

What doctors want patients to know about endometriosis



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Endometriosis, a chronic and often painful condition affecting millions of women worldwide, continues to be a significant yet under-recognized health issue. Characterized by the growth of tissue similar to the uterine lining outside the uterus, endometriosis can cause severe menstrual pain, fatigue, and even infertility. Despite affecting about one in 10 women of reproductive age, many still struggle to receive a timely diagnosis, often enduring years of symptoms before finding relief.

It can take between four and 11 years for women to receive a correct diagnosis of endometriosis. And as many as six out of every 10 cases of endometriosis remain undiagnosed, according to an article in the *American Journal of Obstetrics and Gynecology*. This is because its symptoms can vary greatly and may be caused by other conditions. Beyond that, receiving a definitive diagnosis of endometriosis requires surgery, which can be a barrier to seeking a diagnosis for patients.

The AMA's What Doctors Want Patients to Know™ series gives physicians a platform to share what they want patients to understand about today's health care headlines.

In this installment, Katie Peterson, MD, an ob-gyn at Confluence Health in Wenatchee, Washington, discusses what patients should know about endometriosis.

[Confluence Health](#) is a member of the [AMA Health System Program](#), which provides enterprise solutions to equip leadership, physicians and care teams with resources to help drive the future of medicine.

Abnormal tissue grows outside uterus

“[Endometriosis](#) describes a condition in which tissue from the lining of the uterus—the endometrium—is found outside the uterus,” said Dr. Peterson, noting that “endometrial lesions are often located in the pelvis, but can occur outside the pelvis in the bowel, diaphragm and even lung cavity.”

There are multiple causes

“Endometriosis results when cells from the lining of the uterus implant, grow and illicit an inflammatory response outside the uterine lining,” Dr. Peterson said. “Many theories have been proposed as to why this occurs, and it is likely that the development of endometriosis involves multiple mechanisms.”

One is “genetics. There is a predisposition to mutations that may explain more invasive lesions,” she said. Another likely contributing pathway is “retrograde menstruation, which is when cells flow backwards during the menstrual cycle through the fallopian tubes.”

Another possible mechanism is “stem cells within the uterus or other cells that change into endometrial-like tissues,” Dr. Peterson said. Then there is “premenarcheal endometriosis, which is when early uterine bleeding causes dissemination of endometrial cells.”

Endometriosis is common

“One out of 10 women of reproductive age have endometriosis,” Dr. Peterson said, noting “it is most commonly diagnosed among women in their 30s and 40s.”

“Recent efforts include work towards earlier diagnosis, that can facilitate earlier understanding and treatment for patients,” she added. Additionally, “up to 50% of females presenting with infertility will have endometriosis, and up to 70% of females presenting for evaluation of [chronic pelvic pain](#) will have endometriosis.”

And while “endometriosis typically affects women during menstruating—reproductive—years, peak prevalence is 25–35 years old,” Dr. Peterson

said.

Chronic pain is a common symptom

“The most common symptom of endometriosis is chronic pain. This pain often occurs just before and during a women’s menstrual cycle,” Dr. Peterson explained. “Women can also experience [pain with sex](#). If endometriosis affects the bowel or bladder, women can also have pain with bowel movements or during urination.”

“Aside from pain, women can also have heavy menstrual cycles. Endometriosis can also cause infertility,” she said. “However, some women with endometriosis will have no symptoms, and only learn they have the condition when they have an unrelated procedure.”

Several risk factors are at play

Women who have family history of endometriosis or who are nulliparous—meaning they have never given birth to a live child—are at increased risk of endometriosis, Dr. Peterson said. Other factors that place women at increased risk include “prolonged exposure to estrogen from early menarche or late menopause, shorter menstrual cycles, heavy menstrual bleeding, obstruction of menstrual outflow, taller height and lower body mass index.”

There are also factors that decrease a person’s risk of developing endometriosis such as “multiple births, extended intervals of lactation and later age of menarche—after 14 years old,” she added.

Endometriosis has four stages

“There are four surgical stages of endometriosis,” Dr. Peterson said. “Stage 1 is minimal disease characterized by isolate implants and no significant adhesions.”

“Stage 2 involves superficial implants that are less than 5 cm in aggregate and are scattered on the peritoneum and ovaries with no significant adhesions,” she explained. “Stage 3 is multiple implants, both superficial and deeply invasive, and may have adhesions around the tubes and ovaries.”

Then “stage 4 is multiple superficial and deep implants, including large endometriomas of the ovary and filmy and dense adhesions,” Dr. Peterson said. “This system provides a standard approach for reporting operative findings but does not necessarily correlate with the severity of symptoms.”

“However, more advanced endometriosis does suggest a worse prognosis for fertility treatments,” she added.

Diagnosis involves laparoscopy

“Endometriosis is diagnosed with surgery with a procedure called laparoscopy where a camera is used to look inside the abdomen,” Dr. Peterson said. “At time of laparoscopy, a surgeon will look for tissue consistent with endometriosis, and may also remove tissue—perform a biopsy—that a pathologist can review to confirm diagnosis of endometriosis.”

“Suggestive findings on clinical exam include tenderness with vaginal examination, palpable nodules in the posterior fornix of the vagina, pelvis masses or immobility of the cervix or uterus,” she said. But a “true diagnosis requires a surgical procedure, although patients can be presumptively diagnosed based on symptoms, or improvement in symptoms with appropriate treatment.”

“Additionally, endometriosis symptoms—pain and heavy bleeding—are often found associated with other conditions and are not specific just to endometriosis,” Dr. Peterson cautioned.

Medications and surgery are options

“Treatment of endometriosis can include medications, surgery or both,” Dr. Peterson said. Medications include drugs such as “ibuprofen, combined contraceptives of estrogen and progestin taken in a continuous fashion, [progestins](#)—pills, arm implant or hormone continuing IUD, gonadotropin-releasing hormone analogs, GnRH agonists, danazol, aromatase inhibitors and neuropathic pain treatments.”

Then there is “surgical removal of endometriosis and nerve transection,” she said. “Surgery is used to remove endometriosis tissue from spaces where it doesn’t belong. Removing this tissue can improve pain and fertility. Most patients achieve initial pain relief after surgery.”

Endometriosis can’t be prevented

“Given that the cause is not completely understood, it is not possible to prevent endometriosis,” Dr. Peterson said. “However, it is likely that some of the treatments that help symptoms also prevent spread or worsening inflammation associated with the disease.

“Most notably, hormonal treatments that suppress ovulation and menstruation may prevent worsening of endometriosis,” she added.

Mental health is affected

“Endometriosis is a chronic condition that will likely require management for a significant portion of someone’s life. This can be very difficult,” Dr. Peterson said, noting that “like other chronic pain disorders, endometriosis is associated with increased risks of depression and [anxiety](#).”

“I find that my patients sometimes benefit from community found within endometriosis support groups, from care at an endometriosis specific clinic if available, and from taking part in relevant research that may help both their symptoms and those of other women in the future,” she said. Meanwhile, “treating chronic pain often requires broad treatment modalities.

“For example, pelvic floor physical therapists are an important resource to help with pelvic floor tension and pain,” Dr. Peterson added. “And there is some evidence that acupuncture may help with endometriosis-related pain.”

Infertility is a concern

“Per the American College of Obstetricians and Gynecologists, almost four out of 10 women with [infertility](#) have endometriosis,” Dr. Peterson said. That is because “endometriosis can cause inflammation and scarring that blocks the fallopian tubes.”

“Additionally, inflammation can damage the egg or sperm and interfere with their movement through the fallopian tube,” she said, noting that other complications of endometriosis can be “ovarian cysts, urinary or bowel symptoms, endometriosis beyond the pelvis and chronic pain.”

Ovarian cancer can develop

“Patients with endometriosis have a two to four times [risk of ovarian cancer](#),” Dr. Peterson said. “The highest risk of [ovarian cancer](#) is for patients with deeply infiltrating endometriosis or endometriomas,” which are cystic lesions that form in the ovaries.

Menopause doesn’t stop endometriosis

“The course of endometriosis is varied. Some women will have findings consistent with endometriosis, and minimal symptoms. Some women have minimal findings and marked symptoms,” Dr. Peterson said. “Therefore, it is difficult to predict the untreated course for any specific patient.”

“There are times when symptoms usually—but not always—decrease, including both pregnancy and menopause,” she said, noting that while “endometriosis may remain active after [menopause](#) ... severe symptoms are uncommon after the menopause transition.”

And while “there is no current cure for endometriosis ... there is always hope for managing symptoms,” Dr. Peterson said.