

**LAKE COUNTRY NOW**

# Endometriosis can be isolating, says one woman, who published a memoir to support others with this 'invisible illness'

**Alex Groth**

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Melissa Marks was 12 when she started to experience pain in her abdomen and lower back. She had no idea where the pain was coming from, but it didn't get better. In fact, it escalated. By her junior year of high school, she quit softball and her pain worsened to the point that she was canceling plans with friends and family. She persuaded her parents to take her to a doctor.

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Years went by, and the pain just kept getting worse. It was a never-ending cycle of doctors not believing her pain.

She graduated from the University of Wisconsin-Whitewater in 2012, moved to Madison and started a new job.

As a recent college graduate, she wanted to make some extra money and found an infertility clinic where she could sell her own eggs. But when the doctors couldn't retrieve any, they told her she might have endometriosis, a disease where the tissue that lines the uterus starts to grow outside the reproductive system.

She had never heard of it before. Symptoms include stomach pain, back pain, blood in the stool, exhaustion — all symptoms that Marks had experienced. It is also associated with infertility.

Marks is one of thousands of women in the U.S. dealing with the pain of endometriosis and infertility. Infertility affects one in eight couples of childbearing age, caused by complications in both men and women, according to the American Society of Reproductive Medicine. Compounding the problem in many states — including Wisconsin — insurance is not required to cover infertility treatment.

What followed for Marks were years of medications and surgeries.

She married her husband, Chris, in 2016, and they began in vitro fertilization, where fertilization occurs outside the womb in a laboratory and then the embryo is transferred to the uterus. The first two transfers were unsuccessful. The third transfer worked, and she became pregnant in early March 2020.

But then the COVID-19 pandemic arrived, exacerbating the isolation Marks had been feeling, and she wanted to tell her story to help others feel less alone. Marks, of Summit, self-published her memoir, "Fight Faithfully: The strength it takes to keep fighting when no one can see your pain," in September 2021. It's available through Amazon.

The writing process was therapeutic for Marks, and helped her reflect on what she calls an "invisible illness."

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## **An invisible illness**

"The sad truth of endometriosis is that very often young girls who complain of pain or painful periods are told that everyone's periods are painful; just live with it," said Bala Bhagavath, UW Health's fertility clinic's medical director of Generations of Fertility Care.

On average it takes about 12 years and four doctors to get a diagnosis for endometriosis, which affects one in six women, said Bhagavath.

Not all woman who have endometriosis are infertile, but 30% to 50% of women with endometriosis may experience infertility, according to ASRM.

Treating the disease can involve a risky surgery, especially if the tissue has grown against the bowel or bladder, said Bhagavath.

Medical professionals still don't know what causes endometriosis, he said. "We know that surgery does help, but not always. It has risks. We have new medications on the market, but the way these medications work is by putting someone through artificial menopause."

After giving birth to her daughter on Dec. 9, 2020, Marks' pain was "unexplainable." In the fall of 2021, Marks had a full hysterectomy.

"At the end of the day, there's always a risk of lesions growing back, and the hysterectomy that I had is supposed to be the most effective ways to get rid of endometriosis because if the uterus is gone, the lesions have a really hard time developing," Marks explained.

Research has shown that couples who experience the struggles associated with endometriosis and infertility are at increased risk for anxiety and depression, said Diane Schadewald, nursing professor at University of Wisconsin-Milwaukee.

"Going through an IVF cycle can be very stressful. There's the thought of, 'Why can't I conceive just the same as other people can?' she said.

## **The fight for care**

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Not all insurance companies are required to cover infertility treatments. In Wisconsin, a bill before the state Legislature would add Wisconsin to the 19 other states that already cover fertility diagnosis and treatment. The bill was introduced by Sen. Kelda Roys and Rep. Jodi Emerson.

As of April 2021, 13 states have passed fertility insurance coverage to include IVF coverage, and 11 states have fertility preservation laws for medically induced infertility, according to Resolve.

The average cost of an IVF cycle in the U.S. is about \$12,400, according to ASRM.

And while IVF can work — more than 1.2 million babies were born via IVF in the United States between 1985 and 2017 — it isn't always successful. The average success rate for IVF in 2015 was 31.8%, according to ASRM. Some couples might have to go through multiple cycles for a successful transfer.

"The exorbitant cost of fertility treatment is a barrier for many in their attempts to grow their family. It should not matter where you live or what job you have; coverage for infertility should be included in health care insurance plans," said Roys in a statement about the bill.

The bill was introduced by Democrats and has no Republican co-sponsors. It was referred for review but has little chance of passing in the current Legislature. A reporter reached out to Sen. Mary Felzkowski and Sen. Rob Stafsholt, chair and vice chair, respectively, of the Insurance, Licensing and Forestry Committee, but they did not return calls seeking an interview. Both are Republicans.

"It's an uphill battle," said Bhagavath, who helped write the bill. "Our hope is enough patients will write to their individual representatives and petition them to support the bill."

"Every time I see a patient I have to think about whether they can afford it, and that's not how I'm used to treating patients," said Bhagavath. "It's unfortunately become partisan, and I don't understand why. This is a disease; it impacts everybody."

## 'I believe you'

Melissa Mark's husband found out she had endometriosis when they started dating.



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"Most likely that person who's suffering has dealt with a lot of people in their life who didn't believe them, just because there's nothing they can see with their own eyes. It's just invisible," he said.

For family, friends and colleagues it can be challenging to watch someone you love go through endometriosis or infertility, said Chris Marks. "It's tough to witness as a spouse. You're watching someone you love go through so much pain physically and mentally."

"Looking back on it now, it was inspiring, because Melissa never wanted the disease to limit what she could do, and that's the way she's lived her life. It was never a question for us if we were going to be parents, it was when and how."

"She always wanted to be a mom, more than anything," he said.

To help process the trials of infertility, Novotny, who was diagnosed with infertility, created the ART of Infertility, a traveling exhibit that curates art portraying the realities of living with the disability. She was awarded the Hope Award for innovation by Resolve for using art to break the silence around reproductive grief.

"We don't know how to recognize that grief in our society, and our goal is to make those things visible for others who aren't going through it," said Novotny.

For those who know someone who might have endometriosis or infertility, Bhagavath urged them to take the condition seriously. In 1998, the U.S. Supreme Court ruled that infertility is a disability.

"Do not ignore or condescend your daughters or sisters who are suffering from severe pain," said Bhagavath. "Be compassionate and help them get the help they need."

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Contact Alex Groth at [agroth@gannett.com](mailto:agroth@gannett.com). Follow her on Twitter at [@grothalexandria](https://twitter.com/grothalexandria).