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# ENDOMETRIOSIS

## *What is Endometriosis?*

Endometriosis occurs when tissue that is similar to the lining of the uterus (endometrium) grows in other parts of the body. Most commonly endometriosis is found in the pelvic cavity near the uterus and on ovaries, but it sometimes occurs on the intestines and bladder. Rarely, endometriosis grows in locations away from the pelvis such in the lungs. Even though endometriosis can grow and spread, it is benign (not cancerous).

Endometriosis can cause chronic inflammation, pain, and infertility but some people have no symptoms. Because endometriosis affects people differently, it is difficult to determine how common it is. Estimates based on research suggest that 5-10% of people assigned female at birth have endometriosis.

## *Symptoms*

The most common symptom is pain in the pelvis, lower abdomen, or lower back. Pain most often occurs during menses (periods), but pain may occur before menses, with sexual activity (especially deep penetration), with bowel movements or urination, or all the time. Not everyone with endometriosis has pain. Other symptoms include constipation, diarrhea, and bloating (especially around menses). Some people with endometriosis have difficulty getting pregnant.

## *Main causes of Endometriosis*

No one knows the exact cause. It is likely that certain genes play a role, but there are many other factors. Experts agree the hormone estrogen promotes the growth of endometriosis and treatment often focuses on lowering estrogen levels.

## *Diagnosis*

The only way to definitely diagnose endometriosis is with a biopsy (sample of tissue) that is evaluated under a microscope. Biopsies are performed during a surgical procedure called a laparoscopy that allows surgeons to see the disease and take a biopsy to be evaluated in a laboratory. Currently endometriosis cannot be confirmed by blood tests or imaging like ultrasound or MRI. However, anyone with possible endometriosis based on symptoms noted above should be considered to have a clinical diagnosis of endometriosis and begin medical therapy. Laparoscopy is no longer recommended just to make a diagnosis of endometriosis.

If endometriosis is suspected based on symptoms, medical treatment is recommended even without surgical confirmation. Usually, surgery is recommended for people who do not respond to medical treatment, have infertility, or have large cysts of endometriosis (endometriomas) in their ovaries.

### *Treatment Options*

Hormone treatments are used to decrease the amount of estrogen produced by the ovaries and fat cells, leading to decreased growth and even shrinkage of endometriosis. They should either decrease or stop menstrual flow, helping to prevent new endometriosis from forming. Hormone treatments may include birth control pills, rings, or patches; progestin-containing medications (pills, injections, implants, or IUDs); and antihormones (GnRH-agonists or GnRH-antagonists). Hormonal treatments are often successful for controlling pain (and heavy bleeding) due to endometriosis but do not make the disease go away. For mild to moderate pain, non-steroidal anti-inflammatory medications (NSAIDs) can also be helpful.

For people with severe endometriosis who do not respond to medical treatment and for people with infertility, surgery may be appropriate. Surgery is usually aimed at safely removing or destroying as much of the endometriosis as possible. After surgery, hormonal treatment to prevent periods is recommended to decrease re-growth of endometriosis. A significant number of women who have surgery for endometriosis will continue to have pain, therefore it is important that all sources of pelvic pain are addressed (see Chronic Pelvic Pain)

Some people choose hysterectomy (removal of the uterus) to relieve pain, particularly menstrual pain, related to endometriosis. Hysterectomy is appropriate to consider for people who have completed childbearing and who have already tried other treatments. Depending on the severity of the disease and the age of the patient, ovaries may be removed at the same time. Removal of ovaries in people younger than 40 needs to be carefully considered and balanced against the risks of early menopause. In general, after removal of ovaries and uterus hormone replacement is safe and unlikely to stimulate endometriosis (in only 10% of cases hormone replacement can allow endometriosis to regrow).

### *Complex Pelvic Pain*

Many people with endometriosis have complicated pain. In addition to pain from endometriosis, they have pain from other areas in their pelvis such as pelvic floor muscles, bladder, and bowel. They may also have pain with sexual activity, changes in bowel movements and/or changes in urination. They may also have other chronic pain conditions such as interstitial cystitis/bladder pain syndrome, irritable bowel syndrome, fibromyalgia, chronic fatigue syndrome, vulvodynia, TMJ dysfunction, and headaches. These disorders are called “Chronic Overlapping Pain Conditions” and must also be treated.

When pain lasts longer than a few months, it leads to changes in the brain and spinal cord (the central nervous system or CNS). The CNS interprets and controls pain. Through a process called central sensitization, the CNS can increase pain or cause pain to spread to other areas in the body. Changes may affect mood, coping, and sleep.

For people with this more complex type of pelvic pain, hormonal and/or surgical treatments are often not enough to provide relief of pain and other distressing symptoms. Care from a variety of specialists may be needed to address the specific symptoms and chronic pain in general. If you experience more than 2 chronic overlapping pain conditions, you will likely benefit from interdisciplinary treatments addressing

both body and mind. Dietary changes, physical therapy, and behavioral health are recommended. Medications for specific disorders or chronic pain may be prescribed. For more information about endometriosis visit:

Endometriosis Association	<a href="http://www.endometriosisassn.org">www.endometriosisassn.org</a>
Endometriosis Research Center	<a href="http://www.endocenter.org">www.endocenter.org</a>
Global forum on endometriosis	<a href="http://www.endometriosis.org">www.endometriosis.org</a>
World Endometriosis Society	<a href="http://www.endometriosis.ca">www.endometriosis.ca</a>

For more information about other chronic pelvic pain syndromes visit:

International Pelvic Pain Society [www.pelvicpain.org/public](http://www.pelvicpain.org/public)

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