnant. One woman described fatigue so debilitating she had to nap before entering the house after parking her car. A common theme that emerged? It took many of the women a long time to receive a proper diagnosis.

Elizabeth Stewart, a reproductive endocrinologist at the Mayo Clinic whose specialty is uterine fibroid research, said that menstrual flow lasting for more than seven days, heavy bleeding or being diagnosed as anemic could be telltale signs of fibroids. Ultrasounds are most commonly used to scan for them.

She also pointed out that because there is a genetic component to fibroids, often women will ask other members of their families about their periods. If multiple women have them in a family, they may grow up thinking heavy bleeding and pain could be normal, rather than symptoms requiring medical guidance.

Stewart said many people incorrectly think that fibroids are mostly prevalent with Black women, when the problem is more universal. Fibroids do appear earlier in Black women, mostly in their 20s and 30s, in contrast with their 30s and 40s for White women. And Black women are more likely to develop larger fibroids and to undergo hysterectomy and myomectomy.

But despite the universal prevalence of fibroids, historically, there has been a lack of research and funding for such research.

Earlier this year, the Stephanie Tubbs Jones Uterine Fibroid Research and Education Act, supported by Rep. Yvette D. Clarke (D-N.Y.), Sen. Cory Booker (D-N.J.) and Sen. Shelley Moore Capito (R-W.V.), was introduced to earmark \$150 million over five years to fund research and education regarding fibroids. More research, many doctors say, is long overdue.

Erin Wolff, a reproductive endocrinologist in Bethesda, Md., spent almost a decade working in reproductive medicine at the National Institutes of Health. She pointed out that while NIH has 27 centers or institutes dedicated to specific areas of research, none are dedicated to women's health, which falls under the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

For former CIA and FBI agent Tracy Walder, the news of potentially more money into fibroid research is welcome. She started her period when she was 9, she said, and comes from a family that didn't really discuss menstruation, so she didn't realize her period

was heavier than what's considered normal. When she was at the CIA, she was prescribed birth control pills, which helped manage her periods. But when the pill she used was discontinued, and she stopped using oral birth control, her periods got worse again, she said.

In her mid-30s, when she wanted to conceive, Walder started in vitro fertilization. Her fertility doctor told her that she had fibroids, which is the first time she heard that she had them. He warned her that the hormones she'd need to take may cause her fibroids to grow, while also saying she may need to take them four times longer than the average IVF candidate. Eventually he recommended a surrogate, which she found, but still continued with the hormones for an embryo transfer.

The day after the transfer, Walder, who is now a college professor in Texas, passed out while teaching. When she got to the hospital, she was told she had 80 fibroids and was at risk for an imminent uterine rupture. She was immediately rushed into surgery to remove her uterus, cervix and fallopian tubes, she said, but was ultimately able to keep her ovaries.

Six months later, Walder's mother mentioned that her mother, Walder's grandmother, had a hysterectomy and thought it may have been caused by fibroids. "That information would have been really helpful when I was 10," said Walder, who hopes to destigmatize taboos about periods and gynecological issues. "We could have done something earlier."

In the past couple of years, two new medications have emerged to treat the heavy bleeding associated with fibroids without surgery: Oriahnn, which was approved by the Food and Drug Administration in 2020, and Myfembree, which was approved this year. Wolff said she is hopeful that the newer drugs will help some patients have another treatment option that could help avoid surgery.

Manhattan-based OB/GYN Bernadith Russell expressed caution regarding the new medications, saying that they are too new to draw any conclusions, but said she has been prescribing them for some people before surgery is their only treatment option. Russell said many fibroids can remain small and not cause other health problems, but women should see their doctor if they show symptoms: menstrual bleeding heavy enough to change a pad or tampon more than every four hours, pain with sex or penetration, frequent urination, or an enlarged abdomen.

Despite Kristina Tamanini not having the more common symptoms, her doctors discovered a fibroid in March 2019. She had gone in to check for kidney stones, because she was experiencing abdominal pain. She was told that the fibroid was small and that it may go away on its own. In December, Tamnini, who lives in Maryland, found out the mass was not that small.

"I finally found out about the sheer mass of my 27-centimeter uterine parasite, and they started to take things seriously," Tamanini said. She was rushed to see an oncologist to see if her fibroid was cancerous, and said she entered a period of stress and depression,

causing her to lose 20 pounds ahead of the surgery to remove it. She consulted with several doctors, who recommended a hysterectomy.

In March 2020, the then-30 year old went into surgery, hoping she would not need a complete hysterectomy. After more than five hours, and significant blood loss necessitating a blood transfusion, she came out of surgery to discover she had an exploratory laparotomy, or a surgical incision into the abdominal cavity, and myomectomy, an operation to remove the fibroids. The two-month recovery was extremely painful, Tamanini said.

Now that more than a year has passed, she wished there had been discussions earlier about the potential complications from the fibroid.

“I am now an infertile 31-year old woman with no children, a huge scar down my stomach ... and I will now have a lifetime of emotional pain from this outcome,” she said. “No woman should have to endure this.”