Endometriosis

An overview of endometriosis: what it is, what its symptoms are, and how it is diagnosed and treated.

The Gynecological Sourcebook, Third Edition

Endometriosis is a disease affecting women in their reproductive years. It was widely undiagnosed until recently. The name, as you've probably guessed, comes from the word endometrium. The clinical definition of endometriosis is an "abnormal growth of endometrial cells." Roughly 5.5 million women throughout North America have endometriosis. Endometriosis was at one time coined "husbanditis" because the pain that characterizes endometriosis was seen as a woman's excuse to get out of her marital duties. In the past, treating women who complained of pelvic pain ranged from tranquilizers to hysterectomies. Unfortunately, many women today are still being told that their symptoms are "in their heads" when, in fact, endometriosis is a physical disease causing real physical symptoms. What happens is that endometrial tissue forms outside the uterus in other areas of the body. This tissue then develops into small growths, or tumors. (Doctors may also refer to these growths as nodules, lesions, or implants.) These growths are usually benign (noncancerous) and are simply a normal type of tissue in an abnormal location. Cancers that arise in conjunction with endometriosis appear to be very rare.

The most common location of these endometrial growths is in the pelvic region, which affects the ovaries, the fallopian tubes, the ligaments supporting the uterus, the outer surface of the uterus, and the lining of the pelvic cavity. Forty to 50 percent of the growths are in the ovaries and fallopian tubes. Sometimes the growths are found in abdominal surgery scars, on the intestines, in the rectum, and on the bladder, vagina, cervix, and vulva. Other locations include the lung, arm, thigh, and other places outside the abdomen, but these are rare.

Since these growths are in fact pieces of uterine lining, they behave like uterine lining, responding to the hormonal cycle and trying to shed every month. These growths are blind – they can't see where they are and think they're in the uterus. This is a huge problem during menstruation; when the growths start "shedding," there's no vagina for them to pass through, so they have nowhere to go. The result is internal bleeding, degeneration of the blood and tissue shed from the growths, inflammation of the surrounding areas, and formation of scar tissue. Depending on where these growths are located, they can rupture and spread to new areas, cause intestinal bleeding or obstruction (if they're in or near the intestines), or interfere with bladder function (if they're on or near the bladder). Infertility affects about 30 to 40 percent of endometriosis sufferers, and as the disease progresses, infertility is often inevitable.

The most common symptoms of endometriosis are pain before and during periods (much worse than normal menstrual cramps), pain during or after intercourse, and heavy or irregular bleeding. Other symptoms may include fatigue, painful bowel movements with periods, lower back pain with periods, diarrhea and/or constipation with periods, and intestinal upset with periods. If the bladder is involved, there may be painful urination and blood in the urine with periods. Irregular menstrual cycles and heavier flows are also associated with endometriosis, but women with severe endometriosis usually continue to have regular, albeit painful, periods. Some women with endometriosis may have no symptoms at all.

It's important to note that the amount of pain is not necessarily related to the extent or size of the growths. Tiny growths, called petechiae, have been found to be more active in producing prostaglandins, which may explain the significant symptoms that seem to occur with smaller growths.

The Stages of Endometriosis

Endometriosis can vary in terms of severity. Like other diseases, it is categorized into four stages -- the higher the number, the more severe the endometriosis. Stage I is when your endometriosis is minimal and still very thin and "filmy," hence easier to treat. Stage II is mild endometriosis; the endometriosis is still on the thin side but is situated more deeply into your surrounding tissues. Stage III is moderate endometriosis; here, your endometriosis is denser mixed with some Stage I or Stage II symptoms. Stage IV means severe endometriosis. In this case, the endometriosis is dense and deep, a bad combination.

Signs to Watch for

Since endometriosis includes so many seemingly unrelated symptoms, it's often missed or simply misdiagnosed. The following is a checklist of symptoms to watch for. If you have at least two of these symptoms during your period or even experience them chronically, you may want to get checked out for endometriosis.

- pelvic pain and/or painful intercourse
- infertility (often the only symptom women experience, even with Stage IV)
- abnormal cycles or periods
- nausea and/or vomiting
- exhaustion
- bladder problems
- frequent infections
- dizziness
- painful defecation
- lower backaches
- irritable bowels (loose, watery, and often bloody diarrhea often mistaken for irritable bowel syndrome, or IBS)
- other stomach problems
- low-grade fever

Painful Statistics

A questionnaire distributed by the Endometriosis Association revealed that 100 percent of respondents experienced pain one to two days prior to their periods. In addition, 71 percent reported pain midcycle; 40 percent reported pain other times; 20 percent reported pain throughout their cycle; while 7 percent reported intermittent pain with no particular pattern. The pain reported in this questionnaire was mostly abdominal, but the pain of endometriosis can manifest in emotional symptoms such as mood swings, depression, irritability, anxiety, anger, feelings of helplessness, fear, powerlessness, and insecurity. And the financial consequences of endometriosis can be painful, too. Women in the United States aren't always covered for the various diagnostic tests or treatments.

What Causes Endometriosis?

Nobody knows for certain what causes endometriosis, but currently environmental factors are identified as the chief cause. Recently, a laundry list of man-made chemicals, called organochlorines, have been found to be breaking down in the environment into a substance that mimics estrogen. These "environmental estrogens" as they're called, are being linked to an alarming increase in estrogen-dependent conditions such as endometriosis, fibroids, and a variety of reproductive cancers. Dioxins, in particular, have been linked to endometriosis. In a University of South Florida study, female monkeys fed very small amounts of dioxins went on to develop moderate to severe endometriosis within four years.

This estrogen theory is backed up by a few other facts. Men taking estrogen tend to develop endometriosis, while women born to mothers who took the drug DES (diethylstilbestrol) tend to have an increased incidence of this disease.

There are a few other worthwhile theories. One is the theory of retrograde menstruation, also known as the transtubal migration theory. During menstruation, some of the menstrual tissue backs up into the fallopian tubes, is implanted in the abdomen, and grows. Some researchers believe that all women experience some menstrual tissue backup, which is normally taken care of by their immune systems. An immune system problem or hormonal problem allows this tissue to take root and develop into endometriosis.

Another theory suggests that the endometrial tissue is distributed from the uterus to other parts of the body through the lymphatic system or blood system. A genetic theory suggests that it may be carried in the genes of certain families, or that certain families may be predisposed to the disease.

The most interesting theory proposes that remnants of the woman's embryonic tissue (from when she herself was an embryo) may later develop into endometriosis, or that some adult tissues retain the ability they had in the embryo stage to transform into reproductive tissue under certain circumstances.

Surgical transplantation of endometrial tissue has been cited as the cause in cases where endometriosis is found in abdominal surgery scars. This latter theory is certainly not possible if endometriosis occurs when surgery doesn't!

Diagnosis and Treatment

The only way to diagnose endometriosis is with an instrument called a laparoscope (a tubelike telescope with a light in it), used in a procedure known as laparoscopy. The procedure is a form of minor surgery. After a general anesthetic is administered, your abdomen is distended (expanded) with carbon dioxide gas to make the organs easier to see. A tiny incision is made, and a laparoscope is inserted into it. By moving the laparoscope around, your surgeon can check for any signs of endometrial tissue outside the uterus.

Although your doctor can often feel the endometrial growths during a pelvic exam, and your symptoms may be telltale signs of endometriosis, no competent physician would confirm the diagnosis without performing a laparoscopy procedure. The bottom line is that if you've been told you have endometriosis, but you haven't had a laparoscopy procedure done, insist that your doctor perform one, or get a second opinion. Often, the symptoms of ovarian cancer are identical to those of endometriosis. If you've been misdiagnosed with endometriosis due to your doctor's failure to confirm it through a laparoscopy, he or she may miss an early diagnosis of ovarian cancer crucial for successful treatment.

A laparoscopy procedure also indicates the location, extent, and size of the endometrial growths and will help your doctor better guide you in treatment decisions and family planning.

Laparoscopy is the only way to absolutely diagnosis the condition. Unfortunately, doctors commonly misdiagnose women with endometriosis and treat them for conditions they really don't have. Again, this occurs because of the confusing group of symptoms which characterize endometriosis. Symptoms sometimes mimic pelvic inflammatory disease (PID), irritable bowel syndrome (IBS); or a host of other ailments.

If you suspect you have endometriosis, experts recommend requesting a pelvic exam during your period, when endometriosis is in full flare. This may help your doctor find certain clues that will

send you in the right diagnostic direction. For example, transvaginal ultrasound is very useful in finding many of the physical clues that endometriosis leaves behind, such as cysts or masses. You may want to even request a transvaginal ultrasound even when your doctor doesn't order it.

Treatment for endometriosis has varied over the years, and there is still no absolute cure. If you don't have any symptoms, and you're not planning to have any (more) children, then no treatment is necessary, just regular checkups. If you have only mild symptoms, and infertility is not a factor, simple painkillers like acetaminophen (Tylenol) or ibuprofen may be all that's needed.

For severe symptoms, depending on where the growths are located and their size, your doctor may recommend a hysterectomy and removal of the ovaries. Before you decide whether this is indicated, get a few separate opinions from other doctors. Although hysterectomy is considered a definitive cure, research has shown that women who undergo a hysterectomy for endometriosis sometimes experience a recurrence of the disease.

Conservative surgery involves removing the growths themselves, rather than any reproductive organs. One procedure, which was shown on The Learning Channel's "The Operation," is called operative laparoscopy. Through a laparoscope, surgery is done with a laser, a cautery, or small surgical instruments. Again, as with more radical surgery, recurrence is common after this procedure. Conservative surgery is the treatment of choice for women under thirty-five who are diagnosed with endometriosis in the early stages and who want to have children. About 40 percent of these women will go on to conceive. After conservative surgery, between 20 and 50 percent of endometriosis patients will need more radical surgery.

If you're infertile or don't wish to get pregnant, simply going on a progestin-containing oral contraceptive or a progesterone supplement, such as Provera, may control your endometriosis. This works for as long as you're taking the synthetic hormones, and sometimes the therapy can force endometriosis into remission for months or years after going off the hormones.

If that doesn't work, your doctor may recommend you take the drug danazol (a testosterone derivative). When a low dose of danazol is taken (roughly 100 to 200 mg per day), many women experience relief as well as a scanty menstrual flow. But there are "androgenic" (or progesterone-related) side effects to danazol, which include weight gain, acne, muscle cramps, unwanted hair growth, voice-deepening, water retention, and occasionally, liver problems since the liver has to metabolize this drug.

If you're not having success with danazol, there is a slightly more severe treatment with a GnRH, which is often used in fertility treatments. This drug "copies" your natural GnRH, thereby shutting it down and throwing you into a sort of "controlled" menopause. Synthetic hormones introduced into your body as "copies" are called analogues or agonists. GnRH is administered through injection, as a pump spray, or nasal spray. Brand names include Lupron, Synarel, or Zoladex. GnRH is strong medication and should only be considered in very severe situations.

If you decide to have surgery to treat endometriosis, GnRH therapy is sometimes recommended for about two to three months prior to surgery to dry up your menstrual flow.

Pregnancy As a Cure

Believe it or not, pregnancy does cause endometriosis to go into temporary remission, because you don't ovulate when you're pregnant. Furthermore, permanent remission of endometriosis has been known to occur after childbirth; the growths in this case shrink, and the pain associated with the disease stops. The problem is, the longer you have endometriosis, the greater your chance of becoming infertile. If you have been diagnosed with endometriosis, are planning to have children, and are in a position to have a family (that is, you have a supportive partner and are financially

stable), then getting pregnant is a good idea. In other words, why wait? In addition, the disease may also worsen with time.

Pregnancy as a prescription is not feasible in many cases. Infertility may have already set in, while many women don't have the means in place to have a child. Even under the best of circumstances, women with endometriosis have a higher risk of ectopic pregnancy and miscarriage. One study found that full-term pregnancies and labor are more difficult when the mother has endometriosis.

Menopause

In general, menopause does cure endometriosis, which is why a hysterectomy is performed. But a severe case of endometriosis can be reactivitated if you begin hormone replacement therapy or continue producing hormones after menopause, which is common. In fact, the oldest woman to be diagnosed with endometriosis was age seventy-eight. Some doctors suggest no replacement hormone be given for about three to nine months after menopause or a hysterectomy procedure.

The Future of Endometriosis

The first case of endometriosis may have been documented in 1600 B.C., according to ancient Egyptian writings. However, endometriosis has been recognized as a real disease only in the twentieth century. In the past, endometriosis either was considered rare or was simply undiagnosed; today, it's a major cause of painful periods and infertility in women.

Until recently, a large percentage of endometriosis patients (one endometriosis clinic reports as many as 75 percent) were dismissed as neurotic or overly sensitive to pain. The pain breakdown goes something like this: 45 percent complain of painful periods (cramps, back pain); and 37 percent complain of painful intercourse. At a recent conference on endometriosis, representatives of patient self-help groups from the United Kingdom and North America emphasized the frequent delays in diagnosis. A study revealed that 27 percent of endometriosis patients complained of symptoms for six years before a diagnosis was made. Diagnosis and education about endometriosis are improving, but the most important thing you can do if you have the disease is to educate yourself.

A blood test for endometriosis is on the horizon. This blood test would look for CA-125, a protein found in the pelvic organs of women who have endometriosis. A researcher at the Bowman Gray School of Medicine in Winston-Salem, North Carolina, found that as many as 73 percent of women with moderate endometriosis had elevated CA-125 levels, while 100 percent of women with severe endometriosis had elevated levels of CA-125. However, CA-125 is also elevated with ovarian cysts and with certain kinds of reproductive cancers.

Adenomyosis: Internal Endometriosis

There is a sister condition to endometriosis known as adenomyosis, in which the endometrial tissue (the uterine lining, glands, and connective tissue) invades the deeper muscle layers of the uterus. Usually there's a barrier between the endometrium and the deeper layers of the uterine wall that acts as a defense against invasion from endometrial tissue. Women who develop adenomyosis don't seem to have this defense.

Unlike endometriosis, some researchers believe that adenomyosis may set in after pregnancy and delivery; women in their forties and fifties who have given birth to at least one child are more likely to develop adenomyosis. Other researchers believe that, like endometriosis, genetics plays a role, and still others believe it may have to do with some sort of hormonal imbalance. The bottom line is that no one knows exactly what causes it, but treatments are available.

Looking at the Symptoms

About 40 percent of the time in cases of adenomyosis, women have no symptoms, but when they do, the symptoms are similar to endometriosis: painful and heavy periods and sometimes chronic pelvic pain. The more involved the uterine glands are, the heavier the flow; the deeper the penetration into the uterine wall, the greater the discomfort. An enlarged, soft, or tender uterus is a classic sign adenomyosis.

Diagnosis and Treatment

In the past, adenomyosis was diagnosed only by a pathologist, often after a hysterectomy was performed for another uterine problem. Adenomyosis is often present in conjunction with other uterine conditions such as fibroids. Therefore, to diagnose this condition accurately, your doctor must play detective. The diagnosis is difficult. It may be possible to detect adenomyosis with a magnetic resonance imaging (MRI) scan or a hysteroscopy (a telescope, similar to the laparoscope, placed through the cervix). However, an MRI is expensive, while a hysteroscope will at least rule out fibroids under the uterine lining.

Until recently, a hysterectomy was the suggested course of treatment for adenomyosis, but many doctors believe that adenomyosis can be treated the same way endometriosis is. Women have responded well to danazol, progesterone, or oral contraceptives. If conservative regimens fail, then unfortunately a hysterectomy is the only solution.