

Endometriosis

Finding help for pain & pregnancy

Endometriosis is a common health problem in women,¹ affecting at least 5.5 million women in North America alone.² Endometriosis gets its name from the word endometrium, which is the tissue lining the uterus (womb).¹ During a woman's menstrual cycle, this tissue thickens in preparation for a fertilized egg (pregnancy). If there is no fertilization, the tissue breaks down and bleeds with each menstrual cycle, allowing it to exit the body.

In endometriosis, the tissue that normally lines the uterus grows *outside* the uterus. Most commonly, it is found on the ovaries, fallopian tubes, tissue that holds the uterus in place, outer surface of the uterus, or lining the pelvic cavity. Other sites for growths can include

the bladder, bowel, cervix, rectum, vagina, or vulva. In rare cases, endometriosis has been found in other parts of the body, such as the lungs, brain, and skin.¹

"In endometriosis, displaced endometrial tissue continues to act as it normally would: it thickens, breaks down, and bleeds with each menstrual cycle. And because this displaced tissue has no way to exit your body, it becomes trapped."³

"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"² (this is called adhesions, where abnormal tissue binds organs together³).

"This process can cause pain – sometimes severe – especially during your period. Fertility problems also may develop [with or without pain symptoms]. Fortunately, effective treatments are available."³

Suspecting Endometriosis?

Signs & symptoms

"The most common symptom of endometriosis is pain in the lower abdomen or pelvis, or the lower back, mainly during menstrual periods."¹ The amount of pain a

In endometriosis, the tissue that normally lines the uterus grows outside the uterus.

woman feels is not an indicator of the severity of the endometriosis. Some women have severe pain with only a few endometrial growths, while others may have no pain although endometriosis affects large areas,¹ often discovered when she experiences problems with fertility.²

Symptoms of endometriosis can include:

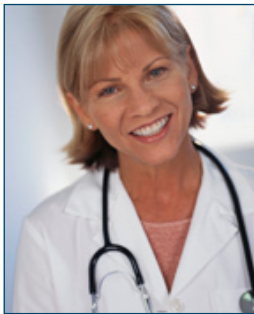
- very painful menstrual cramps; pain may get worse over time;
- chronic pain in the lower back and pelvis;
- pain during or after sex;
- intestinal pain;
- painful bowel movements or painful urination during menstrual periods;
- spotting or bleeding between menstrual periods;
- infertility or not being able to get pregnant;
- fatigue;



- diarrhea, constipation, bloating, or nausea, especially during menstrual periods.¹

If you suffer symptoms of endometriosis, see your doctor.

Women of all ages and races, including teens and post-menopausal women,



can suffer from endometriosis.⁴ Because endometriosis can cause pain and infertility, early diagnosis and treatment is important.

Endometriosis can worsen over time, so see your doctor, preferably a gynecologist who has experience treating endometriosis. If endometriosis is not found and treated, it can grow and damage the fallopian tubes and ovaries, which can make it more difficult to get pregnant.⁵ You may need to see a reproductive endocrinologist if infertility is a concern.⁶ “It is estimated that 30-40 percent of women with endometriosis may have difficulties in becoming pregnant (but this means that 60-70 percent will have no problems!). If fertility is a great wish, then please discuss your symptoms with your physician so that together you can develop the best treatment plan for you.”⁴

Take this [endometriosis self-test](#) and review the answers with your gynecologist or reproductive endocrinologist. Use the following resources to prepare for your appointment:

- [Your Initial Endometriosis Appointment](#)
- [Endo Pain and Symptom Tracker](#)
- [Pain Mapping Worksheet](#).

Endometriosis can be difficult to diagnose. The more information you can give your doctor the better you will equip him/her to make a diagnosis. Because doctors’ appointments are often limited in time, your advanced preparation can help make strides to a more rapid diagnosis.

Diagnosing Endometriosis Tests & procedures

“There is no simple test that can be used to diagnose endometriosis.”⁷ Your doctor will want to talk about your symptoms, medical history, and likely do a pelvic exam.”

“During a pelvic exam, your doctor manually feels (palpates) areas in your pelvis for abnormalities, such as cysts on your reproductive organs or scars behind your uterus. Often, it’s not possible to feel small areas of endometriosis, unless they’ve caused a cyst to form.”³

Your doctor may also perform [imaging tests](#), which allow him/her to see pictures of the inside of your body. These tests may include [vaginal or abdominal ultrasound](#), [MRI](#) (magnetic resonance imaging), or a [CT Scan](#) (computed tomography scan), which can help your doctor rule out other causes of your symptoms.⁵ Your doctor may also want to do blood tests and/or vaginal cultures to rule out infection.⁵

At present, the only way to know for certain if you have endometriosis is by performing a laparoscopy. Laparoscopy is a minor surgical procedure, but because it is an expensive and invasive procedure, other tests will likely be performed first. During laparoscopy, the surgeon is able to look inside your abdomen for signs of endometrial growths (sometimes called implants, lesions, or nodules²). You will

receive a general anesthetic before the procedure begins. Sometimes doctors can diagnose endometriosis just by seeing the growths. Other times, they need to take a small sample of tissue (called a biopsy) and study it under a microscope to help make a diagnosis.¹ “Endometriosis can also be treated during a laparoscopy. If endometrial tissue is found during the laparoscopy, your doctor may decide to remove it right away.”⁸ (For more information on laparoscopy, see the section below regarding *Surgery* under *Treating Endometriosis*.)

“If you have endometriosis, laparoscopy will provide you and your doctor with information about the location, extent, and size of the endometrial implants. This information will help your doctor guide you through treatment options.”³

Symptoms of endometriosis, including pain and fertility issues, can be treated with medicine, hormone therapy, surgery, or a combination of these treatments.

Treating Endometriosis Medicine – hormone therapy – surgery – infertility treatments

There is currently no cure for endometriosis; even having a hysterectomy (removal of the uterus) or removing the ovaries does not guarantee that areas of endometriosis will not still be present elsewhere in the body, or that endometrial growths and their accompanying symptoms will not come back.² Symptoms of endometriosis, including pain

and fertility issues, however, can be treated with medicine, hormone therapy, surgery, or a combination of these treatments. Treatment choices depend on whether you want to control pain or become pregnant. Typically, your doctor will try more conservative approaches first before recommending surgical approaches.

Medicine. Medicines for pain can range from milder doses of over-the-counter (OTC) drugs to strong prescription



medicines. Most commonly, OTC anti-inflammatory drugs will be recommended first, which may relieve pain and bleeding in some women.⁹ These drugs may include ibuprophen (e.g., Advil, Motrin) or naproxen (e.g., Aleve). If you are taking the maximum dose of these drugs and finding no relief, however, your doctor may prescribe a stronger prescription pain medicine or consider other options, such as hormone therapy.

Hormone Therapy. “Each month a woman’s ovaries produce hormones that stimulate the cells of the uterine lining (endometrium) to multiply and prepare for a fertilized egg.”¹⁰ For this reason, using therapies that alter the hormonal actions of the body may help with endometriosis. When considering hormone therapy, you and your doctor should first discuss your desires about pregnancy. Hormone therapies will usually keep you from becoming pregnant during treatment. The National Institutes for Health² offers the following information about the different hormone therapies available that may assist you as you and your doctor discuss the options:

“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.

Some women have less pain from endometriosis after pregnancy, but the reason for this is unclear.

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.”²

Surgery. If your endometriosis is extensive or your pain severe and not helped by other treatments, surgery may be recommended. There are several surgical treatments, some more invasive and requiring more recovery time than others. You will also want to discuss your desires about pregnancy before any surgical treatment. The National Institutes of Health² offers the following information about surgical treatments currently available that may assist you as you and your doctor as you discuss the options.

“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) or destroy them with intense heat and seal the blood vessels without stitches (a process called cauterizing 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 can remove the endometriosis. (In severe cases, laparotomy is also used to do a hysterectomy [removal of the uterus].)
- 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.
- Health care providers recommend major surgery as

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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."²

Infertility Treatments. For some women, pain is a regular factor in their endometriosis, but for others the first time they find out they have endometriosis is when they have problems getting pregnant. To help with fertility issues, you can discuss and consider the following treatments.

Laparoscopy – (discussed above) is a minor surgery used to remove endometrial growths and can be effective in improving fertility, in addition to treating pain.²

In vitro fertilization (IVF) – is a procedure that makes it possible to combine sperm and egg in a laboratory and then place the resulting embryo 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."² The use of hormones in IVF has been

successful in treating infertility related to endometriosis in some women.²

Help for Endometriosis Get support

Coping with endometriosis can be difficult. It is important to work with your doctor, giving him as much information as you can about your symptoms to get a correct diagnosis. Once you have a diagnosis, it can take some time to find a treatment that works best for you. Stick with it. Together, you and your doctor can work to find ways to reduce pain and find your best options for becoming pregnant. During this time, talking with other women



who have endometriosis can help give you support. See [Endorsed ERC Support Programs & Groups](#) or [The Endometriosis Association](#) support groups site for help.

This document is meant for educational purposes only and is not intended to replace the advice of your doctor or other health care provider.

To view the references used in this newsletter, go to:
<http://fcs.tamu.edu/health/healthhints/2011/feb/ref.php>

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Imaging Tests

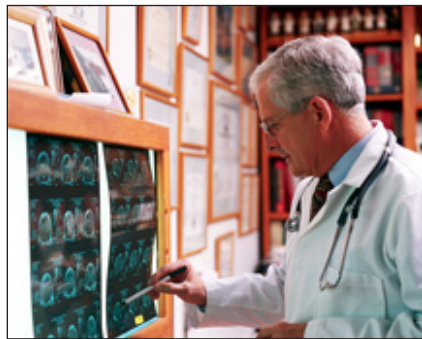
Imaging tests that take pictures of the inside of your abdomen, pelvis, or vagina can help to find the reasons, other than endometriosis, for your symptoms and possibly identify cysts associated with endometriosis.

Both vaginal and abdominal ultrasounds use sound waves to provide a video image of your reproductive organs." Ultrasound imaging won't definitively tell your doctor whether you have endometriosis, but it is a useful tool for identifying cysts associated with endometriosis (endometriomas)."¹

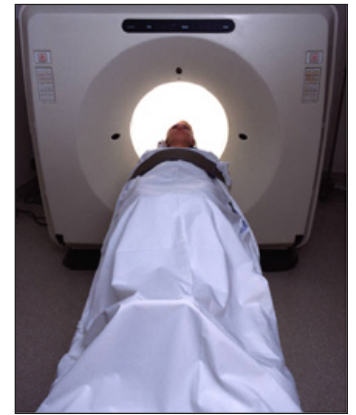
Vaginal Ultrasound. "During a vaginal ultrasound, a wand-shaped scanner (transducer) is inserted into your vagina."¹

Abdominal Ultrasound. "In an ultrasound of the pelvis via the abdomen, a small scanner is moved across your abdomen."¹

MRI (magnetic resonance imaging). In this procedure, a machine uses magnets and radio waves to make a picture.² "For an MRI test, the area of the body being studied is placed inside a special machine that has a strong magnet. In some cases, a dye (contrast material) may be used during the MRI to show pictures of organs or structures more clearly."³



CT Scan (computed tomography scan). A CT scan uses x-rays to make detailed pictures of structures inside of the body. "During the test, you will lie on a table that is hooked to the CT scanner, which is a large doughnut-shaped machine. The CT scanner sends x-ray pulses through the body. Each pulse lasts less than a second and takes a picture of a thin slice of the organ or area being studied."⁴



Sources:

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