

# About one in 10 women experience endometriosis and the symptoms can be painful and devastating

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## MY STORY

**Evelyn, 34, from Melbourne, was in pain for years until she was eventually diagnosed with endometriosis.**

“It came to a tipping point in 2016 when my menstrual cycle was impacting my life, with horrible pain, dizziness and fatigue that left me bed-ridden and barely able to walk,” Evelyn says.

She saw several doctors who put her on a supplement to help her cycle, attributed the pain to inflammation due to a virus, or didn't investigate further.

Evelyn had to advocate for herself to get a diagnosis. She spent a year seeing GPs to try to explain her painful periods, eventually having a transvaginal scan that showed deep infiltrating bowel endometriosis.

Tissue that normally lines the uterus had spread outside her womb to her bowel. Evelyn was told she'd probably had endometriosis for 10 to 15 years.

“Having an invisible illness that deals with the topic of menstruation makes it difficult, at times, to express to other people what you are going through. Just because you look well, doesn't mean you are feeling well,” Evelyn says.

“When I was initially diagnosed, I felt overwhelmed. But having the support of my medical team and reaching out to other women with endometriosis has made me very hopeful that I can manage the disease, have a full life and not be defined by it.”

It's an often silent but debilitating condition, and it can start from the day a girl has her first period.

But in many cases, it will be years before a woman gets a diagnosis to explain symptoms including pelvic pain, bowel problems, back pain, nausea, heavy menstrual bleeding, painful sex and infertility.

About 176 million girls and women worldwide live with endometriosis and the condition can only be fully diagnosed through laparoscopic surgery. As yet, there is no cure.

Endometriosis occurs when the cells lining the uterus, which are usually shed at menstruation, are present within the pelvic cavity or other parts of the body. These cells can then stick to organs and grow to form plaques, lesions or cysts on the ovaries, fallopian tubes, peritoneal lining, bowel or bladder.

## CAUSES AND DIAGNOSIS

Jemma Evans, a senior scientist at the Hudson Institute of Medical Research, says the exact causes of endometriosis are still unclear.

“One theory is retrograde menstruation, when tissue that is usually shed during a period goes up the fallopian tubes and enters the abdominal cavity and then sticks to the bladder or intestines,” Dr Evans explains.

“There also appears to be a genetic component – you're five to seven times more likely to get endometriosis if your mum, sister or close female relative has it.

“Diagnosis can take seven to 10 years because women can brush off symptoms and think heavy or painful periods are normal, and their doctors are presented with relatively non-specific symptoms.

“But endometriosis can cause pain to the point that women nearly pass out, and it can lead to anaemia because women lose so much blood. Lots of women also find sex painful, which can affect their life with their partner.”

## MANAGING THE PROBLEM

Endometriosis is diagnosed through keyhole laparoscopic surgery, which is also a way of treating the condition. The surgery can remove lesions to try to reduce pain and improve fertility. About a third of women with endometriosis face infertility.

The contraceptive pill and hormone implants, such as an intra-uterine device, may also ease symptoms by stopping monthly bleeding and the growth of endometrial cells. In severe cases, a partial or total hysterectomy may be recommended. Some women have multiple surgeries to try to manage endometriosis.

## RESEARCH

Dr Evans is working on a new diagnostic test that would potentially save women from invasive laparoscopic surgery. The test involves hygienically collecting a sample of menstrual fluid in an egg cup-shaped silicon cup, worn like a tampon. That fluid could then be assessed to diagnose or rule out endometriosis: “Our hope would be that a woman can present with symptoms that aren't having too much of an impact on her yet. We could collect her menstrual fluid, analyse it, say 'yes' or 'no' and she could get treated earlier,” Dr Evans says.

Associate Professor Caroline Gargett, head of the Hudson Institute's Endometrial Stem Cell Biology laboratory, is leading a team of scientists examining the role of endometrial stem cells in the formation of lesions.

Researchers are also analysing proteins found in the womb to develop a test for detecting endometriosis as a cause of infertility.

“We want to better understand why endometriosis occurs, and how we can better treat and detect the disease earlier,”

Dr Evans says. 

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