

 **March 2018- National Endometriosis Awareness Month** 

A note from the author—

Happy March NCP friends! This month, I decided to feature a Women's Health topic, especially since I have several family members and friends currently struggling with this condition. There are many illnesses and health conditions that are rarely discussed due to certain associated "stigmas", or because patients feel embarrassed talking about subjects they feel to be "private". Endometriosis seems to be one of those conditions. Although many people have heard of this disease, it is often misunderstood and, even more frequently, mis- or under-diagnosed. In this month's Health Ministry article, I have included a lot of information about Endometriosis, including what it is, how it feels, and how it impacts your health. Also, I have included a lot of questions that women want to ask, but may be too uncomfortable talking to anyone, let alone their doctor, about. This month, celebrate National Endometriosis Awareness Month by learning more about this condition below!



What is Endometriosis?

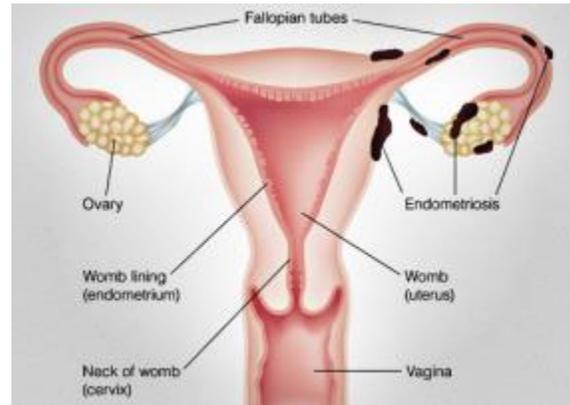
Endometriosis, sometimes called "endo," is a common health problem in women. It gets its name from the word endometrium, the tissue that normally lines the uterus or womb. Endometriosis happens when this tissue grows outside of your uterus and on other areas in your body where it doesn't belong.

Let's get more specific... the Mayo Clinic defines endometriosis as follows: Endometriosis (en-doe-me-tree-O-sis) is an often painful disorder in which tissue that normally lines the inside of your uterus — the endometrium — grows outside your uterus. Endometriosis most commonly involves your ovaries, fallopian tubes and the tissue lining your pelvis. Rarely, endometrial tissue may spread beyond pelvic organs.

With endometriosis, displaced endometrial tissue continues to act as it normally would — it thickens, breaks down and bleeds with each menstrual cycle. Because this displaced tissue has no way to exit your body, it becomes trapped. When endometriosis

involves the ovaries, cysts called endometriomas may form. Surrounding tissue can become irritated, eventually developing scar tissue and adhesions — abnormal bands of fibrous tissue that can cause pelvic tissues and organs to stick to each other.

Endometriosis can cause pain — sometimes severe — especially during your period. Fertility problems also may develop. Fortunately, effective treatments are available.

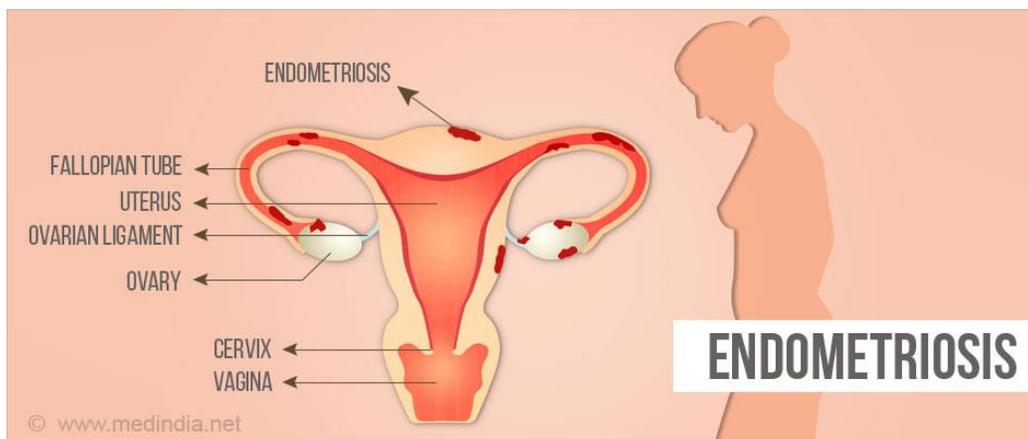


Where does Endometriosis form?

Most often, endometriosis is found on the:

- Ovaries
- Fallopian tubes
- Tissues that hold the uterus in place
- Outer surface of the uterus

Other sites for growths can include the vagina, cervix, vulva, bowel, bladder, or rectum. Rarely, endometriosis appears in other parts of the body, such as the lungs, brain, and skin.



How is Endometriosis different from a regular period?

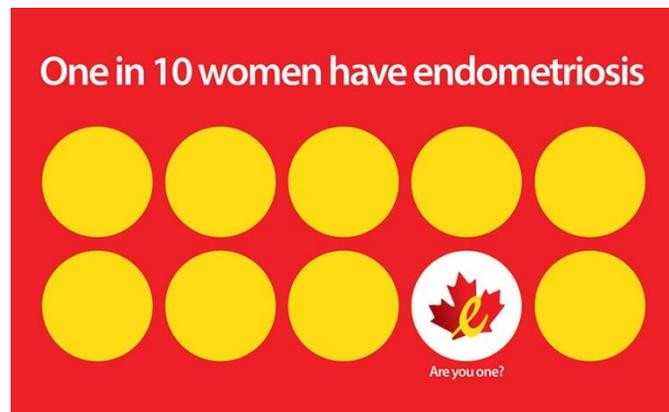
Endometriosis is characterized by the presence of endometrial-like tissue located outside the womb, where it doesn't belong. These fragments are different structurally, and behave differently, from the normal endometrium which is shed during a period.

With endometriosis, the disease occurs on the pelvic structures (and sometimes beyond), causing severe pain, bowel, bladder or other organ dysfunction, inflammation, scarring and adhesions, and in some cases, infertility. Endometriosis represents a significant clinical challenge commonly associated with reduced quality of life in those affected. Symptoms are frequently wide-ranging and often start early in life, but may be underappreciated by medical and lay communities alike.

The Impact of Endometriosis

Endometriosis Awareness takes place across the globe during the month of March (and beyond) with a mission to raise awareness of a disease which affects an estimated 176 million women worldwide. Endometriosis can have a devastating effect on quality of life due to its very painful symptoms; it is the biggest cause of infertility in women, and carries a huge personal and societal cost!

Endometriosis happens when the lining of the uterus grows outside of the uterus. It may affect more than 11% of American women between 15 and 44. It is especially common among women in their 30s and 40s and may make it harder to get pregnant. Several different treatment options can help manage the symptoms and improve your chances of getting pregnant.



What Causes Endometriosis?

Often called a “disease of theories”, the definitive cause(s) of endometriosis remain under debate, though demonstrated association with a number of hereditary, environmental, epigenetic and menstrual characteristics exist. **NO SINGLE RESEARCHER HAS FOUND “THE” ANSWER.** The chronic, inflammatory reaction, infertility and pain associated with endometriosis may also correspond to a variety of co-morbid conditions ranging from autoimmune disease to food and environmental allergies and intolerances.

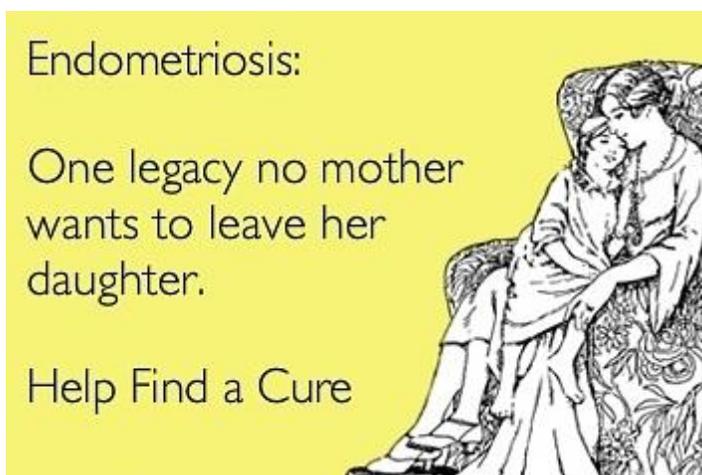
Theories include:

- **Retrograde menstruation.** In retrograde menstruation, menstrual blood containing endometrial cells flows back through the fallopian tubes and into the pelvic cavity instead of out of the body. These displaced endometrial cells stick to the pelvic walls and surfaces of pelvic organs, where they grow and continue to

thicken and bleed over the course of each menstrual cycle. This theory does NOT explain pathogenesis

- **Transformation of peritoneal cells.** In what's known as the "induction theory," experts propose that hormones or immune factors promote transformation of peritoneal cells — cells that line the inner side of your abdomen — into endometrial cells.
- **Embryonic cell transformation.** Hormones such as estrogen may transform embryonic cells (stem cells) — cells in the earliest stages of development — into endometrial cell implants during puberty. These cells have been demonstrated to populate lesions, even in absence of menstruation
- **Surgical scar implantation.** After a surgery, such as a hysterectomy or C-section, endometrial cells may attach to a surgical incision.
- **Endometrial cells transport.** The blood vessels or tissue fluid (lymphatic) system may transport endometrial cells to other parts of the body.
- **Immune system disorder.** It's possible that a problem with the immune system may make the body unable to recognize and destroy endometrial tissue that's growing outside the uterus. Basically, this theory says that, a “broken” immune system allows for implantation of menstrual debris.
- **Genetics** – a 7-10 fold risk exists in women and girls whose mother or relative has disease
- **Environmental Toxins** – can cause cell changes which allow for implantation and errant immune response

No single theory explains endometriosis in all patients. Likely, we are born with mechanisms which, when later combined – “the perfect storm – trigger the disease.



The Symptoms of Endometriosis

The primary symptom of endometriosis is pelvic pain, often associated with your menstrual period. Although many women experience cramping during their menstrual period, women with endometriosis typically describe menstrual pain that's far worse than usual. They also tend to report that the pain increases over time. Although symptoms may vary, classic signs include severe dysmenorrhea, painful sex, chronic pelvic pain, Mittelschmerz (painful ovulation), cyclical or perimenstrual symptoms (i.e. bowel or bladder associated) with or without abnormal bleeding, infertility and chronic fatigue.

Common signs and symptoms of endometriosis may include:

- **Painful periods (dysmenorrhea).** Pelvic pain and cramping may begin before your period and extend several days into your period. You may also have lower back and abdominal pain.
- **Pain with intercourse.** Pain during or after sex is common with endometriosis.
- **Pain with bowel movements or urination.** You're most likely to experience these symptoms during your period.
- **Excessive bleeding.** You may experience occasional heavy periods (menorrhagia) or bleeding between periods (menometrorrhagia).
- **Infertility.** Endometriosis is first diagnosed in some women who are seeking treatment for infertility.
- **Other symptoms.** You may also experience fatigue, diarrhea, constipation, bloating or nausea, especially during menstrual periods.

The severity of your pain isn't necessarily a reliable indicator of the extent of the condition. Some women with mild endometriosis have intense pain, while others with advanced endometriosis may have little pain or even no pain at all.



is this normal?

Worried about your periods? Don't know what to expect? Concerned that what you are going through might not be normal?

If you are worried or concerned about your periods or just want to find out more, visit our website, call our help line, or speak to someone.

Don't suffer in silence.

endometriosis uk
the leading UK charity that supports women living with endometriosis
Registered Charity No. 1035810

Helpline 0808 808 2227
www.endometriosis-uk.org

Poster Design by Kate Sedgwick - www.katesedgwick.co.uk @katerose_sedgwick

The poster features three stylized female figures with long, flowing hair, each holding a large rose. The background is a solid pink color. The text is in a clean, sans-serif font.

Other health conditions you may have

Women with endometriosis also frequently suffer from autoimmune inflammatory diseases, allergies and asthma, and endometriosis shares similarities with several autoimmune diseases including elevated levels of cytokines, decreased apoptosis and cell-mediated abnormalities.

Frequent misdiagnosis

Endometriosis is sometimes mistaken for other conditions that can cause pelvic pain, such as pelvic inflammatory disease (PID) or ovarian cysts. It may be confused with irritable bowel syndrome (IBS), a condition that causes bouts of diarrhea, constipation and abdominal cramping. IBS can accompany endometriosis, which can complicate the diagnosis.

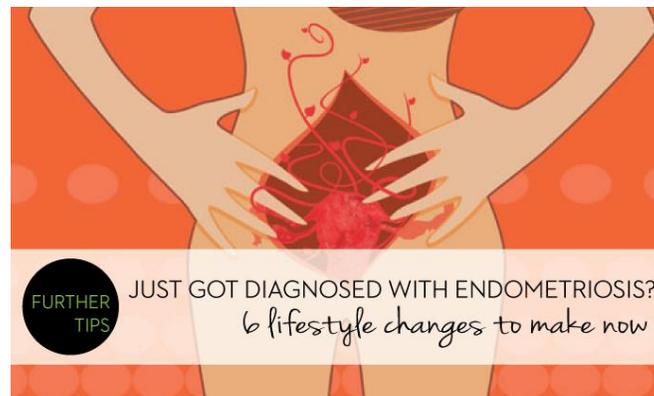
What's the Big Deal? It's Just "Killer Cramps," Right?

Wrong. This mistaken assumption diminishes and invalidates the suffering of every individual with the disease and can lead to feelings of isolation.

So – What IS Normal?? Minor cramping during menses, often treated with over the counter remedies. Each month, tissue lining the uterus (endometrium) breaks down, sheds and exits the body resulting in normal menstruation. Inflammatory hormones – particularly those known as prostaglandins – are linked to the minor cramping and discomfort of a normal period. This is called “dysmenorrhea”. **Dysmenorrhea is not the same as endometriosis**, nor is the disease simply comprised of ‘normal’ endometrium in abnormal places – as many sources and organizations mistakenly assert.

The following are NOT normal:

- Pelvic pain that gets worse after sex or a pelvic exam
- Chronically heavy or long periods
- Bowel or urinary disorders associated with periods
- Painful sexual activity, particularly with penetration
- Significant lower back pain with menses
- Allergies, migraines or fatigue that tends to worsen around menses
- Crippling menstrual pain
- Catamenial pneumothorax (in lung endometriosis)



I can read the symptoms, but what does Endometriosis FEEL like?

Women with endometriosis are more likely to report their pain as “throbbing” and experience dyschezia (constipation) when compared with women with an apparently normal pelvis, and specific menstrual symptoms have been reported to occur more frequently in women with the disease as compared with a control group. Endometriosis is more commonly found on the left side, with at least one study indicating 56% of women having left-sided disease versus 50% having right-sided disease.

Can specific pain symptoms help in the diagnosis of endometriosis? Yes, some studies have shown that pain locations and pain during certain task/times may indicate where the endometriosis tissue has attached inside of the body. Examples from a cohort study of women with chronic pelvic pain are below:

- Women with hematochezia (rectal bleeding) during menses had endometriosis that involved the rectosigmoid colon.
- Flank pain and/or hematuria (blood in urine) was present when the bladder or ureters has endometriosis lesions.
- Sexually active women reported dyspareunia (pain during sex) and frequent backaches, due to scarring of the uterosacral ligaments, nodularity of the rectovaginal septum, cul-de-sac obliteration, and/or uterine retroversion.

ENDOMETRIOSIS: GET THE FACTS

WHAT IS IT? Endometriosis is a disorder in which tissue that normally lines the uterus grows outside the uterus instead.

It affects girls and women of reproductive age, and it can attach to any organ associated with reproduction.

On average in the United States, it takes 10 years from symptom onset to receive an accurate diagnosis.

SYMPTOMS

- Intense pelvic pain
- Infertility
- Long menstrual cycles
- Nausea or vomiting

Causes

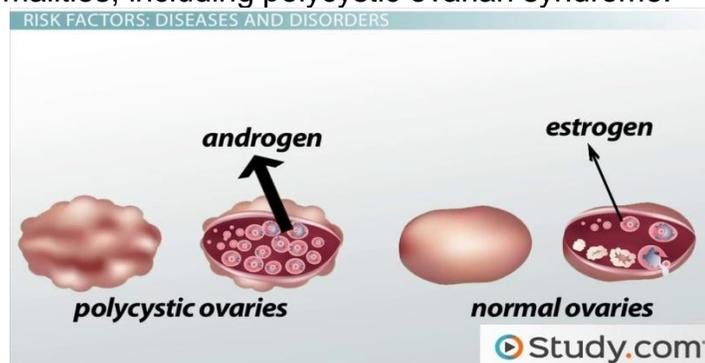
- ▶ The cause is unknown.
- ▶ It cannot be passed from person to person.
- ▶ There may be a genetic component to endometriosis.
- ▶ Research has shown that it can be present during fetal development but may remain inactive until puberty.

Depending on the site, endometriosis may present with secondary symptoms including bowel obstruction, melena (dark feces), hematuria (bloody urine), dysuria (painful urination), dyspnea (difficulty breathing) and swelling in the soft tissues. Parity and infertility have long been associated with endometriosis, with infertility among the chief clinical findings.

What put you at Risk?

Several factors place you at greater risk of developing endometriosis, such as:

- Never giving birth
- Starting your period at an early age
- Going through menopause at an older age
- Short menstrual cycles — for instance, less than 27 days
- Having higher levels of estrogen in your body or a greater lifetime exposure to estrogen your body produces
- Low body mass index
- Alcohol consumption
- One or more relatives (mother, aunt or sister) with endometriosis
- Any medical condition that prevents the normal passage of menstrual flow out of the body
- Uterine abnormalities, including polycystic ovarian syndrome.



Endometriosis usually develops several years after the onset of menstruation (menarche). Signs and symptoms of endometriosis end temporarily with pregnancy and end permanently with menopause, unless you're taking estrogen.



Complications- What can happen AFTER Endometriosis develops?

Infertility

The main complication of endometriosis is impaired fertility. Approximately one-third to one-half of women with endometriosis have difficulty getting pregnant.

For pregnancy to occur, an egg must be released from an ovary, travel through the neighboring fallopian tube, become fertilized by a sperm cell and attach itself to the uterine wall to begin development. Endometriosis may obstruct the tube and keep the egg and sperm from uniting. But the condition also seems to affect fertility in less-direct ways, such as damage to the sperm or egg.

Even so, many women with mild to moderate endometriosis can still conceive and carry a pregnancy to term. Doctors sometimes advise women with endometriosis not to delay having children because the condition may worsen with time.

Ovarian cancer

Ovarian cancer does occur at higher than expected rates in women with endometriosis. But the overall lifetime risk of ovarian cancer is low to begin with. Some studies suggest that endometriosis increases that risk, but it's still relatively low. Although rare, another type of cancer — endometriosis-associated adenocarcinoma — can develop later in life in women who have had endometriosis.



When should I see a doctor?

See your doctor if you have signs and symptoms that may indicate endometriosis. Endometriosis can be a challenging condition to manage. An early diagnosis, a multidisciplinary medical team and an understanding of your diagnosis may result in better management of your symptoms.

There is no known prevention for the disease. Likewise, no single cure has been universally defined. Even in the hands of the best surgical excisionists in the world, there has been recurrence post-surgically in a small number of patients.

Preparing for your Appointment

Your first appointment will likely be with either your primary care physician or a gynecologist. If you're seeking treatment for infertility, you may be referred to a doctor who specializes in reproductive hormones and optimizing fertility (reproductive endocrinologist).

Because appointments can be brief, and it can be difficult to remember everything you want to discuss, it's a good idea to prepare in advance of your appointment.

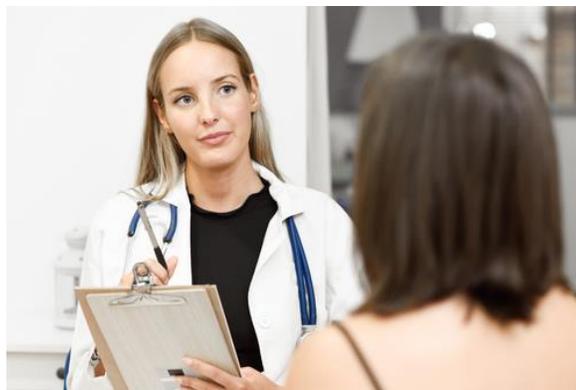
What you can do

- Make a list of any symptoms you're experiencing. Include all of your symptoms, even if you don't think they're related.
- Make a list of any medications, herbs or vitamin supplements you take. Include how often you take them and the doses.
- Have a family member or close friend accompany you, if possible. You may get a lot of information at your visit, and it can be difficult to remember everything.
- Take a notepad or electronic device with you. Use it to make notes of important information during your visit.
- Prepare a list of questions to ask your doctor. List your most important questions first, to be sure you address those points.

For endometriosis, some basic questions to ask your doctor include:

- How is endometriosis diagnosed?
- What medications are available to treat endometriosis? Is there a medication that can improve my symptoms?
- What side effects can I expect from medication use?
- Under what circumstances do you recommend surgery?
- Will I take a medication before or after surgery?
- Will endometriosis affect my ability to become pregnant?
- Can treatment of endometriosis improve my fertility?
- Can you recommend any alternative treatments I might try?

Make sure that you understand everything your doctor tells you. Don't hesitate to ask your doctor to repeat information or to ask follow-up questions for clarification.



What to expect from your doctor

Some potential questions your doctor might ask include:

- How often do you experience these symptoms?
- How long have you had these symptoms?
- How severe are your symptoms?
- Do your symptoms seem to be related to your menstrual cycle?
- Does anything improve your symptoms?
- Does anything make your symptoms worse?

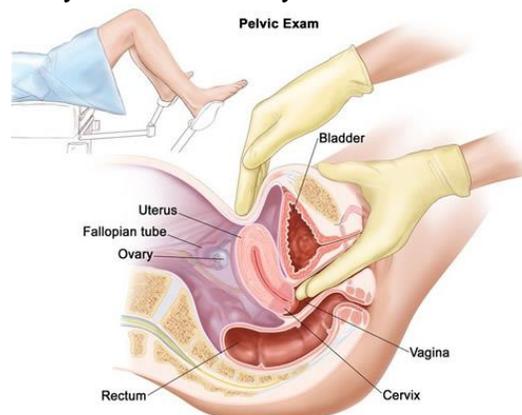


Diagnosing Endometriosis

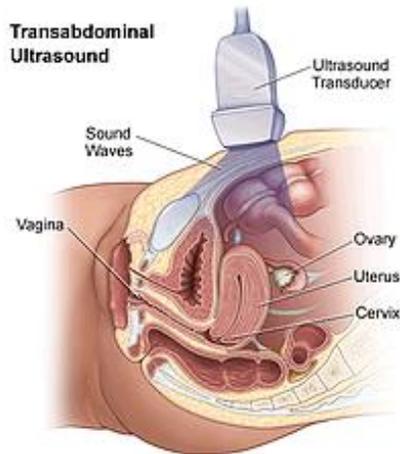
To diagnose endometriosis and other conditions that can cause pelvic pain, your doctor will ask you to describe your symptoms, including the location of your pain and when it occurs.

Tests to check for physical clues of endometriosis include:

- **Pelvic exam.** During a pelvic exam, your doctor manually feels (palpates) areas in your pelvis for abnormalities, such as cysts on your reproductive organs or scars behind your uterus. Often it's not possible to feel small areas of endometriosis, unless they've caused a cyst to form.

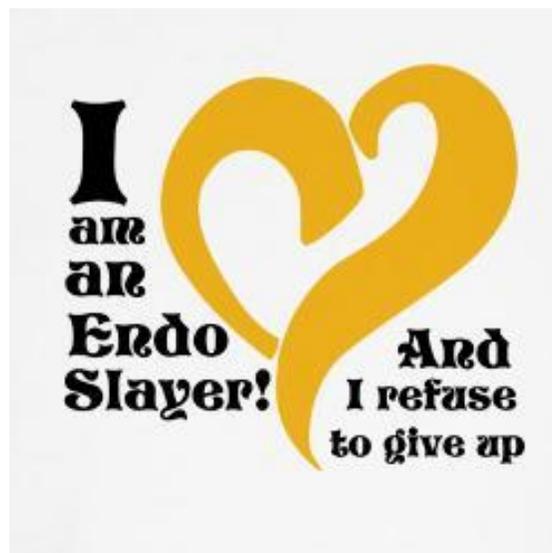


- **Ultrasound.** This test uses high-frequency sound waves to create images of the inside of your body. To capture the images, a device called a transducer is either pressed against your abdomen or inserted into your vagina (transvaginal ultrasound). Both types of ultrasound may be done to get the best view of your reproductive organs. Ultrasound imaging won't definitively tell your doctor whether you have endometriosis, but it can identify cysts associated with endometriosis (endometriomas).



- **Laparoscopy.** Medical management is usually tried first. But to be certain you have endometriosis, your doctor may refer you to a surgeon to look inside your abdomen for signs of endometriosis using a surgical procedure called laparoscopy.

While you're under general anesthesia, your surgeon makes a tiny incision near your navel and inserts a slender viewing instrument (laparoscope), looking for endometrial tissue outside the uterus. He or she may take samples of tissue (biopsy). Laparoscopy can provide information about the location, extent and size of the endometrial implants to help determine the best treatment options.



Treatment Options

Treatment for endometriosis is usually with medications or surgery. The approach you and your doctor choose will depend on the severity of your signs and symptoms and whether you hope to become pregnant.

Generally, doctors recommend trying conservative treatment approaches first, opting for surgery as a last resort. However, minimally invasive laparoscopic excision surgery remains the gold standard for diagnosis and treatment, ideally performed in the specialty treatment setting or performed by an advanced surgeon.

Pain medications

Your doctor may recommend that you take an over-the-counter pain reliever, such as the nonsteroidal anti-inflammatory drugs (NSAIDs) ibuprofen (Advil, Motrin IB, others) or naproxen (Aleve, others), to help ease painful menstrual cramps.

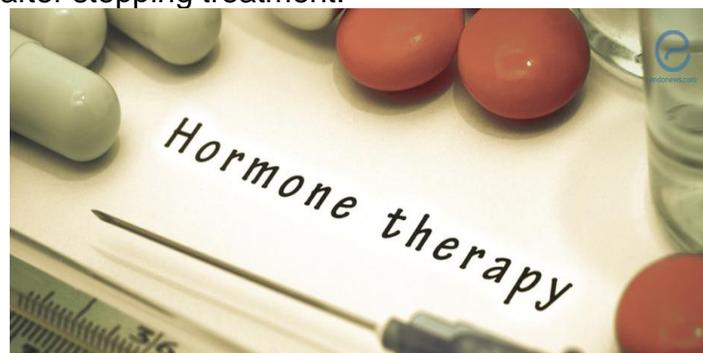
If you find that taking the maximum dose of these medications doesn't provide full relief, you may need to try another approach to manage your signs and symptoms.



Hormone therapy

Supplemental hormones are sometimes effective in reducing or eliminating the pain of endometriosis. The rise and fall of hormones during the menstrual cycle causes endometrial implants to thicken, break down and bleed. Hormone medication may slow endometrial tissue growth and prevent new implants of endometrial tissue.

Hormone therapy isn't a permanent fix for endometriosis. You could experience a return of your symptoms after stopping treatment.

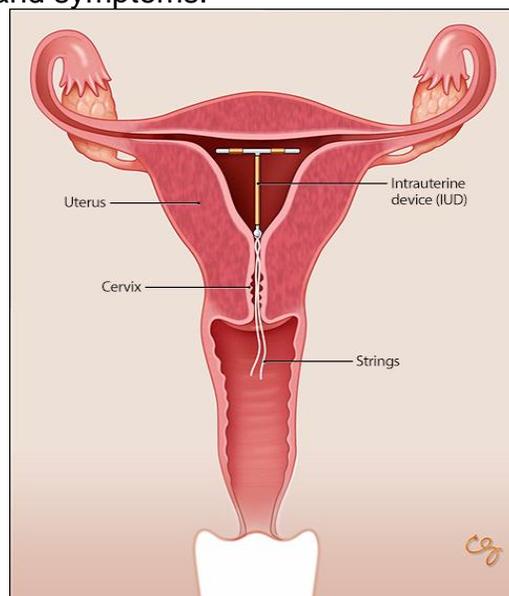


Therapies used to treat endometriosis include:

- **Hormonal contraceptives.** Birth control pills, patches and vaginal rings help control the hormones responsible for the buildup of endometrial tissue each month. Most women have lighter and shorter menstrual flow when they're using a hormonal contraceptive. Using hormonal contraceptives — especially continuous cycle regimens — may reduce or eliminate the pain of mild to moderate endometriosis.
- **Gonadotropin-releasing hormone (Gn-RH) agonists and antagonists.** These drugs block the production of ovarian-stimulating hormones, lowering estrogen levels and preventing menstruation. This causes endometrial tissue to shrink. Because these drugs create an artificial menopause, taking a low dose of estrogen or progestin along with Gn-RH agonists and antagonists may decrease menopausal side effects, such as hot flashes, vaginal dryness and bone loss. Your periods and the ability to get pregnant return when you stop taking the medication.



- **Progestin therapy.** A progestin-only contraceptive, such as an intrauterine device (Mirena), contraceptive implant or contraceptive injection (Depo-Provera), can halt menstrual periods and the growth of endometrial implants, which may relieve endometriosis signs and symptoms.

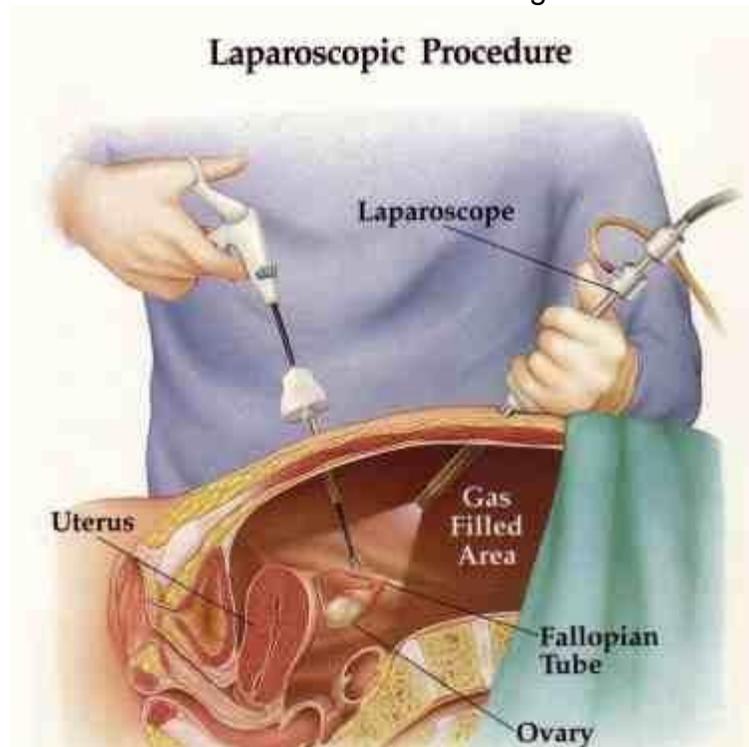


- **Danazol.** This drug suppresses the growth of the endometrium by blocking the production of ovarian-stimulating hormones, preventing menstruation and the symptoms of endometriosis. However, danazol may not be the first choice because it can cause serious side effects and can be harmful to the baby if you become pregnant while taking this medication.

Conservative surgery

If you have endometriosis and are trying to become pregnant, surgery to remove as much endometriosis as possible while preserving your uterus and ovaries (conservative surgery) may increase your chances of success. If you have severe pain from endometriosis, you may also benefit from surgery — however, endometriosis and pain may return.

Your doctor may do this procedure laparoscopically or through traditional abdominal surgery in more extensive cases. In laparoscopic surgery, your surgeon inserts a slender viewing instrument (laparoscope) through a small incision near your navel and inserts instruments to remove endometrial tissue through another small incision.

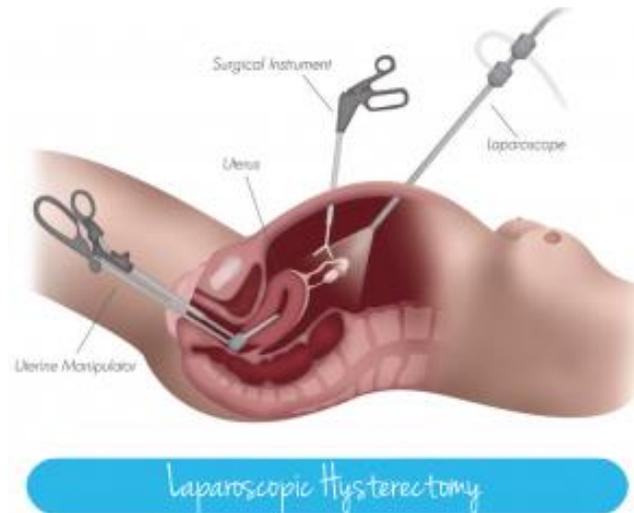


Assisted reproductive technologies

Assisted reproductive technologies, such as in vitro fertilization, to help you become pregnant are sometimes preferable to conservative surgery. Doctors often suggest one of these approaches if conservative surgery doesn't work.

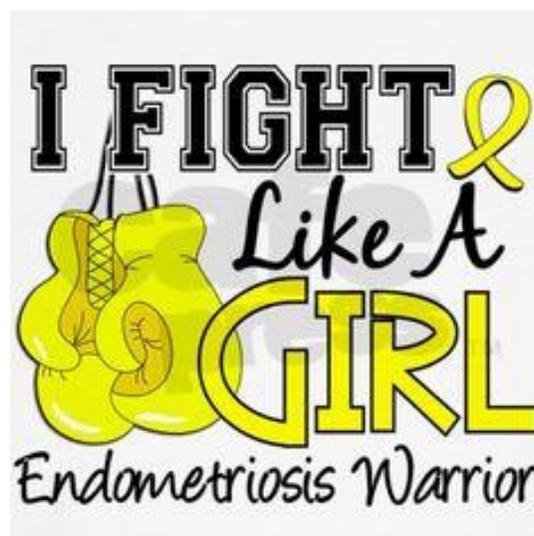
Hysterectomy

In severe cases of endometriosis, surgery to remove the uterus and cervix (total hysterectomy) as well as both ovaries may be the best treatment. A hysterectomy alone is not effective — the estrogen your ovaries produce can stimulate any remaining endometriosis and cause pain to persist. A hysterectomy is typically considered a last resort, especially for women still in their reproductive years. You can't get pregnant after a hysterectomy.



Long-term health risks after hysterectomy may include an increased risk of heart and blood vessel (cardiovascular) diseases and certain metabolic conditions, especially if you have the surgery before age 35.

Finding a doctor with whom you feel comfortable is crucial in managing and treating endometriosis. You may also want to get a second opinion before starting any treatment to be sure you know all of your options and the possible outcomes.



After the Diagnosis

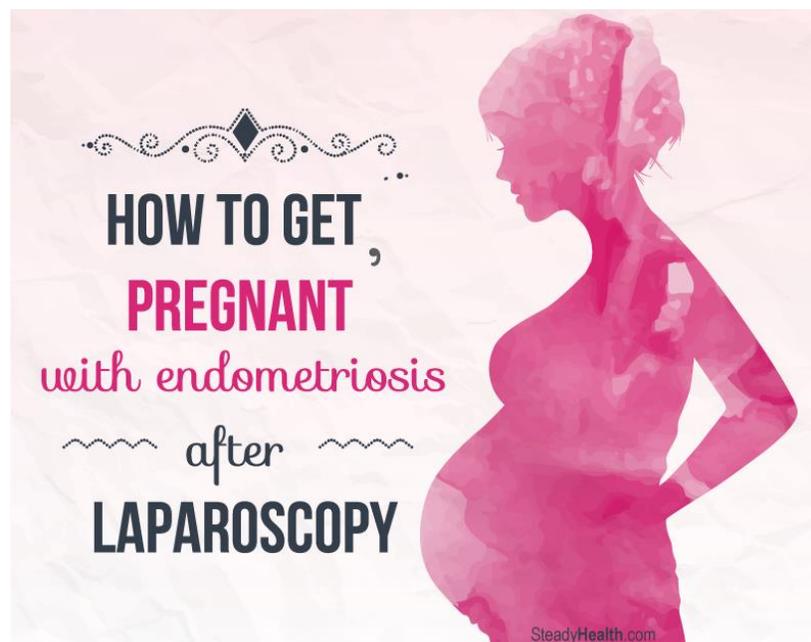
Lifestyle and home remedies

If your pain persists or if finding a treatment that works takes some time, you can try measures at home to relieve your discomfort.

- Warm baths and a heating pad can help relax pelvic muscles, reducing cramping and pain.
- Over-the-counter nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (Advil, Motrin IB, others) or naproxen (Aleve, others), can help ease painful menstrual cramps.
- Regular exercise may help improve symptoms.

Coping and support

If you're dealing with endometriosis or its complications, you may want to consider joining a support group for women with endometriosis or fertility problems. Sometimes it helps simply to talk to other women who can relate to your feelings and experiences. If you can't find a support group in your community, look for one on the internet.



Resources

<https://www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656>

<https://www.womenshealth.gov/a-z-topics/endometriosis>

[https://www.endocenter.org/do-you-have-](https://www.endocenter.org/do-you-have-endo/?gclid=Cj0KCQiA2snUBRDfARIsAIGfpqFz1nGe7csTQ5SSVNYO1VWWk24e21ViBCrCznIIswRkFYWtqscQAnwaAp9REALw_wcB)

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<http://www.endometriosisassn.org/>

<http://endometriosis.org/news/support-awareness/endometriosis-awareness-2018/>

<https://www.awarenessdays.com/awareness-days-calendar/endometriosis-awareness-week-2018/>

<https://www.healthdec.com/health-decisions-post/march-national-endometriosis-awareness-month/>
<http://www.endomarch.org/>