

ENDOMETRIOSIS

What is endometriosis?

Endometriosis occurs when tissue like that which lines the inside of uterus grows outside the uterus, usually on the surfaces of organs in the pelvic and abdominal areas, in places that it is not supposed to grow.

The word endometriosis comes from the word “endometrium”—endo means “inside” and metrium (pronounced mee-tree-um) means “mother.” Health care providers call the tissue that lines the inside of the uterus (where a mother carries her baby) the endometrium.

Health care providers may call areas of endometriosis by different names, such as implants, lesions, or nodules.

In what places, outside of the uterus, do areas of endometriosis grow?

Most endometriosis is found in the pelvic cavity:

- ❑ On or under the ovaries
- ❑ Behind the uterus
- ❑ On the tissues that hold the uterus in place
- ❑ On the bowels or bladder
- ❑ In extremely rare cases, endometriosis areas can grow in the lungs or other parts of the body.

What are the symptoms of endometriosis?

One of the most common symptoms 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 endometriosis is extensive, meaning that the affected areas are large, or that 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
- Heavy menstrual periods
- Premenstrual spotting or bleeding between periods
- Infertility
- In addition, women who are diagnosed with endometriosis may have gastrointestinal symptoms that resemble a bowel disorder, as well as fatigue.

Who gets endometriosis?

Endometriosis can affect any menstruating woman, from the time of her first period to menopause, regardless of whether or not she has children, her race or ethnicity, or her socio-economic status. Endometriosis can sometimes persist after menopause; or hormones taken for menopausal symptoms may cause the symptoms of endometriosis to continue.

Current estimates place the number of women with endometriosis between 2 percent and 10 percent of women of reproductive age. But, it's important to note that these are only estimates, and that such statistics can vary widely.

Does having endometriosis mean I'll be infertile or unable to have children?

About 30 percent to 40 percent of women with endometriosis are infertile, making it one of the top three causes of female infertility. Some women don't find out that they have endometriosis until they have trouble getting pregnant.

If you have endometriosis and want to get pregnant, your health care provider may suggest that you have unprotected sex for six months to a year before you have any treatment for the endometriosis.

The relationship between endometriosis and infertility is an active area of research. Some studies suggest that the condition may change the uterus so it does not accept an embryo. Other work explores whether endometriosis changes the egg, or whether endometriosis gets in the way of moving a fertilized egg to the uterus.

What causes endometriosis?

We don't know the exact cause of endometriosis. Right now, a number of theories try to explain the disease.

Endometriosis may result from something called "retrograde menstrual flow," in which some of the tissue that a woman sheds during her period flows into her pelvis. While most women who get their periods have some retrograde menstrual flow, not all of these women have endometriosis. Researchers are trying to uncover what other factors might cause the tissue to grow in some women, but not in others.

Another theory about the cause of endometriosis involves genes. This disease could be inherited, or it could result from genetic errors, making some women more likely than others to develop the condition. If researchers can find a specific gene or genes related to endometriosis in some women, genetic testing might allow health care providers to detect endometriosis much earlier, or even prevent it from happening at all.

Researchers are exploring other possible causes, as well. Estrogen, a hormone involved in the female reproductive cycle, appears to promote the growth of endometriosis. Therefore, some research is looking into endometriosis as a disease of the endocrine system, the body's system of glands, hormones, and other secretions. Or, 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. So, other researchers are studying the role of the immune system in either stimulating, or reacting to endometriosis.

Other research focuses on determining whether environmental agents, such as exposure to man-made chemicals, cause endometriosis. Additional research is trying to understand what, if any, factors influence the course of the disease. We just don't have answers on the causes yet.

Another important area of NICHD research is the search for endometriosis markers. These markers are substances made by or in response to endometriosis that health care providers can measure in the blood or urine. If markers are found, health care providers could diagnose endometriosis by testing a woman's blood or urine, which might reduce the need for surgery.

How do I know that I have endometriosis?

Currently, health care providers use a number of tests for endometriosis. Sometimes, they will use imaging tests to produce a “picture” of the inside of the body, which allows them to locate larger endometriosis areas, such as nodules or cysts. 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 that you have the condition is by having surgery. The most common type of surgery is called laparoscopy. In this procedure, the surgeon inflates the abdomen slightly with a harmless gas. After making a small cut in the abdomen, the surgeon uses a small viewing instrument with a light, called a laparoscope, to look at the reproductive organs, intestines, and other surfaces to see if there is any endometriosis. He or she can make a diagnosis based on the characteristic appearance of endometriosis. This diagnosis can then be confirmed by doing a biopsy, which involves taking a small tissue sample and studying it under a microscope.

Your health care provider will only do a laparoscopy after learning your full medical history and giving you a complete physical and pelvic exam. This information, in addition to the results of an ultrasound or MRI, will help you and your health care provider make more informed decisions about treatment.

Why does having endometriosis cause pain?

How endometriosis causes pain is the topic of much research. Because many women with endometriosis feel pain during or related to their periods, some researchers are focusing on the menstrual cycle in their search for answers about pain.

Normally, if a woman is not pregnant, her endometrial tissue builds up inside her uterus, breaks down into blood and tissue, and is shed as her menstrual flow or period. This cycle of growth and shedding happens every month or so.

The endometriosis areas growing outside the uterus also go through a similar cycle; they grow, break down into blood and tissue, and are shed once a month. But, because this tissue isn't where it's supposed to be, it can't leave the body the way a woman's period normally does. As part of this process, endometriosis areas make chemicals that may irritate the nearby tissue, as well as some other chemicals that are known to cause pain.

Over time, in the process of going through this monthly cycle, endometriosis areas can grow and become nodules or bumps on the surface of pelvic organs, or become cysts (fluid-filled sacs) in the ovaries. Sometimes the chemicals produced by the endometriosis can cause the organs in the pelvic area to scar, and even to scar together, so they appear as

Is there a cure for endometriosis?

Currently, we have no cure for endometriosis. Even having a hysterectomy or removing the ovaries does not guarantee that the endometriosis areas and/or the symptoms of endometriosis will not come back.

Are there treatments for endometriosis?

There are a number of treatments for both pain and infertility related to endometriosis.

First, let's focus on the treatments for endometriosis pain. They include:

- Pain medication—Works well if your pain or other symptoms are mild. These medications range from over-the-counter remedies to strong prescription drugs.
- Hormone therapy—Is effective if your areas are small and/or you have minimal pain. Hormones can come in pill form, by shot or injection, or in a nasal spray. Common hormones used to treat endometriosis pain are progesterone, birth control pills, danocrine, and gonadatropin-releasing hormone (GnRH). Go to the next section, What are the hormone treatments for endometriosis pain? for more information.
- Surgical treatment—Is usually the best choice if your endometriosis is extensive, or if you have more severe pain. Surgical treatments range from minor to major surgical procedures. Go to the What are the surgical treatments for endometriosis pain? section for more information about these options.

What are the hormone treatments for endometriosis pain?

Because hormones cause endometriosis to go through a cycle similar to the menstrual cycle, hormones can also be effective in treating the symptoms of endometriosis. In fact, if a woman's symptoms do not respond to hormone therapy, health care providers may go over their diagnosis of endometriosis again, to make sure she really has the condition.

Health care providers may suggest one of the following hormone treatments:

- Oral contraceptives or birth control pills—regulate the growth of the tissue that lines the uterus and often decrease the amount of menstrual flow. In general, the therapy contains two hormones, estrogen and progestin. It often works as long as you take the pills. Once you stop the treatment, your ability to get pregnant returns, and your symptoms of endometriosis may also return. Many women continue the treatment indefinitely. 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. Some women may not have pain for several years after stopping treatment. You may have some mild side effects from these hormones, such as weight gain, bleeding between periods, and bloating.
- Progesterone and progestin— improve symptoms by reducing a woman's period or stopping it completely. As a pill taken daily, these hormones will reduce menstrual flow without causing the lining of the uterus to grow. As soon as you stop taking the pill form, you can get pregnant and your symptoms may return. As an injection taken every three months, these hormones will usually stop menstrual flow. It may take a few months for your period to return after you stop taking the injections. When your period returns, so does your ability to get pregnant. You may gain weight or feel depressed while taking these hormones.
- Danocrine—stops the release of hormones that are involved in the menstrual cycle. You will probably get your period only now and then while taking this drug; or, you may not get it at all. You should take steps to prevent pregnancy while you are on this medication because

- danocrine can harm a baby growing in the uterus. Because you should avoid taking other hormones, like birth control pills, while on danocrine, health care providers recommend that you use condoms, a diaphragm, or other “barrier” methods to prevent pregnancy. Common side effects include oily skin, pimples or acne, weight gain, muscle cramps, tiredness, smaller breasts, and breast tenderness. You may also have headaches, dizziness, weakness, hot flashes, or a deepening of your voice while on this treatment.
- Gonadatropin-Releasing Hormone (GnRH) Agonists— block the production of certain hormones to prevent menstruation, which slows or stops the growth of endometriosis, sending the body into a “menopausal” state. GnRH agonist is used daily in a nose spray, or as an injection given once a month or every three months. Most health care providers recommend that you stay on the GnRH agonist for about six months. After that time, your body will come out of the menopausal state. You’ll start having your period again and could get pregnant. After women stop taking GnRH agonists for six months, about 50 percent have some return of their endometriosis symptoms. These medications also have side effects, including hot flashes, tiredness, problems sleeping, headaches, depression, bone loss, and vaginal dryness. Current research is exploring the use of other hormones in treating endometriosis and pain related to endometriosis. Some of these include GnRH antagonists, selective progesterone receptor modifiers, and selective estrogen receptor modulators, also known as SERMs. For more information about these hormones, talk to your health care provider.

Some women also have less pain from endometriosis after pregnancy, but the reason for this is unclear. Researchers are trying to determine whether it is because the hormones released by the body during pregnancy also lessen the growth of endometriosis, or if pregnancy causes changes in the uterus or endometrium that lessen the growth of endometriosis.

What are the surgical treatments for endometriosis pain?

If you have severe pain from endometriosis, your health care provider may suggest surgery. At surgery, your health care provider can locate any endometriosis and see the size and degree of growth; he or she may also remove the endometriosis at that time.

You and your health care provider should talk about possible options for removing endometriosis before your surgery. Then, based on the findings and treatment at surgery, you and your health care provider can discuss medical treatment options for after surgery.

Health care providers may suggest one of the following surgical treatments:

- Laparoscopy— is a way to diagnose and treat endometriosis without making large cuts in the abdomen. Laparoscopy involves a small cut in the abdomen, inflating the abdomen with a harmless gas, and then passing a viewing instrument with a light (called a laparoscope) into the abdomen. The surgeon uses the laparoscope to see the growths. To treat the endometriosis, the doctor can then remove the areas, a process called excising (pronounced eks-size-ing), or destroy them with intense heat and seal the blood vessels without stitches, a process called cauterizing (pronounced kaw-terr-eyes-ing), or vaporizing. The goal is to treat the endometriosis without harming the healthy tissue around it. If your surgeon is going to treat the endometriosis during your laparoscopy, he or she must make at least two more cuts in your lower abdomen, to pass lasers or other small surgical instruments into your abdomen to remove or vaporize the tissue. Doctors don't know the exact role of scar tissue in causing endometriosis pain, but some will remove the scar tissue in case it is causing the pain. Usually, laparoscopy does not require an overnight stay in the hospital. Recovery from laparoscopy is much faster than for major surgery, like laparotomy, a procedure described below.
- Major abdominal surgery, or laparotomy— is a more involved surgical procedure, which requires longer recovery time (often one-to-two months). During laparotomy, doctors either remove the endometriosis and/or remove the uterus (a process called hysterectomy). Doctors may also remove the ovaries and fallopian tubes at the time of a hysterectomy, if the ovaries have endometriosis on them, or if damage is severe. This process is called total hysterectomy and bilateral salpingo-oophorectomy (pronounced byelatt-ur-el sal-ping-go ooh-for-ek-toe-mee). Health care providers recommend major surgery as a last resort for endometriosis treatment. Having the surgery does not guarantee that the endometriosis will not return or that the pain will go away.

- If a woman's pain is extreme, doctors may recommend more drastic procedures that cut the nerves in the pelvis to lessen the pain. One such procedure can be done during either laparoscopy or laparotomy. Another procedure, called a laparoscopic uterine nerve ablation (LUNA) is done during a laparoscopy. Because these procedures cannot be reversed, you and your health care provider will need to talk about these options in great detail before making the final decision about treatment.

What are the treatments for infertility related to endometriosis?

In vitro fertilization (IVF) procedures are effective in improving fertility in many women with endometriosis. IVF makes it possible to combine sperm and eggs in a laboratory and then place the resulting embryos into the woman's uterus. IVF is one type of assisted reproductive technology that may be an option for women and families affected by infertility related to endometriosis.

In the early stages of IVF, a woman takes hormones to cause "superovulation," which triggers her body to produce many eggs at one time. Once mature, the eggs are collected from the woman, using a probe inserted into the vagina and guided by ultrasound. The collected eggs are placed in a dish for fertilization with a man's sperm. The fertilized cells are then placed in an incubator, a machine that keeps them warm and allows them to develop into embryos. After three-to-five days, the embryos are transferred to the woman's uterus. It takes about two weeks to know if the process is successful.

Even though the use of hormones in IVF is successful in treating infertility related to endometriosis, other forms of hormone therapy are not as successful. For instance, hormone therapy that prevents a woman from getting her period, or from ovulating each month, does not seem to improve infertility related to endometriosis. But, researchers are still looking into hormone treatments for infertility due to endometriosis.

Laparoscopy to remove or vaporize the growths in women who have mild or minimal endometriosis is also effective in improving fertility. Some studies show that surgery can double the pregnancy rate. You can review the What

are the surgical treatments for endometriosis pain? section of this publication for more information on laparoscopy.

Is endometriosis the same as endometrial cancer?

Endometriosis is not the same as endometrial cancer. Remember that the word endometrium describes the tissue that lines the inside of the uterus. Endometrial cancer is a type of cancer that affects the lining of the inside of the uterus. Endometriosis itself is not a form of cancer

Does endometriosis lead to cancer?

Current research does not prove an association between endometriosis and endometrial, cervical, uterine, or ovarian cancers. In very rare cases (less than 1 percent) endometriosis is seen with a certain type of cancer, called endometrioid cancer; but, endometriosis is not known to cause this cancer.

But, scientists still don't know what causes endometriosis or what its mechanisms are in the body. In addition, many women are never diagnosed as having endometriosis, which makes linking the condition to other diseases more difficult.

For this reason, women who are diagnosed with endometriosis need to be especially watchful of changes to or in their bodies; they need to communicate these changes to their health care providers as soon as possible, to ensure their own health.

Does endometriosis ever go away?

In most cases, the symptoms of endometriosis lessen after menopause because the growths gradually get smaller. For some women, however, this is not the case.

Additional Information

- Endometriosis Association -
<http://www.endometriosisassn.org/index.html>
- Endometriosis Research Center -
<http://www.endocenter.org/EndoPPF.htm>

Source: NICHD

Reviewed: 11/2007

This pamphlet is provided for informational purposes only. It is not meant to be used for self-diagnosis or treatment. This is not a substitute for consultation with a healthcare provider. If you have any questions or concerns, consult with your physician. Use of trade names is for identification purposes only and does not imply endorsement by St. Anthony's Physician Organization.