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Endometriosis & Advocating for Your Health

1 in 10

Women in the U.S. suffer from endometriosis

176 million

Women worldwide are affected by endometriosis

12 years

The average time it takes to get a proper diagnosis

These are the unfortunate truths of endometriosis — a condition that often goes undiagnosed for many women. In this article we'll dive into what endometriosis is, what the symptoms may be like, why it's so often misdiagnosed, and how you as a patient can advocate for yourself.

What is Endometriosis?

Location, Location, Location

Learning the basics of a biological woman's reproductive system is the first necessary step to understanding the condition endometriosis. Most women have an endometrial tissue that lines the cavity of their uterus. Every month, this tissue normally thickens in response to sex hormones to prepare for pregnancy. If pregnancy does not occur, this endometrial lining is shed in the form of a period (menstruation).

This process is not the same for women with the condition mainly because of the location of the tissue. Women who have endometriosis tend to have their endometrial tissue grow outside of the uterus, causing the tissue to become inflamed — and thus chronic discomfort and pelvic pain. Common sites for endometriosis include your ovaries, uterus, fallopian tubes, and more. Studies have also shown that it's difficult to understand the prevalence of endometriosis, however, for women who have chronic pelvic pain the prevalence of the condition is nearly 33%.

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Signs & Symptoms

- Pelvic pain that begins 1 to 2 days before a period starts, and continues throughout the period
- Abnormal periods
- Lower back pain
- Chronic fatigue
- Pain with vaginal intercourse
- Pain when you pee
- Heavy bleeding
- Irregular periods
- Bloating or nausea during your period
- Diarrhea
- Constipation
- Headaches
- Trouble getting pregnant
- Chronic pelvic pain – commonly described as throbbing, sharp, or even burning.

Why Is It Often Misdiagnosed?

Misdiagnosing endometriosis is partly due to misinformation about the condition, but also because the symptoms are similar to other gynecological issues. Women may believe that their symptoms are “normal” and never even go to the doctor. Period pains are partially to blame for this.

However, there are other times when it’s your doctors who misdiagnose you. The unfortunate part is that some doctors may not recognize the signs, or conduct a proper biopsy. There is certainly a lack of medical research and education on the disease, and that is also to blame.

What Can You Do if You Think You Have Endometriosis?

Start by getting to know your body. Some people opt to journal their symptoms and their pain level to ensure their doctor knows what and when they experience something. Anytime something feels “off” about your body, it’s worth looking into. And most importantly with your doctor, it’s important to be open. Don’t downplay your pain.