Endometriosis

Q: What is endometriosis (en-doh-mee-tree-OH-suhs)?
A: Endometriosis is a common health problem in women. It gets its name from the word, endometrium (en-doh-MEE-tree-um), the tissue that lines the uterus or womb. Endometriosis occurs when this tissue grows outside of the uterus on other organs or structures in the body. Most often, endometriosis is found on the:

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

Other sites for growths can include the vagina, cervix, vulva, bowel, bladder, or rectum. In rare cases, endometriosis has been found in other parts of the body, such as the lungs, brain, and skin.

Q: What are the symptoms of endometriosis?
A: The most common symptom of endometriosis is pain in the lower abdomen or pelvis, or the lower back, mainly during menstrual periods. The amount of pain a woman feels does not depend on how much endometriosis she has. Some women have no pain, even though their disease affects large areas. Other women with endometriosis have severe pain even though they have only a few small growths.

Symptoms of endometriosis can include:

- Very painful menstrual cramps; pain may get worse over time
- Chronic pain in the lower back and pelvis
- Pain during or after sex
- Intestinal pain
- Painful bowel movements or painful urination during menstrual periods
- Spotting or bleeding between menstrual periods
- Infertility or not being able to get pregnant
- Fatigue
- Diarrhea, constipation, bloating, or nausea, especially during menstrual periods

Recent research shows a link between other health problems in women with endometriosis and their families. Some of these include:

- Allergies, asthma, and chemical sensitivities
- Autoimmune diseases, in which the body’s system that fights illness attacks itself instead. These can
include hypothyroidism, multiple sclerosis, and lupus.

• Chronic fatigue syndrome (CFS) and fibromyalgia

• Being more likely to get infections and mononucleosis (ma-no-nu-klee-OH-suhs)

• Mitral valve prolapse, a condition in which one of the heart's valves does not close as tightly as normal

• Frequent yeast infections

• Certain cancers, such as ovarian, breast, endocrine, kidney, thyroid, brain, and colon cancers, and melanoma and non-Hodgkin's lymphoma

Q: Why does endometriosis cause pain and health problems?
A: Growths of endometriosis are benign (not cancerous). But they still can cause many problems. To see why, it helps to understand a woman's menstrual cycle. Every month, hormones cause the lining of a woman's uterus to build up with tissue and blood vessels. If a woman does not get pregnant, the uterus sheds this tissue and blood. It comes out of the body through the vagina as her menstrual period.

Patches of endometriosis also respond to the hormones produced during the menstrual cycle. With the passage of time, the growths of endometriosis may expand by adding extra tissue and blood. The symptoms of endometriosis often get worse.

Tissue and blood that is shed into the body can cause inflammation, scar tissue, and pain. As endometrial tissue grows, it can cover or grow into the ovaries and block the fallopian tubes. Trapped blood in the ovaries can form cysts, or closed sacs. It also can cause inflammation and cause the body to form scar tissue and adhesions, tissue that sometimes binds organs together. This scar tissue may cause pelvic pain and make it hard for women to get pregnant. The growths can also cause problems in the intestines and bladder.

Q: Who gets endometriosis?
A: More than five million women in the United States have endometriosis. It is one of the most common health problems for women. It can occur in any teen or woman who has menstrual periods, but it is most common in women in their 30s and 40s.

The symptoms of endometriosis stop for a time during pregnancy. Symptoms also tend to decrease with menopause, when menstrual periods end for good. In some cases, women who take menopausal hormone therapy may still have symptoms of endometriosis.

Q: What can raise my chances of getting endometriosis?
A: You might be more likely to get endometriosis if you have:

• Never had children

• Menstrual periods that last more than seven days

• Short menstrual cycles (27 days or less)

• A family member (mother, aunt, sister) with endometriosis

• A health problem that prevents normal passage of menstrual blood flow

• Damage to cells in the pelvis from an infection
Q: How can I reduce my chances of getting endometriosis?
A: There are no definite ways to lower your chances of getting endometriosis. Yet, since the hormone estrogen is involved in thickening the lining of the uterus during the menstrual cycle, you can try to lower levels of estrogen in your body.

To keep lower estrogen levels in your body, you can:
- Exercise regularly
- Keep a low amount of body fat
- Avoid large amounts of alcohol and drinks with caffeine

Q: Why is it important to find out if I have endometriosis?
A: The pain of endometriosis can interfere with your life. Studies show that women with endometriosis often skip school, work, and social events. This health problem can also get in the way of relationships with your partner, friends, children, and co-workers. Plus, endometriosis can make it hard for you to get pregnant.

Finding out that you have endometriosis is the first step in taking back your life. Many treatments can control the symptoms. Medicine can relieve your pain. When endometriosis causes fertility problems, surgery can boost your chances of getting pregnant.

Q: How do I know that I have endometriosis?
A: If you have symptoms of this disease, talk with your doctor or your obstetrician/gynecologist (OB/GYN). An OB/GYN has special training to diagnose and treat this condition. Sometimes endometriosis is mistaken for other health problems that cause pelvic pain and the exact cause might be hard to pinpoint.

The doctor will talk to you about your symptoms and health history. The doctor may also do these tests to check for clues of endometriosis:

Pelvic exam. Your doctor will perform a pelvic exam to feel for large cysts or scars behind your uterus. Smaller areas of endometriosis are hard to feel.

Ultrasound. Your doctor could perform an ultrasound, an imaging test to see if there are ovarian cysts from endometriosis. During a vaginal ultrasound, the doctor will insert a wand-shaped scanner into your vagina. During an ultrasound of your pelvis, a scanner is moved across your abdomen. Both tests use sound waves to make pictures of your reproductive organs. Magnetic resonance imaging (MRI) is another common imaging test that can produce a picture of the inside of your body.

Laparoscopy (lap-ar-OS-ko-pee). The only way for your doctor to know for sure that you have endometriosis is to look inside your abdomen to see endometriosis tissue. He or she can do this through a minor surgery called laparoscopy. You will receive general anesthesia before the surgery. Then, your abdomen is expanded with a gas to make it easy to see your organs. A tiny cut is made in your abdomen and a thin tube with a light is placed inside to see growths from endometriosis. Sometimes doctors can diagnose endometriosis just by seeing the growths. Other times, they need to take a small sample of tissue and study it under a microscope.

If your doctor does not find signs of an ovarian cyst during an ultrasound, before doing a laparoscopy, your doctor may prescribe birth control pills to control your menstrual cycle. Sometimes this treatment helps lessen pelvic pain during your period. Some doctors may offer another treatment that blocks the
menstrual cycle and lowers the amount of estrogen your body makes before doing a laparoscopy. This treatment is a medicine called a gonadotropin (go-na-doh-TRO-pen) releasing hormone (GnRH) agonist, which also may help pelvic pain. If your pain improves on this medicine, the doctor will likely think that you have endometriosis.

Laparoscopy is often recommended for diagnosis and treatment if the pelvic pain persists, even after taking birth control pills and pain medicine.

Q: What causes endometriosis?
A: No one knows for sure what causes this disease, but experts have a number of theories:

- Since endometriosis runs in families, it may be carried in the genes, or some families have traits that make them more likely to get it.
- Endometrial tissue may move from the uterus to other body parts through the blood system or lymph system.
- If a woman has a faulty immune system it will fail to find and destroy endometrial tissue growing outside of the uterus. Recent research shows that immune system disorders and certain cancers are more common in women with endometriosis.
- The hormone estrogen appears to promote the growth of endometriosis. So, some research is looking at whether it is a disease of the endocrine system, the body’s system of glands, hormones, and other secretions.
- Endometrial tissue has been found in abdominal scars and might have been moved there by mistake during a surgery.

- Small amounts of tissue from when a woman was an embryo might later become endometriosis.
- New research shows a link between dioxin exposure and getting endometriosis. Dioxin is a toxic chemical from the making of pesticides and the burning of wastes. More research is needed to find out whether man-made chemicals cause endometriosis.
- Endometrial tissue may back up into the abdomen through the fallopian tubes during a woman’s monthly period. This transplanted tissue could grow outside of the uterus. However, most experts agree that this theory does not entirely explain why endometriosis develops.

Q: How is endometriosis treated?
A: There is no cure for endometriosis, but there are many treatments for the pain and infertility that it causes. Talk with your doctor about what option is best for you. The treatment you choose will depend on your symptoms, age, and plans for getting pregnant.

Pain Medication. For some women with mild symptoms, doctors may suggest taking over-the-counter medicines for pain. These include ibuprofen (Advil and Motrin) or naproxen (Aleve). When these medicines don’t help, doctors may prescribe stronger pain relievers.

Hormone Treatment. When pain medicine is not enough, doctors often recommend hormone medicines to treat endometriosis. Only women who do not wish to become pregnant can use these drugs. Hormone treatment is best for women with small growths who do not have bad pain. Hormones come in many forms including pills, shots, and nasal sprays. Common hormones used for endometriosis include:
• **Birth control pills** to decrease the amount of menstrual flow and prevent overgrowth of tissue that lines the uterus. Most birth control pills contain two hormones, estrogen and progestin. Once a woman stops taking them, she can get pregnant again. Stopping these pills will cause the symptoms of endometriosis to return.

• **GnRH agonists and antagonists** greatly reduce the amount of estrogen in a woman's body, which stops the menstrual cycle. These drugs should not be used alone because they can cause side effects similar to those during menopause, such as hot flashes, bone loss, and vaginal dryness. Taking a low dose of progestin or estrogen along with these drugs can protect against these side effects. When a woman stops taking this medicine, monthly periods and the ability to get pregnant return. She also might stay free of the problems of endometriosis for months or years afterward.

• **Progestins.** The hormone progestin can shrink spots of endometriosis by working against the effects of estrogen on the tissue. It will stop a woman's menstrual periods, but can cause irregular vaginal bleeding. Medroxyprogesterone (muh-DROKS-ee-proh-JESS-tur-ohn) (Depo-Provera) is a common progestin taken as a shot. Side effects of progestin can include weight gain, depressed mood, and decreased bone growth.

• **Danazol (DAY-nuh-zawl)** is a weak male hormone that lowers the levels of estrogen and progesterone in a woman's body. This stops a woman's period or makes it come less often. It is not often the first choice for treatment due to its side effects, such as oily skin, weight gain, tiredness, smaller breasts, and facial hair growth. It does not prevent pregnancy and can harm a baby growing in the uterus. It also cannot be used with other hormones, such as birth control pills.

**Surgery.** Surgery is usually the best choice for women with severe endometriosis — many growths, a great deal of pain, or fertility problems. There are both minor and more complex surgeries that can help. Your doctor might suggest one of the following:

• **Laparoscopy** can be used to diagnose and treat endometriosis. During this surgery, doctors remove growths and scar tissue or burn them away. The goal is to treat the endometriosis without harming the healthy tissue around it. Women recover from laparoscopy much faster than from major abdominal surgery.

• **Laparotomy (lap-ar-AW-tuh-mee) or major abdominal surgery** that involves a much larger cut in the abdomen than with laparoscopy. This allows the doctor to reach and remove growths of endometriosis in the pelvis or abdomen.

• **Hysterectomy (his-tur-EK-toh-mee)** is a surgery in which the doctor removes the uterus. Removing the ovaries as well can help ensure that endometriosis will not return. This is done when the endometriosis has severely damaged these organs. A woman cannot get pregnant after this surgery, so it should only be considered as a last resort.
Q: How do I cope with a disease that has no cure?
A: You may feel many emotions — sadness, fright, anger, confusion, and loneliness. It is important to get support to cope with endometriosis. Consider joining a support group to talk with other women who have endometriosis. There are support groups on the Internet and in many communities. It is also important to learn as much as you can about the disease. Talking with friends, family, and your doctor can help.

For more information

You can find out more about endometriosis by contacting womenshealth.gov at 1-800-994-9662. You also can contact the following organizations:

**Endometriosis Association**
Phone Number(s): (414) 355-2200
Internet Address: http://www.endometriosisassn.org

**Endometriosis Research Center**
Phone Number(s): (561) 274-7442
Internet Address: http://www.endocenter.org

**The American College of Obstetricians and Gynecologists**
Phone Number(s): (202) 638-5577; (202) 863-2518 (for publication requests only)
Internet Address: http://www.acog.org

**Eunice Kennedy Shriver National Institute of Child Health and Human Development**
Phone Number(s): 1-800-370-2943
TTY: 1-888-320-6942
Internet Address: http://www.nichd.nih.gov

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