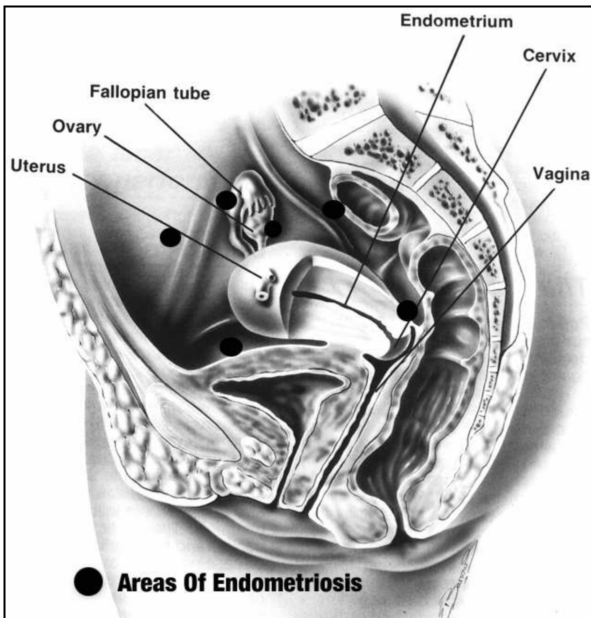
Endometriosis

Southern Ontario
Fertility Technologies

Introduction



Endometriosis is the medical term the occurrence of endometrial tissue (the tissue that lines the uterus) outside the uterus. This is very common in menstruating women. It can grow on the ovaries, fallopian tubes, the ligaments that support the uterus and other organs of the pelvic or abdominal cavity. If it is severe, scar tissue may form around the ovaries and fallopian tubes, blocking the release of the egg and its "pickup" by the tube. Like the lining of the uterus, this displaced endometrial tissue responds to fluctuations of hormones. Endometriosis can build up tissue each month, then break down and bleed during menstruation. The pain produced by endometriosis appears to be related to the degree of this metabolic activity rather than the total amount of abnormal tissue.

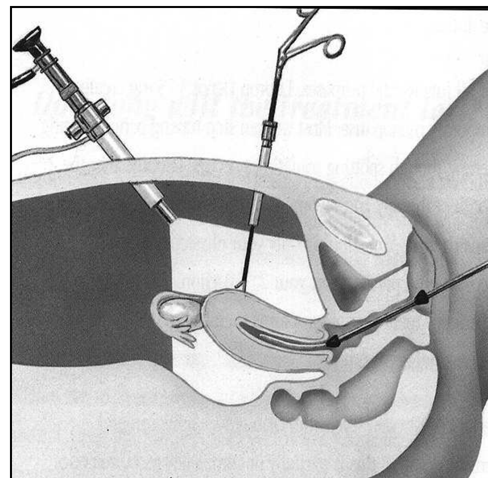
Symptoms of Endometriosis

Some women may not experience any symptoms and still have endometriosis. Many women experience **painful periods, painful intercourse or painful bowel movements**. Endometriosis is associated with **infertility** but not proven to cause it unless it creates scarring that interferes with egg transport in the Fallopian tubes.

Endometriosis is found in 4 to 5 % of women who have a laparoscopy for some unrelated reason. However, in women who have a laparoscopy for pelvic pain or infertility, it is usually present in about 30%. At S.O.F.T., we will usually find some endometriosis in up to 50% of the women who have a laparoscopy for either pelvic pain or infertility.

Cause of Endometriosis

The cause of endometriosis is **not known**. The most widely accepted theory at the present time is that endometriosis occurs in women who have back-flow of blood and endometrial tissue during menses and who's immune system, for some reason does not destroy all the active endometrial cells in this menstrual blood.



Diagnosis of Endometriosis

Endometriosis can be **suspected** because of pelvic pain, infertility, or painful intercourse but can only be **diagnosed** by visualizing it directly.

This is done by “laparoscopy” were a small telescope is used to visualize the abdominal cavity as an outpatient procedure. (A separate information sheet is available on laparoscopy)

Treatment of Endometriosis

Endometriosis **cannot be cured!** This is important to realize right from the beginning. Living with endometriosis can become an emotional roller-coaster because of improvements with treatment and recurrences between treatments.

Endometriosis can be treated **medically or surgically**. Because the growth of endometriosis appears to be dependent on the cycling menstrual hormones, especially estrogen, medical treatments are aimed at depriving the endometriosis of this cycling. Surgical treatment is aimed at removing as much visible endometriosis as possible. Both medical and surgical treatments can be effective with pain but only surgical treatment has been proven beneficial in the treatment of infertility. However, many infertility specialists, including myself, feel that medical treatment of endometriosis is also beneficial for infertility. Some reproductive technologies such as ovulation induction, intrauterine insemination and in vitro fertilization, are also beneficial for endometriosis-associated infertility.

Medical Treatment

Birth control pills may alleviate many symptoms. There effects are not consistent or predictable but, if they work, they are safe and relatively inexpensive. Often, birth control pills given in this circumstance are given “continuously”, allowing no or very few withdrawal periods. A very common way to take birth control pills is 63 days on and 7 days off. This method appears to afford good cycle control with very little break-through bleeding. Having one period every three months instead of monthly is an obvious advantage. A newer method is to discontinue the pill for 5 days, only if spotting occurs for 5 days or bleeding occurs for 3 days. This method allows the pill to adjust to the patient instead of forcing the patient to adjust to the pill. (An information sheet is available on “continuous oral contraceptive pill”)

Progestogens are progesterone-like medications (“provera”) that can be given by either injection or pills. They are often very effective at relieving symptoms, are relatively inexpensive, but are often associated with irregular bleeding. Depo-Provera is the injectable form of this medication. It is used for birth control. Other side effects can be weight gain, nausea, fluid retention, and mood swings. Most of these side effects abate with time. Depo-Provera is associated with a delay in the resumption of regular menstrual cycles and a delay in pregnancy.

Danazol is a pill that reduces the estrogen production of the ovaries and produces a “pseudo-menopause”. Unfortunately it is expensive and can be associated with side effects. However, it is very effective. Side effects include weight gain, hot flashes, acne, excessive hair growth, mood changes and deepening of the voice. Danazol has androgenic (male hormone type) side effects which often limit its dosage and acceptability. In lower dosages, Danazol can increase libido. Danazol cannot be taken in pregnancy.

GnRH agonists are the newest and most effective medical treatment available. These drugs produce an even more profound menopause than danazol, stopping ovulation and menstruation. They cannot be taken orally, therefore injectable and nasal spray forms are available. They too are very expensive but very effective, Up to 90% of users obtaining significant improvement in pain. Side effects include hot flashes, dryness of the vagina,

decreased libido, and headaches. Most studies indicate about 1-2% bone loss / month during use. Sometimes GnRH agonists are combined with "addback" hormone replacement. This alleviates the hot flashes, vaginal symptoms and bone loss while maintaining the effectiveness.

GnRH agonists have received some "bad press" as far as their side effects. Certainly, a medicine like Depo-Lupron, which is the type most often used at S.O.F.T., can cause severe symptoms if used without add-back. However, the way it is prescribed at S.O.F.T., 80% of the women taking it will comment that they have "never felt as well!" The insert below describes the way Depo-Lupron is prescribed at S.O.F.T. and a separate information sheet is available.

> A very effective treatment is "Depo-Lupron with estrace add-back". I have found over a 90% response rate to this treatment and that 80% of women who are taking it to relieve endometriosis pain state that they "have never felt so well!"
>
> The first Depo-Lupron is given on approximately day 21 of the menstrual cycle. The first injection is given in the last part of the cycle because an initial stimulation occurs as a result of the medication. Starting in the last half of the cycle minimizes this. However, the first injection causes a period and it still may cause some aggravation of the pain.
>
> "Down-regulation" or a menopausal like state occurs in the majority of patients in 7 to 10 days and estrace 0.5 mg / day is then begun usually 7 days after the first injection to minimize this. This alleviates most of the hot flashes and bone loss associated with this treatment. However, the estrace dose can be individualized to minimize any side effects.
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> The injection is given monthly for 3 months (every 28 days). More than 3 months treatment does not improve the response or the recurrence rate. Some bleeding can occur with each injection but usually dose not. If it does, it does not decrease the effectiveness of the treatment,
>
> Estrace is continues 30 days after the last injection. When it is stopped, some women will have a period but most will not. It doesn't matter. After stopping the estrace, a period should occur within 35 days, If it does not, a pregnancy test if

A very new treatment we are starting to use at S.O.F.T. is the use of aromatase inhibitors. The one used is Femara (letrozol). We have used this medication at S.O.F.T. a great deal for ovulation induction. Its original use was to block estrogen production in women with estrogen-receptor positive breast cancer.

Surgical Treatment

Surgical treatment can be conservative or extensive depending on the desire for future pregnancies. Conservative surgical treatment is designed to promote fertility and/or relieve pain. It can be done through the **laparoscope** or by open surgery. Endometriosis is destroyed by cautery (burning), laser (vaporization) or excision (cutting away). This produces improvement in pain in 70% of patients.

If childbearing is no longer a factor and the symptoms are severe, a hysterectomy usually with removal of the ovaries is often the most effective treatment available. Hysterectomy alone is about 60% effective for pain relief while hysterectomy with removal

of the ovaries is 90% effective. Patients who have pain from endometriosis after hysterectomy with removal of the ovaries often have bowel involvement and may need additional surgery. If the ovaries are removed, hormone replacement has to be given and in most cases does not appear to flair-up the endometriosis.

Recurrence Rate and Timing

If laproscopic or medical treatment of endometriosis results in significant pain relief, there is a 40 chance of recurrence of the pain in 18 months. Remember, endometriosis cannot be cured! It is not unusual to have to consider multiple laparoscopies or multiple courses of medical treatment in women with severe endometriosis who want children. This can often lead to a situation were 4 or more laparoscopies and/or medical treatments are performed for one women to maintain pain control. Although there is no limit to the number of laparoscopies a person can have, they are surgical procedures and each carries a small but measurable risk.

In many situations, especially if the endometriosis is severe**, both surgery and medical treatment** will be combined. Medical treatment may take place before surgery to facilitate surgery by decreasing the extent of the disease or after to suppress any residual disease not removed by the surgery. Medical and surgical treatment are often “mixed and matched” to achieve the best possible response.

Pain from endometriosis can be controlled in almost all women using combinations of medical and surgical treatment. Most women with endometriosis will be able to have a baby but may require treatment of the endometriosis and/or other infertility treatments.

Long Term

Endometriosis can be a very **frustrating** disease. No cure is available short of a hysterectomy and removal of both ovaries. However, treatment, although it cannot cure the process is usually very effective. Most women can obtain good control of their endometriosis using combinations of conservative surgery (laparoscopy) and medical treatment. About 20% of women experience a spontaneous remission of endometriosis and it is not usually a problem after menopause. Many women with endometriosis are able to have children spontaneously but some require medical or surgical treatment of the endometriosis and/or reproductive technologies (ovulation induction, intrauterine insemination or in vitro fertilization) to achieve a pregnancy.

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