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 one in ten 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

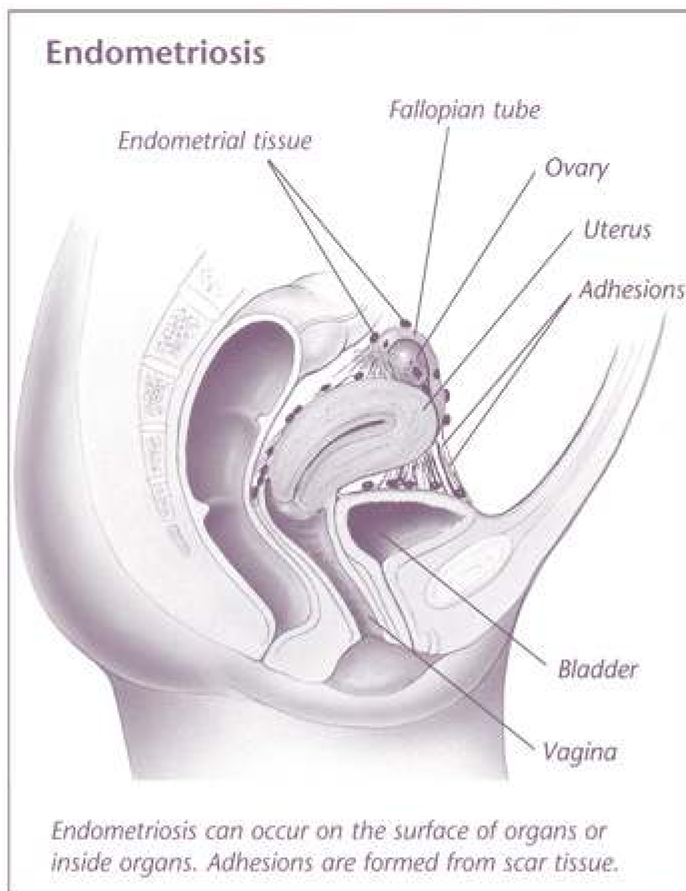
Where Endometriosis Occurs

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

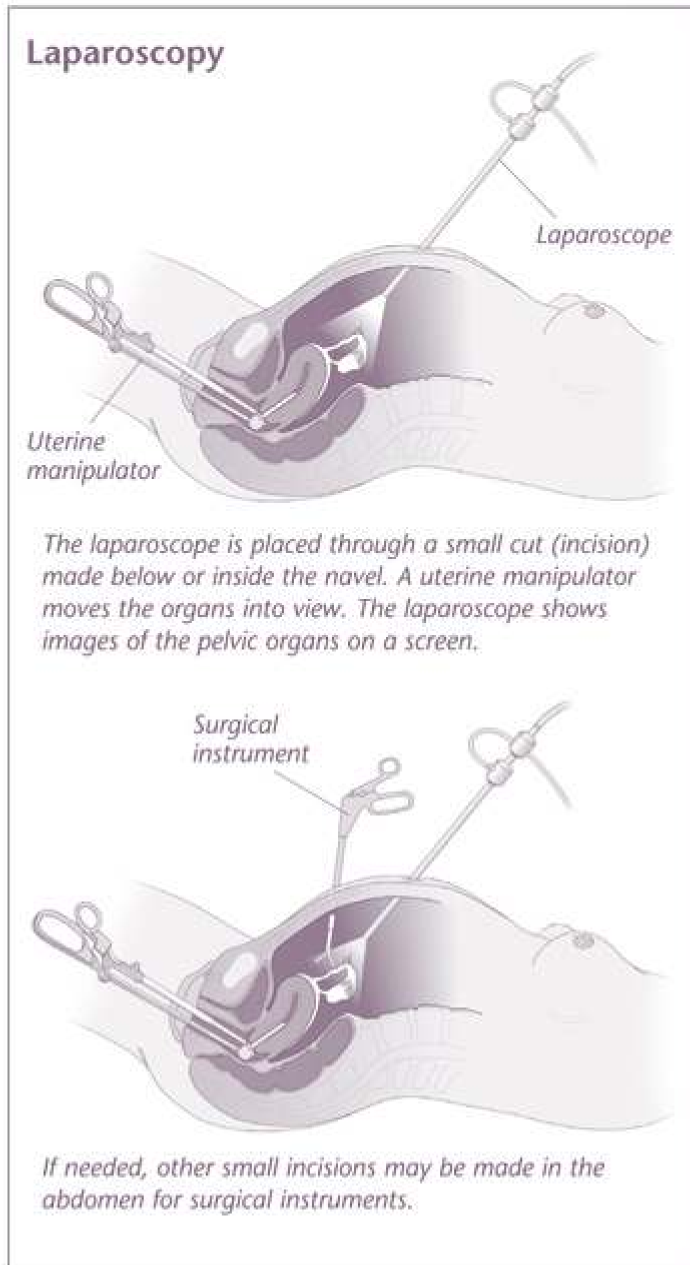
The most common symptom of endometriosis is chronic (long-term) pelvic pain, especially just before and during the menstrual period. Pain that occurs with menstruation is called ***dysmenorrhea***. For women with endometriosis, dysmenorrhea often becomes worse over time. Pain also may occur during sex. 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 provider 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 provider 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 during the procedure. 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 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 affects occur, talk to your health care provider. 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*** 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 provider.

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. However, symptoms may return. About 40–80% of women have pain again within 2 years 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 come back if your ovaries also are removed. If you keep your ovaries, endometriosis is less likely to come back if endometriosis implants are removed at the same time you have the hysterectomy.

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 menopause, you will experience effects caused by lack of estrogen. These effects are similar to those of menopause and 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.

There is a small chance that pain will come back even if your uterus and ovaries are removed. This may be due to endometriosis that was not visible or could not be removed at the time of surgery.

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 provider 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 provider 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 provider.

Glossary

Adhesions: Scarring that binds together the surfaces of tissues.

Anesthesia: Relief of pain by loss of sensation.

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

Bladder: A muscular organ in which urine is stored.

Dysmenorrhea: Discomfort and pain during the menstrual period.

Endometriosis: A condition in which tissue similar to that normally lining 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: DNA “blueprints” that code for specific traits, such as hair and eye color.

Hormone: A substance produced by the body to control the functions of various organs.

Hormone Therapy: Treatment in which estrogen, and often progestin, is taken to help relieve some of the symptoms caused by low levels of these hormones.

Hysterectomy: Removal of the uterus.

Infertility: A condition in which a couple has been unable to get pregnant after 12 months without the use of any form of birth control.

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

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

Laparoscopy: A surgical procedure in which an instrument called a laparoscope is inserted into the pelvic cavity through small incisions. The laparoscope is used to view the pelvic organs. Other instruments can be used with it to perform surgery.

Menopause: The time in a woman’s life when the ovaries have stopped functioning; defined as the absence of menstrual periods for 1 year.

Osteoporosis: A condition in which the bones become so fragile that they break more easily.

Ovaries: Two glands, located on either side of the uterus, that contain the eggs released at ovulation and that produce hormones.

Pelvic Exam: A physical examination of a woman’s reproductive 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 produced naturally by the body.

Rectum: The last part of the digestive tract.

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

Uterus: A muscular organ located in the female pelvis that contains and nourishes the developing fetus during pregnancy.

This Patient Education Pamphlet was developed by the American College of Obstetricians and Gynecologists. Designed as an aid to patients, it sets forth current information and opinions on subjects related to women's health. The average readability level of the series, based on the Fry formula, is grade 6–8. The Suitability Assessment of Materials (SAM) instrument rates the pamphlets as "superior." To ensure the information is current and accurate, the pamphlets are reviewed every 18 months. The information in this pamphlet does not dictate an exclusive course of treatment or procedure to be followed and should not be construed as excluding other acceptable methods of practice. Variations, taking into account the needs of the individual patient, resources, and limitations unique to the institution or type of practice, may be appropriate.

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The American College of Obstetricians and Gynecologists
409 12th Street, SW
PO Box 96920
Washington, DC 20090-6920

12345/65432