PATIENT EDUCATION

The American College of Obstetricians and Gynecologists
WOMEN'S HEALTH CARE PHYSICIANS

Endometriosis

Endometriosis is a condition in which the type of tissue that forms the lining of the uterus (the endometrium) is found outside the uterus. It occurs in about 1 in 10 women of reproductive age. Many women with endometriosis have no symptoms or only mild discomfort. Others have pain that is so severe that it prevents them from doing their normal activities. Endometriosis also is a leading cause of infertility.

This pamphlet explains

- *where endometriosis occurs in the body*
- *who is affected*
- *symptoms of endometriosis*
- *diagnosis*
- *treatment*

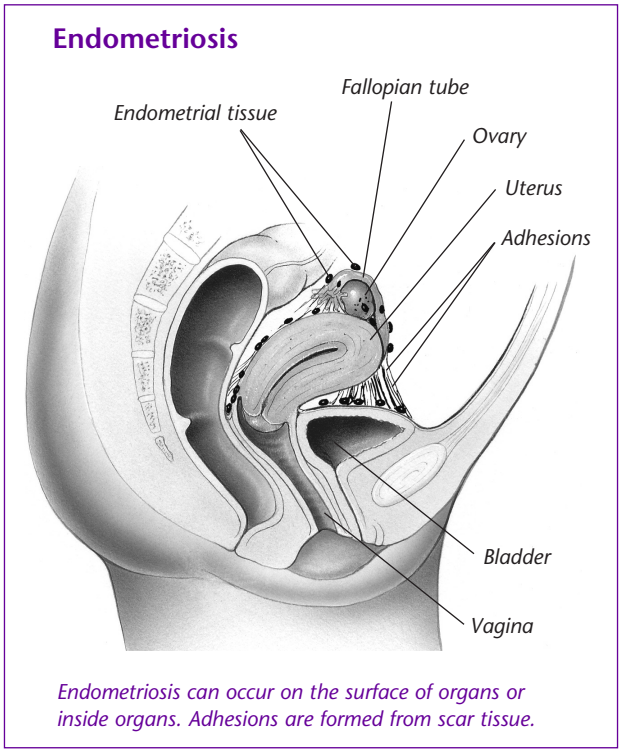
Where Endometriosis Occurs

In endometriosis, areas of endometrial tissue (often called implants) are found outside the uterus, usually inside the pelvis and abdominal cavity. Endometriosis implants most often appear in the following places:

- ***Peritoneum***
- ***Ovaries***
- ***Fallopian tubes***
- Outer surfaces of the uterus, ***bladder***, ***ureters***, intestines, and ***rectum***
- Cul-de-sac (the space behind the uterus)

Implants can grow on the outermost surface of organs or can grow deeper into the walls of some organs like the bladder or intestines. Implants can be quite small or grow to the size of an orange or larger. In rare cases, endometriosis tissue may be found in parts of the body other than the pelvis, such as the lungs.

Endometriosis responds to changes in ***estrogen***, a female ***hormone***. The implants may grow and bleed like the uterine lining does during the menstrual period. Surrounding tissue can become irritated, inflamed, and swollen. The breakdown and bleeding of this tissue each month also can cause scar tissue, called ***adhesions***, to form. Sometimes adhesions can cause organs to stick together. The bleeding, ***inflammation***, and scarring can cause pain, especially before and during menstruation.



Endometriosis can occur on the surface of organs or inside organs. Adhesions are formed from scar tissue.

Who Is Affected by Endometriosis

Endometriosis is most often diagnosed in women in their 30s and 40s, but it can occur in any woman who menstruates. Women with a mother or sister who have endometriosis are more likely to have it. This suggests that endometriosis may be partly inherited—passed down from parent to child through ***genes***. Women who have had children are less likely to have endometriosis.

Endometriosis is commonly associated with infertility. Almost 40% of women with infertility have endometriosis. In severe endometriosis, the fallopian tubes may be blocked by adhesions or scar tissue, which may prevent the egg from moving through the tube. In less severe cases, it is thought that inflammation may damage the sperm or egg. Inflammation also may interfere with their movement through the fallopian tubes and uterus.

Endometriosis symptoms usually go away or get better after ***menopause***. After menopause, the ovaries stop making estrogen. Without estrogen, endometriosis growth generally stops and the implants usually get smaller.

Symptoms

The most common symptom of endometriosis is chronic (long-term) pelvic pain, especially just before and during the menstrual period. Pain that occurs with menstruation is called ***dysmenorrhea***. For women with endometriosis, dysmenorrhea often becomes worse over time. Pain also may occur during ***sexual intercourse***. If endometriosis is present on the bowel, pain during bowel movements can occur. If it affects the bladder, pain may be felt during urination. Heavy menstrual bleeding is another symptom of endometriosis.

The amount of pain does not always match the severity of the condition. For example, some women with slight pain may have a large number of implants and many adhesions. Others who have severe pain may have a small number of implants and few adhesions. Many women with endometriosis have no symptoms. In fact, they may first find out that they have endometriosis if they are not able to get pregnant or while they are having surgery for another reason.

Diagnosis

If you have pain and other symptoms of endometriosis, your health care professional first may do a physical exam, including a ***pelvic exam***. Many of the symptoms of endometriosis are similar to those of other problems, such as irritable bowel syndrome, urinary tract problems, and infections. Your health care professional will need to rule out these other causes.

The only way to tell for sure that you have endometriosis is with surgery. Surgery usually is done if treatment with medications is not effective or if you have infertility. Surgery most often is done by ***laparoscopy***. Laparoscopy involves making a small incision near your navel. A tube called a laparoscope is inserted through the navel into your abdomen. The laparoscope allows the surgeon to view the pelvic organs. Sometimes a small amount of tissue is removed. This is called a ***biopsy***. You will be given ***anesthesia*** for this procedure.

Treatment

Treatment for endometriosis depends on the extent of the disease, your symptoms, and whether you want to have children. Endometriosis may be treated with medication, surgery, or both. When pain is the primary problem, medication usually is tried first.

Medications

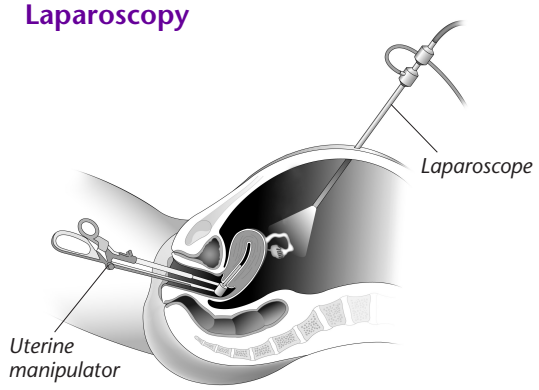
Medications that are used to treat endometriosis include pain relievers and hormonal medications. Hormones may help slow the growth of the endometrial tissue and may keep new adhesions from forming. These drugs typically do not get rid of endometriosis tissue that is already there.

As with most medications, many of these drugs can cause side effects. These medications do not relieve pain in all women. In many women, pain returns after the medications are stopped.

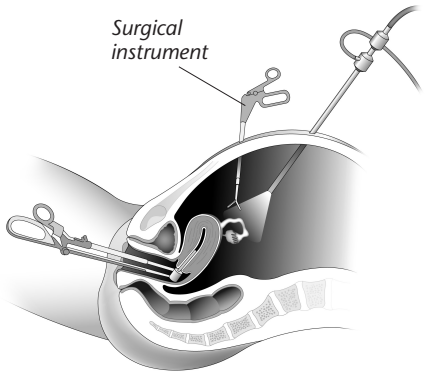
Nonsteroidal anti-inflammatory drugs (NSAIDs). For women with pain related to endometriosis who want to have children, NSAIDs may be tried first. NSAIDs may relieve pain but do not treat any other symptoms of endometriosis.

Birth control pills. Birth control pills that contain the hormones estrogen and ***progestin*** often are prescribed to treat symptoms of endometriosis. They control the

Laparoscopy



The laparoscope is placed through a small cut (incision) made below or inside the navel. A uterine manipulator moves the organs into view. The laparoscope shows images of the pelvic organs on a screen.



If needed, other small incisions may be made in the abdomen for surgical instruments.

menstrual cycle and may shrink areas of endometriosis. Birth control pills help keep the menstrual period regular and can relieve pain. Continuous-dose (also called extended-cycle) pills are a type of birth control pill. These pills reduce the number of menstrual periods that you have or stop them altogether. Side effects of birth control pills may include headache, breast tenderness, nausea, and irregular bleeding. If these side effects occur, talk to your health care professional. If one brand of pill causes side effects, another brand can be tried.

Progestins. Birth control methods that contain only the hormone progestin can be used to shrink endometriosis. Progestin can be given as a pill, shot, or in an implant that is inserted under the skin of the arm. The hormonal ***intrauterine device (IUD)*** also has been used to treat endometriosis-related pain. Possible side effects of progestin include irregular menstrual bleeding, weight gain, and headaches. The shot may decrease bone density for the first few years of use. When the shots are stopped, bone density in the spine returns to levels that are normal for a woman's age within 2 years but is slower to return at the hip. In a small number of women, there can be a temporary delay in fertility after stopping the shots. If you are concerned about these side effects, talk with your health care professional.

Gonadotropin-releasing hormone (GnRH) agonists. These hormones decrease estrogen levels by stopping the function of the ovaries. This causes a short-term condition that is much like menopause. You will not have menstrual periods and will not be able to become pregnant while you are taking GnRH agonists.

GnRH agonists can be given as a shot, implant, or nasal spray. In most cases, endometriosis shrinks and pain is relieved. Side effects of this medication may include the following:

- Hot flashes
- Headaches
- Vaginal dryness
- Decrease in bone density

Treatment with GnRH agonists usually lasts 3–6 months. Some women may need longer treatment. After stopping GnRH agonists, menstrual periods usually resume within 6–10 weeks.

Surgery

Surgery can be done to relieve pain and improve fertility. During surgery, endometriosis implants can be removed by cutting or with a laser.

After surgery, most women have relief from pain. But there is a chance that pain will come back. About 40–80% of women have pain again within 2 years of surgery. This may be due to endometriosis that was not visible or could not be removed at the time of surgery.

The more severe the disease, the more likely it is to return. Taking birth control pills or other medications after having surgery may help extend the pain-free period.

If pain is severe and does not go away after treatment, a ***hysterectomy*** may be a "last resort" option. Endometriosis is less likely to lead to future pain if your ovaries are removed at the time of hysterectomy. Either way, the goal of surgical treatment is to remove as much as possible of the endometriosis that is found outside the uterus.

After a hysterectomy, you will no longer have menstrual periods or be able to get pregnant. If your ovaries also are removed, and you have not yet gone through natural menopause, you will experience effects caused by lack of estrogen. These effects include hot flashes, vaginal dryness, and sleep problems. These symptoms may be more intense than what you would experience if you went through menopause over a few years, as is normal. You also may be at risk of a fracture caused by ***osteoporosis*** at an earlier age than women who go through natural menopause. ***Hormone therapy*** may be prescribed to manage these symptoms and concerns.

Coping

Endometriosis is a long-term condition. Many women have symptoms that occur off and on until menopause. Keep in mind that there are treatment options.

A woman can work with her health care professional in making the right decision for her.

It also may help to talk with other women who are coping with endometriosis. Ask your health care professional to suggest a support group in your area. You also may be able to find resources online.

Some women find that regular exercise or relaxation techniques help them cope with pain and discomfort. These strategies can be useful in addition to medications for pain relief.

Finally…

Endometriosis can cause pain and infertility. It often can be successfully treated. You may need more than one kind of treatment. If you have any symptoms of endometriosis, see your health care professional.

Glossary

Adhesions: Scars that can make tissue surfaces stick together.

Anesthesia: Relief of pain by loss of sensation.

Biopsy: A minor surgical procedure to remove a small piece of tissue. This tissue is examined under a microscope in a laboratory.

Bladder: A hollow, muscular organ in which urine is stored.

Dysmenorrhea: Discomfort and pain during the menstrual period.

Endometriosis: A condition in which tissue that lines the uterus is found outside of the uterus, usually on the ovaries, fallopian tubes, and other pelvic structures.

Endometrium: The lining of the uterus.

Estrogen: A female hormone produced in the ovaries.

Fallopian Tubes: Tubes through which an egg travels from the ovary to the uterus.

Genes: Segments of DNA that contain instructions for the development of a person's physical traits and control of the processes in the body. The gene is the basic unit of heredity and can be passed from parent to child.

Hormone: Substance made in the body that controls the function of cells or organs.

Hormone Therapy: Treatment in which estrogen and often progestin are taken to help relieve symptoms that may happen around the time of menopause.

Hysterectomy: Surgery to remove the uterus.

Infertility: The inability to get pregnant after 1 year of having regular sexual intercourse without the use of birth control.

Inflammation: Pain, swelling, redness, and irritation of tissues in the body.

Intrauterine Device (IUD): A small device that is inserted and left inside the uterus to prevent pregnancy.

Laparoscopy: A surgical procedure in which a thin, lighted telescope called a laparoscope is inserted through a small incision (cut) in the abdomen. The laparoscope is used to view the pelvic organs. Other instruments can be used with it to perform surgery.

Menopause: The time when a woman's menstrual periods stop permanently. Menopause is confirmed after 1 year of no periods.

Osteoporosis: A condition of thin bones, which could allow them to break more easily.

Ovaries: Organs in women that contain the eggs necessary to get pregnant and make important hormones, such as estrogen, progesterone, and testosterone.

Pelvic Exam: A physical examination of a woman's pelvic organs.

Peritoneum: The membrane that lines the abdominal cavity and surrounds the internal organs.

Progestin: A synthetic form of progesterone that is similar to the hormone made naturally by the body.

Rectum: The last part of the digestive tract.

Sexual Intercourse: The act of the penis of the male entering the vagina of the female. Also called "having sex" or "making love."

Ureters: A pair of tubes, each leading from one of the kidneys to the bladder.

Uterus: A muscular organ in the female pelvis. During pregnancy this organ holds and nourishes the fetus.

This is EP013 in ACOG's Patient Education Pamphlet Series.

ISSN 1074-8601

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