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Endometriosis

Q: Why do I need to know about endometriosis?

A: Endometriosis is a common disease that can affect any menstruating woman from the time of her first period to menopause. Sometimes, the disease can last after menopause. There is no cure for endometriosis and it can be hard for a health care provider to figure out if a woman has it. It can also be hard to figure out the best way to treat it if a woman has the disease. Endometriosis can affect a woman in many ways, such as her ability to work and have children, and her relationships with her partner, children, friends, and co-workers. Researchers are working to find out both causes and ways to manage this disease, so that women who have it can lead full lives.

Q: What is endometriosis?

A: When a woman has endometriosis, the tissue that lines her uterus, called the *endometrium*, grows outside of the uterus. No one is sure why this happens. When this tissue grows outside of the uterus, it is mostly found in the pelvic cavity, usually in one or more of these places: on or under the ovaries, behind the uterus, on the tissues that hold the uterus in place, or on the bowels or bladder. In very rare cases, endometriosis areas can grow in the lungs or other parts of the body.

As the tissue grows, it can develop into *growths*, also called *tumors* or *implants*. These growths are usually *benign* (not cancerous) and rarely are associated with cancer. Growths can cause mild to severe pain, *infertility* (not being able to get pregnant), and heavy periods.

The endometriosis growths are affected by the monthly menstrual cycle. Each month, the lining of the uterus thickens to get ready for pregnancy. If a woman does not become pregnant, the lining of the uterus sheds and the woman bleeds. When a woman has endometriosis, the growths outside of the uterus also bleed during her period. But there is no way for the blood to leave her body, and inflammation and scar tissue can develop. Blockage or bleeding in the intestines and problems with bladder function may also occur.

Q: What are the symptoms of endometriosis?

A: A common symptom of endometriosis is pain, mostly in the abdomen, lower back, and pelvic areas. The amount of pain a woman feels is not linked to how much endometriosis she has. Some women have no pain even though their disease affects large areas, or there is scarring. Some women, on the other hand, have severe pain even though they have only a few small areas of endometriosis.

General symptoms of endometriosis can include (but are not limited to):

- Extremely painful (or disabling) menstrual cramps; pain may get worse over time
- Chronic pelvic pain (includes lower back pain and pelvic pain)
- Pain during or after sex
- Intestinal pain
- Painful bowel movements or painful urination during menstrual periods

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- Heavy menstrual periods
- Premenstrual spotting or bleeding between periods
- Infertility (not being able to get pregnant)

Also, women who have endometriosis may have gastrointestinal symptoms that are like those of a bowel disorder, as well as fatigue.

Q: How would I know if I have endometriosis?

A: If you think you might have this disease, talk with your OB/GYN (obstetrician/gynecologist), since she or he is the only type of doctor trained to look for this condition. There are a number of tests a doctor can perform to try to find out if you have endometriosis. Sometimes, imaging tests are used to make a "picture" of the inside of the body, which allows a doctor to locate larger endometriosis areas. The two most common imaging tests are ultrasound, a machine that uses sound waves to make the picture, and magnetic resonance imaging (MRI), a machine that uses magnets and radio waves to make the picture.

The only way to know for sure if you have endometriosis is to have a *laparoscopy*. This is a surgery with general anesthesia in which a tube with a light is placed inside your abdomen. The surgeon can then check your organs and see any growths or tissue from endometriosis. This procedure will show the location, extent, and size of the growths and help you and your doctor make better treatment decisions. Before surgery, you will need to discuss your medical history with your doctor, and have a physical (pelvic) exam.

Q: What causes endometriosis?

A: No one knows for sure what causes this disease. One theory is that during menstruation some of the menstrual tissue backs up through the fallopian tubes into the abdomen, where it implants and grows. Another theory suggests that endometriosis may be genetic, or runs in families.

Researchers also are looking at the role of the immune system and how it either stimulates or reacts to endometriosis. It may be that a woman's immune system does not remove the menstrual fluid in the pelvic cavity properly, or the chemicals made by areas of endometriosis may irritate or promote growth of more areas. Results from a recent study showed that women who have the disease are more likely than other women to have immune system disorders in which the body attacks its own tissues. This study also found that women with endometriosis are more likely to have *chronic fatigue syndrome* and to suffer from *fibromyalgia syndrome*—a disease involving pain in the muscles, tendons, and ligaments. These women also are more likely to have asthma, allergies, and the skin condition *eczema*. So, researchers feel that further study of the immune system in endometriosis may give important clues to finding the causes of and treatment for the disease.

Other researchers are looking into endometriosis as a disease of the endocrine system, the body's system of glands, hormones, and other secretions, since estrogen appears to promote the growth of the disease. Other research is looking at whether environmental agents, such as exposure to man-made chemicals, cause the disease. More

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research is trying to understand what, if any, factors affect the course of the disease.

Another important area of research is the search for endometriosis *markers*. These markers are substances in the body made by or in response to the disease, and can be measured in the blood or urine. If markers are found by a blood or urine test, then a diagnosis for endometriosis could be made without surgery.

Q: What is the treatment for endometriosis?

A: There is no cure for endometriosis. But there are many treatments, each of which has pros and cons. It is important to build a good relationship with your doctor, so you can decide what option is best for you.

Pain Medication

For some women with mild symptoms, no further treatment other than medication for pain may be needed. For women with minimal endometriosis who want to become pregnant, doctors are saying that, depending on the age of the woman and her amount of pain from the disease, the best thing to do is to have a trial period of unprotected sex for six months to one year. If she does not get pregnant in that time, then further treatment may be needed.

Hormone Treatment

For patients who do not wish to become pregnant, but need treatment for their disease, their doctors may suggest hormone treatment. Hormone treatment is most effective when growths are small. Hormones can come in pill form, by shot or injection, or in a nasal spray. There are several hormones used for this treatment including a combination of estrogen and progestin such as birth control pills, a progestin alone, *Danocrine* (a weak male hormone), and *GnRH agonists* (gonadotropin releasing hormone).

Birth control pills control the growth of the tissue that lines the uterus and often decrease the amount of menstrual flow. They usually contain two hormones, estrogen and progestin. Once a woman stops taking them, the ability to become pregnant returns, but the symptoms of endometriosis also may return. Some women take birth control pills continuously, without using the sugar pills that signal the body to go through menstruation. When birth control pills are taken in this way, the menstrual period may stop altogether, which can reduce pain or get rid of it entirely. Some birth control pills contain only progestin, a progesterone-like hormone. Women who can't take estrogen use these pills to reduce menstrual flow. With these pills, some women may not have pain for several years after stopping treatment. All birth control pills might cause some mild side effects like weight gain, bleeding between periods, and bloating.

Danocrine has become a more common treatment choice than either progestin or combination hormone pills. Side effects with Danocrine include oily skin, pimples or acne, weight gain, muscle cramps, tiredness, smaller breasts, breast tenderness, headaches, dizziness, weakness, hot flashes, or a deepening of the voice. Women on Danocrine probably will only get a period now and then, or might not get it at all. Women who take Danocrine also should take steps to prevent preg-

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nancy because it can harm a baby growing in the uterus. Because other hormones, like birth control pills, should be avoided, health care providers recommend that you use condoms, a diaphragm, or other "barrier" methods to prevent pregnancy.

GnRH agonists (used daily in a nose spray, or as an injection given once a month or every three months) prevent the body from making certain hormones to prevent menstruation. Without menstruation, the growth of endometriosis is slowed or stopped. These medications can cause side effects, such as hot flashes, tiredness, problems sleeping, headaches, depression, bone loss, and vaginal dryness. Most health care providers recommend that a woman stay on a GnRH agonist for about six months. After that time, the body will start having a period again and a woman could get pregnant. But, after that time, about half of women have some return of their endometriosis symptoms.

Surgery

Surgery is usually the best choice for women with extensive endometriosis, or those with severe pain. There are both minor and major surgeries that can help. Your doctor might suggest one of the following surgical treatments:

- Laparoscopy – also used to diagnose the disease, your doctor can treat you with this surgery as well. If your doctor is going to treat the endometriosis during this surgery, he or she must make at least two more cuts in your lower abdomen, to pass lasers or other small surgical tools into your abdomen. Then he or she will remove the growths and scar tissue or destroy them with intense heat and seal the blood vessels without stitches. The goal is to treat the endometriosis without harming the healthy tissue around it. Recovery from laparoscopy is much faster than for major surgery, like laparotomy.
- Laparotomy – this is a last resort for endometriosis treatment because it is major abdominal surgery in which your doctor either removes the endometriosis and / or removes the uterus (a process called hysterectomy). He or she also might remove the ovaries and fallopian tubes at the time of a hysterectomy, if the ovaries have endometriosis on them, or if damage is severe. Having the surgery does not ensure that the disease will not return or that the pain will go away.

Q: How do I cope with a disease that has no cure?

A: You may feel many emotions—sadness, fright, anger, confusion—and feel alone. It is important to get the support you need to cope with endometriosis. It is also important to learn as much as you can about the disease. Talking with friends, family, and your health care provider can help. You might want to join a support group to talk with other women who are going through the same thing. ■

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For More Information…

You can find out more about endometriosis by contacting the National Women's Health Information Center (NWHIC) at 1-800-994-9662 or the following organizations:

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

Endometriosis Research Center
Phone Number(s): (800) 239-7280
Internet Address:
http://www.endocenter.org/

The American College of Obstetricians and Gynecologists
Phone Number(s): (800) 762-2264 x 192
(for publication requests only)
Internet Address: http://www.acog.org/

This FAQ was adapted from Here's What We Do Know…Endometriosis from the National Institute of Child Health and Human Development (NICHD).

December 2002