Endometriosis: Clarifying Facts from Myths

Northwestern Medicine Comprehensive Endometriosis Program
Endometriosis is a disorder that affects your reproductive organs and menstrual cycle. The tissue that lines the uterus is called the endometrium. Normally, if a woman doesn’t get pregnant, this tissue is shed along with substantial amounts of blood each month during her period. A portion of this shed endometrium and blood travels backward through the tubes and stays in the lower abdomen for several days. In 10 to 20 percent of women, this endometrial tissue mixed with blood and inflammatory cells implants on abdominal organs and survives; this is called endometriosis. Each month, this misplaced tissue responds to the hormonal changes of the menstrual cycle. It builds up, breaks down, becomes inflamed and bleeds. Because the blood has nowhere to go, the surrounding tissue becomes inflamed or swollen. Endometriosis can also cause scar tissue, chronic inflammation and pain, and is associated with heavy periods. Endometriosis is a main cause of infertility in women. This can happen if the tissue implants in the ovaries or fallopian tubes. Tissue can also implant on other organs in the abdomen, on the diaphragm or travel all the way to the lungs on rare occasions.

What is Endometriosis?
What Causes Endometriosis?
The biggest risk factor for endometriosis is repeated and heavy ovulatory cycles associated with backward menstruation into the abdominal cavity. Women who do not menstruate rarely develop endometriosis. It is not clear why not all menstruating women develop endometriosis. Our research suggests the programming of genes is defective in endometrial or immune cells of women who eventually develop endometriosis. (Figure 1)

What are the Risk Factors for Endometriosis?
While any woman may develop endometriosis, the following women seem to be at an increased risk for the disease:

- Repetitious and heavy ovulatory periods
- Women who have a mother, sister or daughter with the disease
- Women who gave birth for the first time after age 30
- Women with an inborn anatomic abnormality of the uterus or vagina

What are the Symptoms of Endometriosis?
While each woman may experience symptoms differently, these are the most common symptoms:

- Severe pain and cramps, which may be felt in the abdomen or lower back during your period
- Pain during sex
- Abnormal or heavy menstrual flow
- Infertility
- Fatigue
- Painful urination during your periods
- Painful bowel movements during your periods
- Other gastrointestinal problems, such as diarrhea, constipation and/or nausea during your periods

Painful periods may start as early as the teenage years. The amount of pain a woman has isn’t always related to the severity of the disease. Some women with severe disease may have no pain. Other women with a milder form of the disease may have severe pain or other symptoms.

How is Endometriosis Diagnosed?
First, your physician will review your medical history. You will also have a physical exam and a pelvic exam. If necessary, a laparoscopy may be offered to diagnose and surgically remove endometriosis. This uses a thin tube with a lens and a light at the end. It’s inserted into an incision in the abdominal wall to see into the pelvic area. The health care provider can often find the locations, extent and size of the misplaced tissue. Other tests may include:

- **Biopsy:** For this test, a small tissue sample is removed from the body and examined.
- **Ultrasound:** This imaging test uses high-frequency sound waves to create an image of the organs. It is particularly helpful for diagnosing blood-filled ovarian cysts caused by endometriosis.
- **Magnetic resonance imaging (MRI):** This imaging test provides a three-dimensional view of organs or tissue. It can find problems that may not show up on ultrasound.
The tissue that lines your uterus is called the endometrium. Endometriosis is growth of this tissue in abnormal places, often outside the uterus. These growths are called endometrial implants. During the menstrual cycle, the endometrium swells. Any implants will swell too. This can cause symptoms, such as pain. The condition may also result in trouble getting pregnant. However, endometriosis can be treated. Hormones and surgery are the two most common options. Talk to your health care provider about what treatment plan is best for you.

**Medical Therapy**
The main goal is to stop ovulatory cycles and menstruation, which cause and maintain endometriosis tissue. Estrogen and progesterone are the main hormones that control your ovulation and menstrual cycle. Medicines can help control these hormones. This helps limit the swelling of all endometriosis and endometrial tissues. For pain management, long-term medical therapy is necessary to stop or minimize ovulatory cycles and menstruation. Medical therapy is used alone or together with surgery. Medical therapy, however, usually stops ovulation and prevents a woman from becoming pregnant.

**Common types of medical therapy include:**

**Birth Control Pills:** These stop ovulation, decrease or eliminate menstruation and prevent the hormone levels from fluctuating like they would during a normal menstrual cycle.

**Progestins:** These are synthetic equivalents of progesterone. They also interrupt ovulation and menstruation, and help keep estrogen levels low.

**Aromatase Inhibitors:** These are used together with either birth control pills or progestins. They intensify the beneficial effects of birth control pills and progestins and stop estrogen formation in endometriosis implants and reduce inflammation and therefore pain. Serdar E. Bulun, MD, chair of Department of Obstetrics and Gynecology, and his team discovered the beneficial use of these medications in endometriosis. (Figure 2)
**GnRH Agonists:** These hormones stop ovulation, menstrual periods and prevent the body from making estrogen. They may cause severe hot flashes, depressive symptoms and bone loss. They help with pain and may be used with low doses of other hormones to help prevent side effects.

**Danazol:** This is a weak male hormone. It stops ovulation and lowers a woman’s production of estrogen and progesterone. This is less commonly used. A non-hormonal form of birth control must be used with this therapy.

**Nonsteroidal Anti-Inflammatory Drugs (NSAIDs):** These are analgesics that help with inflammation and pain, but they do not treat the endometriosis.

**Surgery**

If medical therapy doesn’t control the problem, surgery can be performed. During surgery, endometrial implants are surgically removed. Resection or removal of these implants, vs. burning or vaporizing them with electric current or laser, gives rise to a better control of pain with longer lasting pain relief. This may help women get pregnant if the endometriosis was causing fertility problems. If a woman does not want to get pregnant, in some cases, the uterus may be removed. This is called a hysterectomy. For effective pain control, the ovaries should be removed along with the uterus.

There are two techniques for doing surgery:

**Laparoscopy:** This is surgery done through small incisions in your belly button and abdominal wall. An instrument called a laparoscope (a thin, lighted tube) is used. It is put through one of the small incisions. Surgical tools are put through the other small incisions. Laparoscopy is the preferred initial treatment over laparotomy. Our physicians at Northwestern Medicine in expert hands, laparoscopy gives rise to better results.

**Laparotomy:** This is surgery done through one larger incision in your abdomen. It may also be used when pelvic organs, such as your bowel, are involved.
How We Help Women Diagnosed with Endometriosis

The Comprehensive Endometriosis Program at Northwestern Medicine provides accurate diagnosis and world-class treatments for women diagnosed with endometriosis.

Serdar E. Bulun, MD, chair of the Department of Obstetrics and Gynecology is a world-renowned expert in the use of aromatase inhibitors to treat women with endometriosis. A multidisciplinary team at Northwestern Medicine Prentice Women’s Hospital joins Dr. Bulun by offering leading-edge diagnostics testing as well as personalized combinations of a variety of treatments to women with endometriosis and pelvic pain. We also participate in many clinical trials that help us learn more about endometriosis and how to best treat them.

If you come to Northwestern Medicine to be treated for endometriosis, we will work with you to find a treatment plan that works for you.

Need a second opinion?
The team at the Comprehensive Endometriosis Program at Northwestern Medicine is committed to meeting the needs of women affected by endometriosis through a multidisciplinary team approach and are available for second opinion consultations on your medical and surgical treatment options for endometriosis.

Please call 312.694.6067 or visit nmendometriosis.nm.org to arrange a second opinion consultation.