

# Understanding and Managing **Endometriosis**

What you should  
know about  
treatment  
options

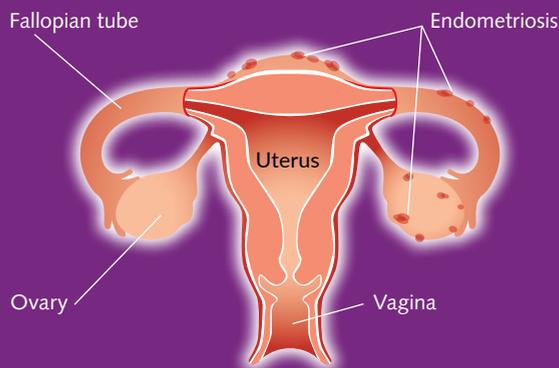


## What is endometriosis?

Do you feel pain during your monthly period, or do you have lower abdominal pain all month? If so, you may be suffering from endometriosis. Endometriosis can cause such intense pain that it interferes with your normal daily activities, as well as your health and well-being. As you will learn by reading this booklet, endometriosis can be managed successfully.

Endometriosis is a condition in which endometrial tissue, which normally lines the inside of the uterus, is found outside the uterus on other organs.

The clumps of tissue that grow outside the uterus are often called implants. They are most often found on the ovaries, the fallopian tubes, the outer walls of the uterus, the intestines and other organs in the belly.



Endometrial tissue responds to estrogen, a female hormone. When you have endometriosis, the implants outside your uterus act like the tissue lining your uterus. During your menstrual cycle, the implants grow or thicken and then break down and bleed. The blood from implants cannot flow out of your body, and can cause the surrounding tissue to become irritated and swollen.

The monthly breakdown and bleeding can also cause lesions and scar tissue to form. The bleeding, inflammation and scarring can cause pain, especially before and during menstruation.

## Common symptoms

Although symptoms may change over time, if you have endometriosis, you probably have one or more of the following:

- Cramping and menstrual pain (dysmenorrhea)
- Pain during sexual intercourse
- Pelvic pain

## Your symptoms

Every woman has symptoms that are unique to her situation. They may peak during monthly periods or appear in the middle of each cycle. What are your current symptoms?

## Answer Yes or No to the following questions:

### Cramps

- |   | YES                      | NO                       |
|---|--------------------------|--------------------------|
| • Do you have to limit your normal activities each month due to painful periods?        | <input type="checkbox"/> | <input type="checkbox"/> |
| • Are your cramps becoming more painful with each passing year?                         | <input type="checkbox"/> | <input type="checkbox"/> |
| • Do your cramps start in the middle of your menstrual cycle?                           | <input type="checkbox"/> | <input type="checkbox"/> |
| • When you have cramps, do you also experience nausea, vomiting or intestinal problems? | <input type="checkbox"/> | <input type="checkbox"/> |

### Pelvic pain

- |   |                          |                          |
|---|--------------------------|--------------------------|
| • Do certain movements or positions cause pelvic pain?                | <input type="checkbox"/> | <input type="checkbox"/> |
| • Do you have lower back (lumbar) pain before or during your periods? | <input type="checkbox"/> | <input type="checkbox"/> |
| • Do you have pain during bowel movements or urination?               | <input type="checkbox"/> | <input type="checkbox"/> |

### Pain during sexual intercourse

- |   |                          |                          |
|---|--------------------------|--------------------------|
| • Do you avoid having sex because of pain?  | <input type="checkbox"/> | <input type="checkbox"/> |
| • Do you feel deep-seated pain in the vagina during sexual intercourse?             | <input type="checkbox"/> | <input type="checkbox"/> |
| • Is having sex more painful at certain times of the month or in certain positions? | <input type="checkbox"/> | <input type="checkbox"/> |

## Endometriosis

Endometriosis can affect your reproductive organs as well as your menstrual cycle. Other organs in the abdominal cavity and pelvic area may also be affected by endometriosis.

### Your reproductive organs

Certain hormones (chemical messengers) are released by the brain and send signals to your ovaries to produce other hormones. Each month, hormones stimulate ovulation and cause the walls of the uterus to thicken. Any endometrial tissue outside the uterus will also react to these hormones.

The endometrium is a layer of blood vessels and tissue that lines the inside of the uterus.

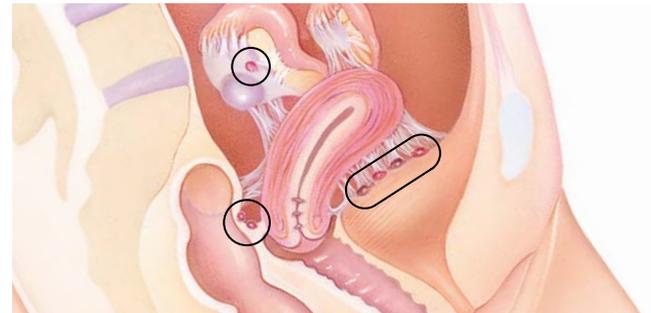
In endometriosis, endometrial tissue also forms outside the uterus. This growth, called a lesion, can occur on reproductive organs, the bladder, and/or intestines.

## Your menstrual cycle

In most women, the menstrual cycle is about 28 days. During the first weeks of each cycle, the mucous membrane grows inside the uterus. If there is no fertilization, this mucous membrane is eliminated during your period.

In endometriosis, the lesions outside the uterus also grow, which can cause pressure on nearby nerves or organs. These lesions also release blood during menstruation, which can provoke intense pain and cause the formation of scar tissue. Endometriosis lesions can vary in colour and shape. They can be as small as grains of sand or as large as a grapefruit.

### Lesions can cause painful bleeding during menstruation



○ = Lesions

## Causes of endometriosis

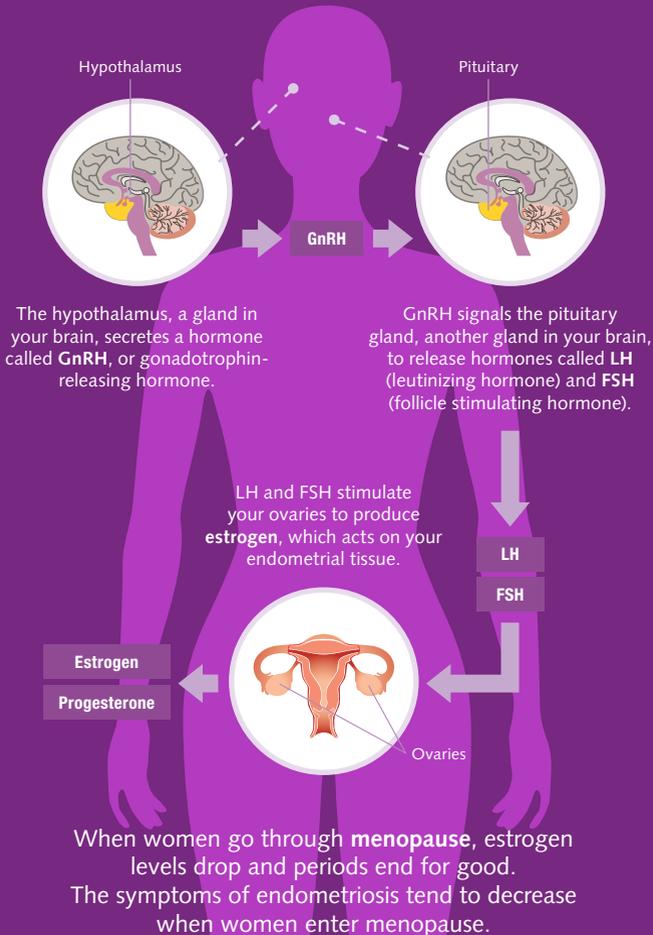
While the precise cause is unknown, there are several possible causes:

- Menstrual blood carrying endometrial cells may stay behind in the Fallopian tubes and empty into the pelvic cavity
- Endometrial cells could be present in the pelvic cavity from birth
- Lesions can appear if the immune system is not sufficiently active to prevent them from growing and spreading
- Endometrial cells can circulate in the blood vessels and be delivered into the pelvic cavity

## Hormones and endometriosis

While the cause of endometriosis is not known, experts have observed that estrogen makes endometriosis worse. Women who are of childbearing age—from their teens into their 40s—have high levels of estrogen. It is during these years that women can develop endometriosis.

### How is estrogen produced?



## Diagnosis of endometriosis

### The medical evaluation

Endometriosis, or other causes of your symptoms, can only be diagnosed after a thorough medical evaluation. Your healthcare professional can begin by asking you questions about your symptoms. A pelvic exam and one or more tests may be needed. Your healthcare professional will then help plan a treatment that's right for you.

### Medical history

Your past history of menstrual, intestinal, and urinary problems can help determine the cause of your problem. You may be asked questions such as:

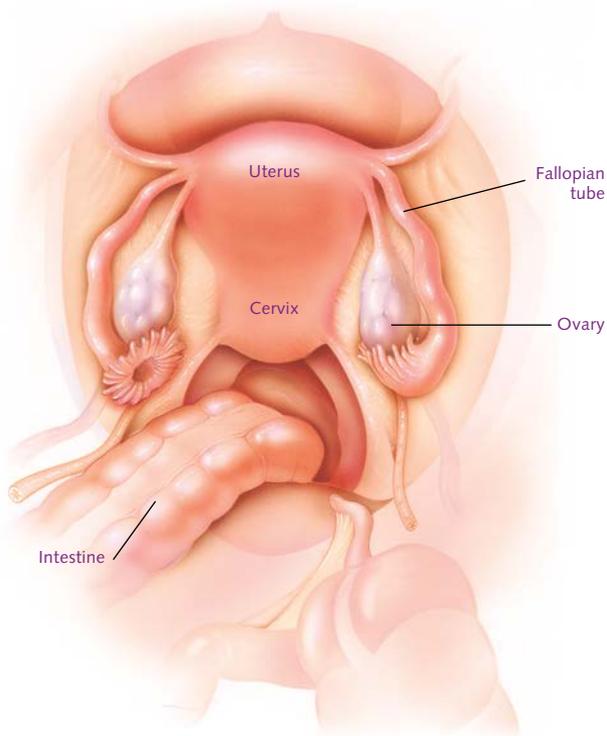
- How old were you when you had your first period?
- Did you begin having cramps or other symptoms immediately or only after a few years?
- Do you have a family member (mother, aunt, sister) with endometriosis?

Your answers to these types of questions can help your physician make a diagnosis.

## Stages of endometriosis

Your physician can use laparoscopy to assess the stage of your endometriosis. Stages are classified as follows: minimal (Stage I), light (Stage II), moderate (Stage III), or severe (Stage IV). Several factors are considered during staging, including the number, size and location of lesions. The stage also depends upon the surface area affected and on how close the lesions are to other organs.

Your physician can use this picture to show you the location of any lesions



## Treatment option: hormone therapy

Hormone-based therapies can be used to treat endometriosis. These include combined hormonal contraception, progesterone-based drugs, or GnRH agonists with 'add-back' therapy (low doses of estrogen and/or progestin), if the first two options are not effective.

### Combined hormonal contraception

Combined hormonal contraception is often prescribed to treat endometriosis. Your healthcare professional might prescribe combined hormonal contraception without the usual seven-day break each month. This method prevents you from menstruating, and may be a useful option for women who experience their worst endometriosis symptoms during their period.

### How combined hormonal contraception works

This therapy reduces the pain caused by endometriosis by suppressing menstruation and inhibiting the growth of endometriosis lesions.

### Side effects of combined hormonal contraception

Possible side effects include:

- Headache
- Nausea
- Breast tenderness
- Breakthrough bleeding

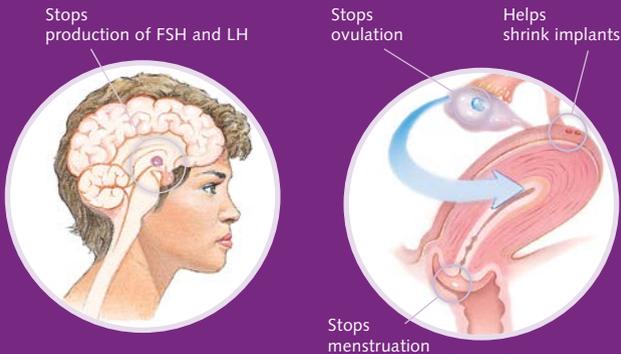
Please consult your healthcare professional regarding other possible adverse events with combined hormone-based therapy.

## Progestin therapy

Progestin therapy is widely used for birth control and has also been studied for the relief of endometriosis pain. It can be administered in a pill form or as an injection.

### How progestin therapy works

Progestin therapy helps to lessen the effects of the estrogen that stimulates endometriotic growth in your body.



### Side effects of progestin therapy

With injection-based progestin therapy there can be a delay between when therapy is stopped and when ovulation resumes. For this reason, this is not an effective option if you are planning to conceive in the near future. As well, progestin therapy may be associated with breakthrough bleeding. This therapy can be a good option for women with endometriosis who have had a hysterectomy.

Please consult your healthcare professional regarding other possible adverse events with progestin-based therapy.

## Intrauterine system (IUS)

The IUS is a common method of birth control, consisting of a T-shaped device which is inserted into your uterus. This may be an effective therapy for lessening your pain caused by endometriosis.

### How the intrauterine system works

The device releases a progestin hormone which counteracts the effects of estrogen. The IUS can provide continuous therapy for five years or until it is removed by a healthcare professional.

### Side effects of intrauterine system

Side effects are similar to other hormonal therapies, including:

- Irregular bleeding or spotting for the first 3–6 months
- Headaches
- Nausea
- Depression
- Breast tenderness

Please consult your healthcare professional regarding other possible adverse events with the IUS.

## GnRH agonist therapy

A GnRH agonist (or gonadotropin-releasing hormone agonist) is a hormone, given by injection or nasal spray. It will cause you to stop menstruating. This effect helps reduce the pain associated with endometriosis and reduce endometrial lesions.

### How GnRH agonist therapy works

Treatment with a GnRH agonist leads to a decrease in estrogen, to the levels that women have after menopause.

### Side effects of GnRH agonist therapy

The side effects of this type of medication tend to be similar to symptoms you might experience in menopause due to the decrease in estrogen levels:

- Loss of bone mineral density
- Hot flashes
- Mood swings
- Vaginal dryness
- Smaller breasts
- Headaches

Please consult your healthcare professional regarding other possible adverse events with GnRH agonists.

These symptoms can be relieved with 'add-back therapy', which consists of low doses of estrogen and/or progestin. Add-back therapy is routinely given when a GnRH agonist is prescribed.

## Danazol

Danazol is a hormone that is taken orally which causes you to stop menstruating, and is effective in relieving the pain of endometriosis.

### How danazol works

Danazol is a weak male hormone that lowers the level of estrogen and progesterone in a woman's body.

### Side effects of danazol

Side effects of danazol include:

- Weight gain
- Acne
- Excessive hair growth
- Raised cholesterol levels
- Breast atrophy

Please consult your healthcare professional regarding other possible adverse events with danazol.

## Treatment option: surgery

In some cases, surgery is the best option for treating endometriosis. The procedure can vary greatly, from minor surgery to complete removal of all reproductive organs. Your healthcare professional will discuss the choices for surgery and their effects on fertility. Your age, severity of endometriosis, and the desire to bear children are key factors in deciding on the surgical option that's best for you.

### Surgical laparoscopy

A laparoscope is often used in the diagnosis, but also for treatment of endometriosis. Guided by a video image provided by the instrument, the physician uses special instruments to eliminate lesions. They may be cut out (excised), burned away, or removed by a laser. Laparoscopy requires only a few tiny incisions, which limits the amount of bleeding and scarring. This procedure often is performed in outpatient clinics. After returning home, you may need 3 to 10 days for a full recovery. This option is designed for women who want to bear children.

### Laparotomy

This surgical procedure requires a 12.5 to 15 cm (5 to 6 inches) incision. This option is often used for larger lesions or for a lesion that cannot be treated with the laparoscope. It is often used when pelvic organs, such as the intestine, are affected. Lesions may be cut out (excised), burned away, or removed by a laser. You will probably stay in the hospital for a short time, and full recovery may take 4 to 8 weeks.

### Hysterectomy

This procedure involves surgical removal of the uterus. Lesions can also be removed from the pelvic cavity. In severe cases, your physician may also recommend removal of the ovaries and Fallopian tubes. After a hysterectomy, you can no longer have children. Also, depending on your age, removal of the ovaries can cause menopausal symptoms. Hysterectomy is often performed through an incision in the abdomen, although the uterus may be removed through the vagina or by laparoscopy. In such cases, convalescence is shorter.

#### Incision site for hysterectomy



## Living with endometriosis

Once you know that you have endometriosis, you will need to think about your treatment choices. There are also some things you can do to help yourself feel better.

### Lifestyle changes

If you are diagnosed with endometriosis, your healthcare professional will discuss lifestyle changes with you. Changes to your exercise and relaxation routines, and maintaining a balanced diet to stay healthy, may help ease the symptoms of endometriosis.

### Controlling intense emotions

In addition to bouts of pain, you may experience emotional problems or sudden mood changes. You may feel irritated, confused, or depressed. Don't suffer in silence. Talking it over with someone you trust can do a world of good, as can taking up pleasant activities.

### Pain management

The therapies used to treat endometriosis may take at least one menstrual cycle to become effective. For this reason, your healthcare professional may recommend pain relief medication for use until the long-term treatment begins to work.

You can take nonprescription medications, such as non-steroidal anti-inflammatory drugs (examples are ASA and ibuprofen). They are more effective if you start taking them before you expect the pain to start, and repeating every six hours to maintain effective relief.



## Early detection

Having cramps or intense pain during your period isn't normal. A teenager who suffers from intense cramps or excessive bleeding should be examined by a healthcare professional. This is even more important if a close relative has endometriosis.

### Hope for the future

Researchers continue to conduct research into causes of endometriosis and new treatments continue to be investigated.

### For more information about endometriosis

Please visit [www.endometriosisinfo.ca](http://www.endometriosisinfo.ca)

Presented by the Society of Obstetricians and Gynaecologists of Canada (SOGC).

Should you require any additional information regarding your condition and/or your treatment, speak with your healthcare professional.





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