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Endometriosis and Adenomyosis

ENDOMETRIOSIS and ADENOMYOSIS: AN OVERVIEW

The tissue that lines the uterus is called the endometrium. It is the endometrium that thickens each month in preparation for a possible pregnancy. If a pregnancy does not occur the endometrium sheds off resulting in the normal monthly period with bleeding from the uterus exiting through the vagina. **Endometriosis** occurs when this endometrial tissue grows somewhere other than inside the uterus. This incorrectly placed endometrial tissue bleeds each month however the blood is not able to pass out of the body and can cause scarring, pain and the other complications of endometriosis. Endometriosis within the muscle of the uterus is called **Adenomyosis** and can cause enlargement of the uterus along with heavy, painful, and irregular periods. Adenomyosis is also known as "**endometriosis interna**" referring to the fact that it is endometriosis within the muscle of the uterus.

WHAT IS ENDOMETRIOSIS?

As described above endometriosis is normal endometrial (uterine lining) tissue growing in the wrong place. It often appears on structures deep within the pelvis or within the uterus itself (adenomyosis). Endometriosis is commonly found on the ovaries, fallopian tubes, surface and muscle of the uterus and cul-de-sacs (spaces behind and in front of the uterus). It can also be found on the bowel, bladder, ureters (tubes that drain the kidneys), and the rectum. Although rare, endometrial tissue may also be found in other parts of the body such as the brain, lungs and skin. Endometrial tissue that grows in the ovaries may cause a blood filled cyst (endometrioma) to form.

Endometrial tissue outside the uterus responds to changes in hormones and breaks down and bleeds like the lining of the uterus during the menstrual cycle. This bleeding can cause pain, especially before and during your period. The breakdown and bleeding of this tissue each month also can cause inflammation and scarring. This scarring can cause pain and interfere with your ability to get pregnant. The symptoms of endometriosis often worsen over time. In many cases, treatment helps to keep the condition from getting worse.

No one is certain of the cause of endometriosis. For most women, a small amount of blood and endometrial cells flow backwards through the fallopian tubes into the abdomen during their period ("retrograde menstruation"). These cells are usually destroyed and cleared by the body's immune system however, in some cases, the cells attach to pelvic tissues and grow resulting in endometriosis. This continued growth of the endometrial cells may represent a failure of the immune system to eliminate them. Another possible origin of the endometrial cells may be through blood and lymph vessels ("hematologic spread"). In the rare cases where endometriosis is found in sites beyond the abdominal cavity (i.e. brain, lungs, skin) it is thought they grew from embryonic stem cells left at these sites during development. Likely all of these methods of cellular transport play a role in the establishment and progression of endometriosis.

WHO IS AT RISK?

Endometriosis is most common in women in their 30s and 40s but can occur at any time in women who menstruate. Endometriosis occurs more often in women who have never had children. Endometriosis used to be called "working women's disease" because it was found more often in women who delayed childbirth while pursuing a career. The basic principle is that endometriosis grows in response to estrogen thus the more menstrual cycles one has the higher the chance of endometriosis developing. There is also a genetic component to the development of endometriosis where women with a mother, sister, or daughter with endometriosis are more likely to have it. It is important to note that endometriosis is found in about three quarters of women who have chronic pelvic pain.

SYMPTOMS

The most common symptom of endometriosis is pain. Such pain may be constant, occur with sex, during bowel movements or urination, or exist just before or during your menstrual cycle. Endometriosis can cause difficulties getting pregnant due to the formation of scar tissue blocking the tubes and ovaries or from the hostile pelvic environment created in the pelvis by the endometriosis. Endometriosis may also be responsible for blood in the urine or stool. Endometriosis in the uterus (adenomyosis) can cause the uterus to be enlarged and cause heavy, painful and irregular periods. Women often find that some endometriosis symptoms are relieved or reduced while they are pregnant or taking birth control pills (states of reduced estrogen exposure). In fact, many of the drugs used to relieve the symptoms of endometriosis are based on the effects of hormones produced during pregnancy.

The amount of pain experienced does not always tell you how much endometriosis is present. Some women with slight pain may have extensive endometriosis. Others who have significant pain may have very few or small endometrotic implants. Many women with endometriosis have no symptoms. In fact, they may first find out that they have endometriosis when they are having difficulties getting pregnant.

DIAGNOSIS

If you have symptoms of endometriosis you will initially receive a physical exam. During the pelvic exam we will very carefully try to locate areas of pain or abnormal structure (cysts, masses etc.). An ultrasound will be done to look at the structure of the uterus and ovaries and to look for any abnormal cysts or masses. It is important to note that a definitive diagnosis of endometriosis can be made only with surgery. If other causes of pelvic pain can be ruled out we may assume you have endometriosis and begin treatment without any further exams or surgery ("empirical treatment").

Endometriosis can be mild, moderate, or severe. The extent of the disease can be confirmed only by looking directly inside the abdomen. This is usually achieved through an outpatient laparoscopy. Laparoscopy is a minor surgery during which we use a tiny telescope (laparoscope) to look into your abdomen and pelvis. Sometimes a small amount of tissue (biopsy) is removed during the procedure to confirm the diagnosis however usually this is not needed to make the diagnosis. This part of the diagnosis is also part of the treatment as any visible endometriotic and scar tissue will be destroyed during the surgery.

TREATMENT

Treatment for endometriosis depends on the extent of the disease, your symptoms, and whether you want to have children. It may be treated with medication, surgery, or both. Although treatments may relieve pain and infertility for a time symptoms often come back after treatment.

MEDICATIONS

Medications to treat endometriosis may be directed at the pain itself (narcotics, NSAIDS) or at the source of the pain (birth control pills, hormone suppressants). Direct control of pain and symptoms is best if you are trying to get pregnant or if your pain occurs only occasionally. Non-steroidal anti-inflammatory drugs (i.e. Cataflam, Ponstel, ibuprofen) can be very effective for pain, cramps and bleeding. In more severe cases narcotics (i.e. Vicoprofen, Darvocet, Tylenol with codeine) are needed. Neither of these classes of drugs alter the course of the disease, they only treat the symptoms.

The goal of hormonal treatment of endometriosis is to treat the pain and reduce (or stop) the growth of the implants. Most hormone treatment is designed to stop the ovaries from releasing hormones or prevent the hormones from working normally. The hormones most often prescribed include oral contraceptives (Birth Control Pills), Gonadotropin-releasing hormone medicines, progestin, Danazol and the new aromatase inhibitors (i.e. Femara). As with most medications, there are side effects linked to hormone treatment. Some women may find the relief of pain is worth the side effects.

Birth control pills are often prescribed to treat symptoms of endometriosis. The hormone in them helps keep the menstrual period regular, lighter, and shorter and can relieve pain. We often will prescribe the pill in a way that prevents you from having periods at all.

Gonadotropin-releasing hormone agonists (i.e. Lupron) puts you into medical menopause by stopping the ovaries from producing estrogen. In most cases, in the absence of estrogen, endometriosis shrinks and the pain is relieved. Side effects in women taking this medication may include hot flashes, headaches, vaginal dryness, and thinning bones. Treatment with this Lupron most often lasts at least 3 months. To help reduce the amount of bone loss from long-term use, we may prescribe hormones or medications to take along with GnRh agonists. In many cases, this therapy also may reduce other side effects. After stopping GnRH treatment, you will have periods again in about 6-10 weeks. Unfortunately the endometriosis often returns once the medication is stopped.

Progesterone can also be used to shrink endometriosis. Progestin works to mature endometrial cells and slow their growth. Although you will no longer have a monthly menstrual period when taking progestin, you may have irregular vaginal bleeding. Progestin is taken as a pill or injection. Side effects in women taking this medication may include mood changes, weight changes, bloating, and sexual problems.

Danazol is another type of hormone that shrinks endometrial tissue. It lowers the effectiveness of estrogen by blocking its receptor. It is taken as a pill for at least 6 months. You will no longer have a menstrual period while taking Danazol. Danazol is a weak androgen (i.e. testosterone) and its side effects are related to its androgenic activity (i.e. weight gain, acne, deepening of the voice, and hirsutism (unwanted hair growth)).

Aromataze inhibitors (ie femara) are a class of drugs that reduce ovarian estrogen production by blocking the enzyme that makes estrogen (the aromatase enzyme). Femara is widely used in breast cancer patients to reduce estrogen and prevent recurrence of estrogen responsive cancers. We also use Femara for fertility treatments. Femara's use in endometriosis is experimental at this time however early results are promising.

SURGERY

As mentioned above, the only way to definitely diagnose endometriosis is through direct examination of the pelvic tissues during either a laparoscopic or open surgery. Most commonly we resort to surgery after attempts to control your symptoms medically have failed. The surgery of choice is a laparoscopy and hysteroscopy which allows us to simultaneously diagnose and treat pelvic pain and fertility problems. During laparoscopy endometriosis can be visualized and removed. In addition the surgery allows us to determine the condition of the uterus, ovaries and fallopian tubes. Unfortunately not all cases can be handled with laparoscopy. If there is too much scarring or it is not possible to safely perform a laparoscopy a laparotomy (open) surgery will be done. If your goal is pregnancy then we try to remove as much disease as possible while preserving (or enhancing) the function of the tubes, ovaries and uterus. If you no longer desire children then a hysterectomy may be your treatment of choice. In extreme cases the ovaries are removed to prevent recurrence of endometriosis. "Definitive treatment" for endometriosis is removal of the uterus and both ovaries. We always try to do disrupt the body as little as possible and balance your symptoms with the degree and type of treatment. Many individuals are treated with both surgery and medications to help extend the symptom-free period. Symptoms return within 1 year in about half of women who have had surgery but kept their uterus and ovaries. The more severe the disease, the more likely it is to return. Endometriosis is less likely to come back if your ovaries also are removed because your estrogen levels are significantly lowered.

COPING

Endometriosis is a long-term condition. Many women have symptoms that occur on and off until menopause. Keep in mind that along with medication and surgery pain can also be treated with biofeedback and relaxation. As with all conditions we encounter in this office once we are comfortable that you are safe (i.e. no big ovarian cysts or cancer threats) you decide what therapy is best for you and you lifestyle. Our job is to work together with you towards a point were your body (pain, bleeding, infertility, etc) is not getting in the way of you enjoying your life or achieving your goals.