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# The "silent" pain of endometriosis

Compassionate care can change the lives of women with this condition.

By Amanda Perkins, DNP, RN

Approximately 200 million women worldwide and more than 6.5 million women living in the US have endometriosis, according to the Endometriosis Foundation of America and the Office on Women's Health. The estimated annual cost of endometriosis in the US is $110 billion, including money spent as a result of medical care and missed work/school. The estimated annual cost of this disorder can be determined, but what can't be determined is the cost to a woman's life and emotional health.

Endometriosis can lead women to feel helpless and frustrated because it has no known cause, no cure, and is hard to see, leading to misbelief in or misunderstanding of symptoms. This article discusses the basics of endometriosis, signs and symptoms, diagnosis, treatment, and complications.

## The basics

Endometriosis can affect any female who's started menstruating, although it's more common in women who are between ages 30 and 40. With endometriosis, the uterine lining, also known as the endometrium, grows outside the uterus. In women with endometriosis, the uterine lining most commonly grows on the ovaries, fallopian tubes, uterosacral ligaments supporting the uterus, and outer surface of the uterus (see *Common sites of endometriosis*). Additionally, the uterine lining may grow on the vagina, cervix, bowel, bladder, posterior cul-de-sac between the uterus and bladder, and/or rectum. In rare cases, it may even be found on the lungs, brain, and skin.

The endometrial growths respond to a woman's menstrual cycle and bleed in the same way that the uterine lining bleeds, leading to swelling and pain. In the uterus, endometrial bleeding exits the body via the vagina, whereas endometrial bleeding in other parts of the body won't be able to exit, causing pain and inflammation. In addition to bleeding, the tissue grows in response to estrogen and progesterone. When the endometrial tissue grows outside the uterus, inflammation develops because the immune system attempts to remove these cells. This inflammation will eventually lead to the development of scar tissue, adhesions, internal bleeding, bowel and bladder dysfunction, constipation, pain with sex, and infertility.

The exact cause of endometriosis is unknown, although the following have been identified as potential causes:

- menstrual flow dysfunction, such as retrograde menstrual flow in which tissue shed during menstruation flows through the fallopian tubes and into other areas of the body, leading to endometrial growth outside the uterus
- genetics (If a woman's mother or sister has endometriosis, she's six times more likely to develop the disorder.)

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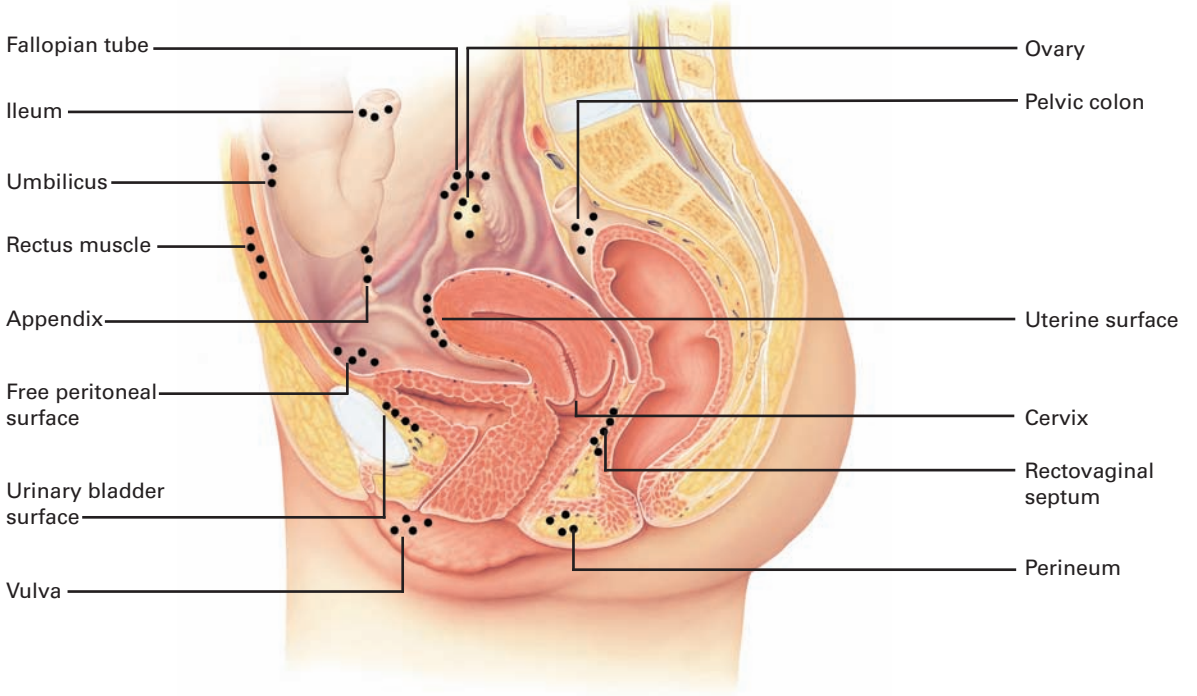
## Common sites of endometriosis




Source: Lippincott's Nursing Advisor, 2012.

- immune system dysfunction in which the immune system fails to find and destroy endometrial tissue that grows outside the uterus
- hormones (Estrogen appears to enhance the growth of endometrial tissue.)
- giving birth for the first time after age 30
- surgery, specifically abdominal surgery, can result in endometrial tissue being picked up and deposited elsewhere in the body.

Certain risk factors have been identified and associated with endometriosis, including:

- having no pregnancies
- periods lasting longer than 7 days
- short menstrual cycles lasting 27 days or less
- family history
- medical conditions in which the flow of menstrual blood is blocked.

Interestingly, endometriosis can be present at birth, although it doesn't become activated until the first menstrual period.

### Signs and symptoms

The following signs and symptoms are associated with endometriosis:

- pain (most common)
- bleeding/spotting between periods
- long periods
- heavy menstrual flow
- bowel disorders
- urinary disorders
- infertility
- diarrhea
- constipation
- bloating
- nausea
- vomiting
- pain during sex
- chronic fatigue
- neuropathy.

The pain associated with endometriosis may include pain in the lower back and

pelvis, pain during/after sex, intestinal pain, painful bowel movements, pain with urination, and menstrual cramps. In many cases, painful bowel movements and urination are most prominent during menstruation. The patient may report back pain that travels down the back of her legs due to sciatica. It's important to understand that the pain a woman experiences may intensify over time. Women with endometriosis may also report chronic fatigue, which isn't a matter of simply feeling tired at the end of a long day. These patients feel physically exhausted and may have difficulty completing everyday tasks as a result.

When endometrial tissue develops on the ovaries, blood can become embedded in the tissue and surrounded by a fibrous cyst called an endometrioma, which is different than a typical ovarian cyst. Endometriomas can encapsulate the ovaries, creating adverse signs and symptoms that may lead to infertility and an increased risk of ovarian cancer. In some cases, surgical treatment may be necessary, including biopsy, drainage and coagulation of the cyst, removal of the cyst from the ovary, and laser ablation.

For some women, a reduction in symptoms may occur during pregnancy due to increased progesterone levels. Additionally, once a patient goes through menopause, symptoms may improve as the level of estrogen declines. In some instances, a woman may have silent endometriosis, which is often associated with infertility. The patient may not know that she has endometriosis until she has difficulty conceiving.

## Diagnosis

The diagnosis of endometriosis often takes years, sometimes up to 10 years or more. Often, the woman will be misdiagnosed before the diagnosis of endometriosis. In fact, some women are misdiagnosed multiple times. Irritable bowel syndrome is a common misdiagnosis because this disorder has some symptoms that mimic endometriosis. Another common misdiagnosis is when women are told that the symptoms they're experiencing aren't real or that the symptoms are normal. It's important to understand that being diagnosed can bring a sense of relief for the patient, validating the symptoms she's experiencing.

### did you know?

Endometriosis has been poorly understood for centuries. Research has shown that hysteria—a disorder that was presumed to be psychological in nature—was most likely endometriosis. Treatment for hysteria consisted of bloodletting, straightjacket use and/or committal to an asylum, chemical douches, genital mutilation, being hung upside down, and, in some instances, executions. It was believed that pregnancy was the cure for hysteria. Women were urged to get married and become pregnant as soon as possible after starting menstruation.

Diagnosis may be made based on a pelvic exam, imaging, medications, and/or laparoscopy. When a healthcare provider completes a pelvic exam on a patient with potential endometriosis, he or she feels for cysts or scars located behind the uterus. Imaging tests may include an ultrasound, a computed tomography scan, or MRI to identify associated problems such as cysts. These tests are often performed before diagnostic laparoscopy. Two medications used to aid in diagnosis are hormonal birth control and gonadotropin-releasing hormone (GnRH) agonists. If pain improves when taking hormonal medications, a patient is believed to most likely have endometriosis. However, the only way to make a definitive diagnosis is via a diagnostic laparoscopy with biopsy. Laparoscopy is a surgical procedure that allows the healthcare provider to look within the patient's pelvis, find endometrial tissue, and biopsy the tissue for microscopic analysis. Currently, there's no lab test that's diagnostic for endometriosis.

Endometriosis has four stages: minimal, mild, moderate, and severe. The staging of

## key points

When assessing a patient with known, or suspected, endometriosis, ask the following questions:

- Do you have a family history of endometriosis?
- Have you ever given birth? If yes, at what age did you give birth to your first child?
- Did your symptoms improve while you were pregnant?
- Do you have any problems with infertility?
- Have your symptoms improved with menopause?
- Have you ever had any surgical procedures? If yes, what type of procedure?
- Do you have any problems with your menstrual cycle? If yes, describe the problems that you experience.
- Do you experience chronic pain? If yes, where's the pain and how would you rate/describe the pain?
- Do you frequently feel fatigued?
- Do you have any urinary or bowel disorders? If yes, describe the problems that you experience.

endometriosis is dependent on location, how far the endometrial tissue has spread, how deep the endometrial tissue is, the presence and size of endometriomas, and the presence of adhesions. The level of pain isn't related to the stage and plays no role in determining the stage.

## Treatment

Endometriosis can't be prevented or cured, so treatment is often based on the presenting symptoms. However, it's believed that the following can lower a woman's chances of developing endometriosis:

- taking hormonal birth control with low doses of estrogen
- exercising regularly and for more than 4 hours per week to decrease body fat, which correlates with lower levels of estrogen
- avoiding large amounts of alcohol and caffeinated drinks because alcohol and caffeine have been shown to increase estrogen.

The symptoms of endometriosis can be treated with the following:

- low-dose oral contraceptives
- hormonal intrauterine device (IUD)
- hormone (GnRH) therapy
- pain medications
- acupuncture
- chiropractic services
- herbs and supplements
- changes in diet
- surgery.

If a patient isn't pregnant or trying to get pregnant, birth control is typically the first-line treatment. Birth control can be given as an extended cycle, where the patient has a few periods per year, or on a continuous cycle, where the patient has no periods. Both these options decrease bleeding, often decreasing pain in the process. Another form of birth control that may be used to decrease bleeding and pain is an IUD. Although IUDs can prevent pregnancy for up to 7 years, they may not be effective at controlling pain and bleeding for that amount of time.

Birth control can reduce heavy bleeding and pain, shrink ovarian cysts for some women, and slow down endometrial tissue growth. However, it doesn't cure endometriosis or prevent it from advancing. And once birth control is stopped, any symptoms that have improved will return. Additionally, the symptoms that return may be worse than they were before the start of birth control because the endometrial tissue continued to grow during treatment.

The patient can also be given a GnRH agonist, usually for a short period of time, which will stop the body from making the hormones responsible for ovulation and the menstrual cycle. This medication will basically put the patient into a temporary menopause, which is associated with negative adverse reactions such as hot flashes and emotional fluctuations. Treatment with GnRH may also improve the likelihood of a woman with endometriosis becoming pregnant. Once the medication is stopped, the likelihood of becoming pregnant increases.

Symptoms may be managed with pain medications such as ibuprofen or naproxen, acupuncture, chiropractic services, and herbs and/or supplements. Research has shown that acupuncture is effective, safe, and well tolerated by patients with endometriosis and is associated with very few to no adverse reactions. At this time, it's recommended that more research be conducted on the use of acupuncture for patients with endometriosis.

Proper nutrition is often an important facet of symptom management, with many healthcare providers recommending the avoidance or elimination of gluten and dairy. The following foods have been identified as inflammatory foods and should be avoided by those with endometriosis:

- white sugar
- dairy
- common cooking oils
- deep-fried foods
- processed foods
- red meat
- gluten.

Foods with anti-inflammatory properties that can be beneficial include:

- cumin
- turmeric
- berries
- pineapple
- papaya
- broccoli
- cauliflower
- sweet potatoes
- olive oil
- shiitake mushrooms
- salmon
- green tea
- nuts.

Surgery is used as a treatment for endometriosis when the patient has severe symptoms, if hormonal birth control isn't working, or if the patient is having problems with fertility. The gold standard for surgical treatment is laparoscopic excision surgery. Because most of the endometrial tissue is found below the surface, deep excision must be performed, which involves the removal of the entire lesion. If surgery doesn't include removal of the tissue below the surface, the patient's symptoms will often return quickly. Once surgery has been completed, the patient will be started back on hormonal birth control unless she's trying to become pregnant.

Other types of surgical procedures that may be performed are ablation and cauterization. Ablation involves the use of lasers to destroy endometrial tissue. Cauterization is when the tissue is burned off. These procedures aren't ideal because it's preferred to use minimal heat and electricity, which can't be avoided with ablation and cauterization. Additionally, these procedures only remove the tissue at the surface and, as a result, aren't effective for a prolonged period of time. They also lead to the development of scar tissue, which can increase the patient's symptoms.

Many women believe that having a hysterectomy will cure endometriosis, but this isn't factual because it doesn't remove the lesions found outside the uterus. A hysterectomy will work for adenomyosis, a sister disease in which endometrial cells develop in the muscle tissue of the uterus

## did you know?

Endometriosis can be found in men in rare cases. The cause of endometriosis in men is unknown, but it's believed that estrogen plays a role. A man's estrogen levels may be increased if he's taking estrogen for cancer treatment, has liver damage, or is obese. Endometriosis can be very difficult to diagnose in female patients and is likely more difficult to detect in male patients. In most cases, endometriosis in the male patient will develop on the bladder, lower abdominal wall, and/or inguinal region. Treatment for endometriosis in men includes surgery and/or stopping hormonal treatment.

Sources: Endometriosis News. Endometriosis in men. 2019. https://endometriosisnews.com/endometriosis-in-men.
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(see *Understanding adenomyosis*). If the patient does undergo a hysterectomy, it's important to provide emotionally supportive care.

## Associated conditions and complications

The following medical conditions have been associated with endometriosis:

- infertility
- allergies
- asthma
- chemical sensitivities
- autoimmune diseases
- chronic fatigue syndrome
- fibromyalgia
- certain cancers, such as ovarian and breast cancer.

As many as 50% of women with fertility problems have endometriosis. The length of time a woman has endometriosis is relational to her risk of infertility. The longer the endometrial tissue grows, the higher the risk of infertility. In addition to problems with infertility, it isn't uncommon for women with endometriosis to report pain with sex, which may be due to adhesions that occur in the vagina and rectum. As a nurse, it's important to address this topic with the patient, understanding that it may be an uncomfortable topic for her to discuss.

Endometriosis can negatively affect a woman's life, leading to problems with school, work, finances, social life, relationships, and overall well-being. Women with endometriosis experience chronic pain.

### Understanding adenomyosis

Adenomyosis occurs when endometriosis develops in the uterine muscle. Patients with adenomyosis have uterine thickening because endometrial tissue grows in the outer muscular walls of the uterus. This condition is most common in women who've had multiple births. Patients can have both adenomyosis and endometriosis.

Signs and symptoms of adenomyosis include painful menstruation, heavy bleeding, prolonged bleeding, and an enlarged uterus. Patients with adenomyosis may develop adenomyomas—masses or growths inside the uterus. Diagnosis can be made with ultrasound, MRI, or after a hysterectomy. Treatment may include pain medications and hormone therapy to decrease pain and bleeding. If pain medications and hormone therapy don't control symptoms effectively, the patient may opt for a hysterectomy.

### on the web

**American College of Obstetricians and Gynecologists:** www.acog.org/Patients/FAQs/Endometriosis
**Cleveland Clinic:** https://my.clevelandclinic.org/health/diseases/10857-endometriosis
**Endometriosis Association:** https://endometriosisassn.org
**Endometriosis Foundation of America:** www.endofound.org
**Endometriosis.org:** www.endometriosis.org
**Johns Hopkins Medicine:** www.hopkinsmedicine.org/healthlibrary/conditions/gynecological_health/endometriosis_85,p00573
**Mayo Clinic:** www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656
**MedlinePlus:** https://medlineplus.gov/endometriosis.html
**National Institutes of Health:** www.nichd.nih.gov/health/topics/endometriosis
**Office on Women's Health:** www.womenshealth.gov/a-z-topics/endometriosis
**TeensHealth:** https://kidshealth.org/en/teens/endometriosis.html

Research has shown that chronic pain can lead to changes in the brain, including neural networks and brain morphology. Because the woman may experience changes to the midbrain—the area responsible for the inner persona—endometriosis can literally lead to personality changes. In some instances, a lack of awareness or understanding by loved ones is associated with little to no support, which can lead to negative emotional consequences for the patient. Due to the fact that this disorder presents with symptoms that can't be seen, it can negatively affect nearly every aspect of a woman's life, often with those around her unaware of the pain with which she's struggling.

## Raising awareness

It's essential for women with endometriosis to know that they have an advocate, especially because many young women are told that the pain they're experiencing is normal. Education needs to be provided to adolescent girls so they know what's

normal and abnormal when it comes to menstruation and associated pain. It's also recommended that adolescent boys be educated about menstruation so they have an understanding of what's normal and abnormal. It's believed that this education will lead to healthier relationships and better understanding for women who develop endometriosis. Additionally, we need to understand that the family and significant others of women with endometriosis can be emotionally affected. Be ready and available to provide support for these individuals as needed.

Endometriosis is a silent disease—one that can't be seen or heard—yet it affects millions of women worldwide. Nurses can help shed light on this condition through education and by providing understanding, empathetic care. ■


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