# Patient education: Endometriosis (Beyond the Basics)

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## INTRODUCTION

Endometriosis is a condition where tissue, similar to the tissue that normally grows inside the uterus, also grows outside of the uterus. The tissue inside the uterus is called "endometrium" and the tissue outside of the uterus is called "endometriosis". The most common places where endometriosis occurs are the ovaries, the fallopian tubes, the bowel, and the areas in front, in back, and to the sides of the uterus.

Some women with endometriosis have few or no symptoms while others have pain or difficulty becoming pregnant. There is no cure for endometriosis, but there are several treatment options. The best treatment depends on your individual situation.

More detailed information about endometriosis is available by subscription. (See 'Professional level information' below.)

## ENDOMETRIOSIS CAUSES

The cause of endometriosis is not known. A common theory is that some menstrual blood and endometrium flows backwards from the uterus through the fallopian tubes and into the pelvis during a menstrual period (figure 1). This tissue then grows where it lands in the pelvis. This is called the retrograde menstruation theory. There are several other theories and there is ongoing research to find a cause for this condition.

## ENDOMETRIOSIS SYMPTOMS

Some women with endometriosis have no symptoms. The most common symptom is pain in the pelvic area, especially with periods.

**Pain** — Pelvic pain caused by endometriosis can occur:

- Just before or during the menstrual period. In some women, painful periods get worse over time. (See "Patient education: Painful menstrual periods (dysmenorrhea) (Beyond the Basics)".)
- Between menstrual periods, with worsened pain during the period.
- During or after sex.
- With bowel movements or while urinating, especially during the period.

Pelvic pain can be caused by many other conditions, including pelvic floor muscle spasm, pelvic infections, and irritable bowel syndrome. A doctor or nurse can help to figure out if endometriosis may be the cause of your pain.

**Difficulty getting pregnant** — Endometriosis can make it more difficult to become pregnant. This might occur because endometriosis may cause scar tissue to develop, which can damage the ovaries or fallopian tubes. Even women with endometriosis who do not have scar tissue can have difficulty becoming pregnant.

In women who become pregnant, endometriosis does not harm the pregnancy. Symptoms of endometriosis often improve after pregnancy.

**Endometriomas (chocolate cysts)** — Women with endometriosis can develop ovarian cysts

containing endometriosis; this is called an endometrioma. Endometriomas are usually filled with old blood that resembles chocolate syrup; thus, they are sometimes called chocolate cysts. Endometriomas are sometimes seen during a pelvic ultrasound or felt during a pelvic examination.

## ENDOMETRIOSIS DIAGNOSIS

Your doctor or nurse might suspect that you have endometriosis based on your symptoms of pelvic pain or painful menstrual periods. However, the only way to know for sure if you have endometriosis is to have surgery so a doctor can actually see and biopsy the abnormal tissue. Endometriosis cannot be diagnosed by ultrasound, x-ray, or other noninvasive methods.

Endometriosis is considered mild, moderate, or severe depending on what is found during surgery. Women with mild disease can have severe symptoms, and women with severe disease can have mild symptoms.

In some cases, your doctor will recommend a medicine as the first treatment for symptoms that make her suspect endometriosis. This might include a nonsteroidal anti-inflammatory medicine (ibuprofen/Advil) or hormonal birth control. (See 'Endometriosis treatment' below.)

If treatment does not improve your pain within one to three months, another type of medication may be tried, or surgery can be discussed as a reasonable next step. (See 'Surgery' below.)

In other cases, surgery is performed to diagnose endometriosis and remove it before you take any medicine. Talk to your doctor or nurse about which approach is right for your situation. It is important to note that surgery does not cure endometriosis and will not necessarily lead to improvement in your symptoms long term.

## ENDOMETRIOSIS TREATMENT

There are several treatment options for women with endometriosis:

- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Hormonal birth control
- Other forms of hormone treatment (gonadotropin-releasing hormone analogues)
- Surgery

The best treatment depends on your future plans to become pregnant and what symptoms are most bothersome.

**Nonsteroidal anti-inflammatory drugs** — NSAIDs are a type of pain medicine that can help to relieve the pain caused by endometriosis. The medicine works by stopping the release of prostaglandins, one of the main chemicals responsible for pain in general as well as painful menstrual periods. Starting these medications one to two days before your period works best to prevent prostaglandin production and therefore reduce pain. It may take some time, and several doses, for the NSAIDs to block the prostaglandin production and reduce pain. NSAIDs do not shrink or prevent the growth of endometriosis.

Most NSAIDs are available without a prescription, including:

- Ibuprofen (sold as Advil, Motrin, and store brands). Follow the package instructions. In general, two tablets are taken for the first dose and one tablet every four to six hours, as needed, thereafter. These should be taken with food and may be most effective if started one to two days before the onset of pain. Physicians may prescribe higher doses.

- Naproxen sodium (sold as Aleve, Anaprox, Naprosyn, and store brands). Follow the package instructions, as the dose and frequency differ depending on the formulation. In general, two tablets are taken for the first dose, and one tablet is taken every 8 to 12 hours, as needed, thereafter, depending on the formulation. All tablets should be taken with food and a full glass of water. Like ibuprofen, naproxen may be more effective if begun a day or two prior to the onset of typical menstrual pain. Physicians may prescribe higher doses.

- If over-the-counter NSAIDs are not effective, prescription doses and formulations may be helpful.

- The disadvantage of NSAIDs is that they do not always relieve endometriosis-related pain. NSAIDs probably work better when combined with another treatment, like hormonal birth control. Serious side effects from NSAIDs, although uncommon, include stomach upset, kidney problems, and worsened high blood pressure.

**Hormonal birth control treatments** — Hormonal birth control, including the pill, patch, and the vaginal ring are often helpful in treating pain because they reduce heavy bleeding. Daily oral progestin pills as well as injectable and implantable long-acting progestins may be very effective in managing endometriosis-related pain. A progestin-containing intrauterine device can also be very effective in treating pain. Hormonal birth control works best in women who do not have

severe pain unrelated to the period.

Women with endometriosis are often advised to take hormonal birth control continuously (skipping the placebo pills) for three or more months. This allows you to have fewer periods and have less pain and bleeding during each period. This is explained in detail separately. (See "Patient education: Hormonal methods of birth control (Beyond the Basics)", section on 'Continuous dosing'.)

The most common side effects of estrogen-containing hormonal birth control are:

- Nausea
- Breast tenderness
- Irregular vaginal bleeding or spotting

These side effects usually improve after using the treatment for several months. Serious side effects (eg, blood clots, stroke, heart attack) are rare in women who do not smoke. (See "Patient education: Hormonal methods of birth control (Beyond the Basics)".)

**Progestins** — Progestins are a synthetic form of a natural hormone called progesterone. This treatment might be recommended for women who do not get pain relief from or who cannot take hormonal birth control that contains estrogen (such as smokers). Progestins are available by prescription and usually given as a pill or injection. Progestins are not used if you are trying to become pregnant. A progestin-containing intrauterine device delivers very low levels of progestin directly to the uterus and results in markedly lighter and less painful bleeding episodes with fewer systemic side effects.

Side effects of progestins can be bothersome for some women. The most common side effects include: bloating, weight gain, irregular vaginal bleeding, acne, and rarely, worsened depression.

**Gonadotropin-releasing hormone analogues** — Gonadotropin-releasing hormone (GnRH) analogues (agonists and antagonists) are medicines that work by causing a temporary menopause. The treatment causes the ovaries to stop producing estrogen, which causes the endometriosis implants to shrink.

This treatment reduces pain in over 80 percent of women, including women with severe pain. GnRH analogues are not used if you are trying to become pregnant.

Examples of GnRH agonists include:

- Nafarelin (Synarel) – Nasal spray taken twice per day
- Leuprolide (Lupron) – Shot taken once every one or three months
- Goserelin (Zoladex) – Shot taken once every 28 days

Examples of GnRH antagonists include:

- Elagolix (Orilissa) – Oral tablet taken twice daily

Adult women can take the full dose of a GnRH agonist therapy for up to 12 months or GnRH antagonist treatment for up to 24 months. For GnRH agonists and antagonists, there are concerns about bone loss over time. One way to minimize bone loss is to take hormonal "add-back" treatment (adding very small amounts of either estrogen or a synthetic progestin) in addition to the GnRH analogue.

Taking hormonal add-back can also help to treat the most common side effects of GnRH analogues, which are menopausal symptoms (hot flashes, vaginal dryness, decreased libido, insomnia). (See "Endometriosis: Long-term treatment with gonadotropin-releasing hormone agonists".)

**Aromatase inhibitors** — These drugs block the enzyme (aromatase) that increases estrogen levels in tissue. There is increasing evidence that endometriosis tissue makes its own aromatase.

Examples of aromatase inhibitors include letrozole and anastrozole. Both medications are pills that are taken once a day. Combining these drugs with hormonal birth control, progestins, or GnRH agonists may be more effective than any of them alone. This may be a strategy for long-term management of endometriosis pain in women who are not attempting pregnancy since the side effects appear minimal [1,2].

**Surgery** — Surgery might be an option to treat endometriosis if you:

- Have severe pain localized to a specific area and tender on examination.
- Have tried medicines but still have bothersome pain (attributable to endometriosis) in a specific spot on pelvic examination.
- Have a growth or mass in the pelvic area. Surgery may be necessary to remove the mass

and figure out if endometriosis, or another problem, is the cause.

- Are having trouble getting pregnant and endometriosis might be the cause.

The goal of surgery is to remove endometriosis implants and scar tissue. More than 80 percent of women who have surgery have less pain for several months after surgery. However, there is a good chance that the pain will come back unless you take some form of treatment after surgery (like hormonal birth control).

**Laparoscopy** — Laparoscopy is one way to perform surgery, and is commonly used to diagnose and treat endometriosis. During laparoscopy, a doctor makes several small cuts to place instruments inside the abdomen and pelvis. One of these instruments has a light and camera, which allows the doctor to see the organs on a screen.

**Treatment of an endometrioma** — Medicines are unlikely to make an endometrioma go away. Surgery to remove the endometrioma if it is larger than 4 to 5 cm, symptomatic or enlarging, is usually recommended because surgery can confirm the diagnosis, prevent complications (such as rupture of the endometrioma), and treat any symptoms, such as pain. Removing smaller endometriomas is not recommended because their relationship to infertility is unclear, and surgery on the ovary will diminish its ability to produce eggs over time. However, small endometriomas may enlarge over time and result in symptoms, at which point they can be removed. (See "Endometriosis: Management of ovarian endometriomas".)

**Removal of the uterus or ovaries** — Your doctor might recommend surgery to remove your uterus or ovaries or both if:

- You have tried other treatments but continue to have severe symptoms.
- You do not want to become pregnant in the future.
- You want a permanent treatment.
- Surgery to remove the uterus is called hysterectomy. (See "Patient education: Abdominal hysterectomy (Beyond the Basics)".)
- Surgery to remove the ovaries and fallopian tubes is called salpingo-oophorectomy. It is not always necessary to remove the ovaries to treat endometriosis; this decision will depend on your age and your preferences.

**Hormone therapy after surgery** — If your ovaries are removed, your doctor or nurse might recommend hormone therapy (estrogen) after surgery. This is especially true for women under age 50 who are not yet menopausal. Estrogen can help to minimize menopausal symptoms like hot flashes, night sweats, vaginal dryness, and bone loss and reduce the long-term health consequences of surgical menopause. (See "Patient education: Menopausal hormone therapy (Beyond the Basics)".)

## INFERTILITY TREATMENT

There are several options for treating infertility in women with endometriosis. The best treatment depends on individual factors, including your age, if there are other fertility issues, and how severe your endometriosis is. Treatment options include:

- A fertility medicine (such as clomiphene/Clomid, anastrozole, or letrozole). (See "Patient education: Ovulation induction with clomiphene (Beyond the Basics)".)
- Fertility medicines with intrauterine insemination. (See "Patient education: Infertility treatment with gonadotropins (Beyond the Basics)".)
- Surgery to remove endometriosis. (See 'Surgery' above.)
- In vitro fertilization (IVF). (See "Patient education: In vitro fertilization (IVF) (Beyond the Basics)".)

More detailed information about endometriosis and infertility is available. (See "Treatment of infertility in women with endometriosis".)

## WHERE TO GET MORE INFORMATION

Your health care provider is the best source of information for questions and concerns related to your medical problem.

This article will be updated as needed on our web site (www.uptodate.com/patients). Related topics for patients, as well as selected articles written for health care professionals, are also available. Some of the most relevant are listed below.

**Patient level information** — UpToDate offers two types of patient education materials.

**The Basics** — The Basics patient education pieces answer the four or five key questions a patient might have about a given condition. These articles are best for patients who want a general overview and who prefer short, easy-to-read materials.

Patient education: Endometriosis (The Basics)
Patient education: Painful periods (The Basics)
Patient education: Infertility in women (The Basics)
Patient education: Ovarian cysts (The Basics)
Patient education: Uterine adenomyosis (The Basics)

**Beyond the Basics** — Beyond the Basics patient education pieces are longer, more sophisticated, and more detailed. These articles are best for patients who want in-depth information and are comfortable with some medical jargon.

Patient education: Painful menstrual periods (dysmenorrhea) (Beyond the Basics)
Patient education: Hormonal methods of birth control (Beyond the Basics)
Patient education: Abdominal hysterectomy (Beyond the Basics)
Patient education: Menopausal hormone therapy (Beyond the Basics)
Patient education: Ovulation induction with clomiphene (Beyond the Basics)
Patient education: Infertility treatment with gonadotropins (Beyond the Basics)
Patient education: In vitro fertilization (IVF) (Beyond the Basics)

**Professional level information** — Professional level articles are designed to keep doctors and other health professionals up-to-date on the latest medical findings. These articles are thorough, long, and complex, and they contain multiple references to the research on which they are based. Professional level articles are best for people who are comfortable with a lot of medical terminology and who want to read the same materials their doctors are reading.

Endometriosis: Management of ovarian endometriomas
Endometriosis in adolescents: Diagnosis and treatment
Endometriosis: Long-term treatment with gonadotropin-releasing hormone agonists
Reproductive surgery for female infertility
Endometriosis: Treatment of pelvic pain
Treatment of infertility in women with endometriosis
Endometriosis: Pathogenesis, clinical features, and diagnosis
Clinical features, diagnostic approach, and treatment of adults with thoracic endometriosis

The following organizations also provide reliable health information.

- National Library of Medicine

(www.nlm.nih.gov/medlineplus/endometriosis.html)

- The American Congress of Obstetricians and Gynecologists

(www.acog.org/For_Patients)

[3-7]



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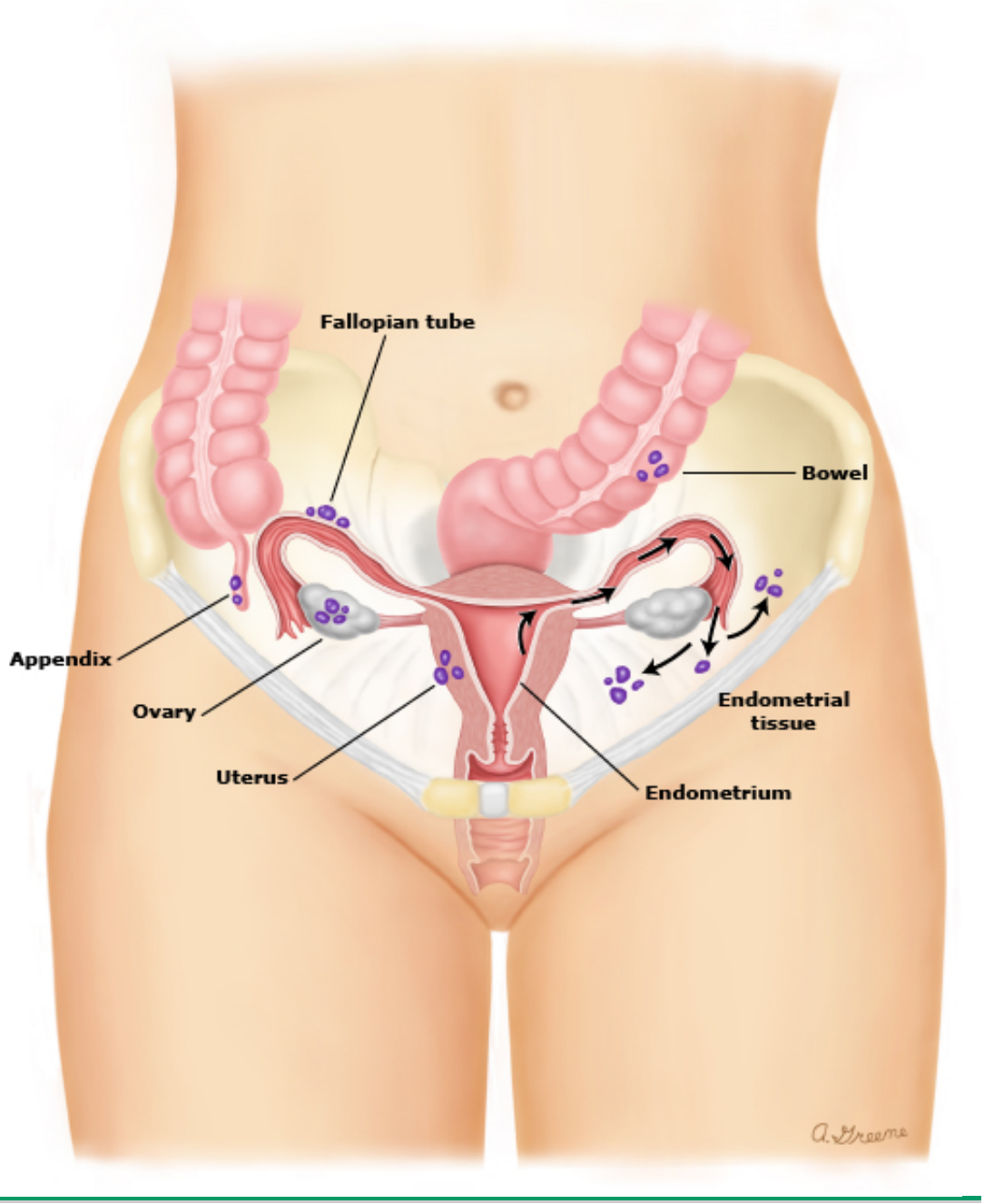
## GRAPHICS

### Areas where endometriosis can be found




This figure shows some of the areas in the body (purple spots) where endometriosis can be found. Common areas affected by endometriosis include the ovaries, the tubes connecting the ovaries to the uterus (fallopian tubes), and the bowel. Endometriosis can also grow in front, in back, and to the sides of the uterus. Sometimes the doctor can feel the tissue when doing a pelvic exam.

Graphic 78942 Version 5.0

## Contributor Disclosures

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