

Endometriosis: An Overview

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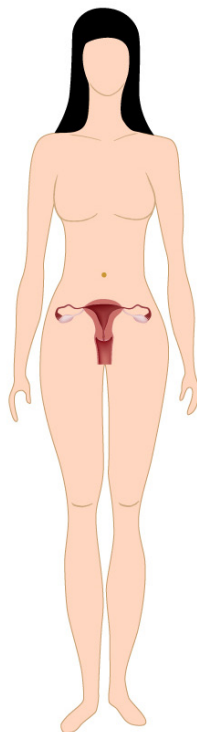
Welcome to the BC Women's Centre for Pelvic Pain and Endometriosis. This handout will give you some basic information about endometriosis. It will also explain how endometriosis is diagnosed and treated.

What is Endometriosis?

It is a condition that can occur after a woman begins having menstrual periods until menopause. Most women with endometriosis have pain during their menstrual cycle or during sexual activity. Other women do not have pain, but have problems becoming pregnant. They may also have abnormal bleeding or ovarian cysts. For some women, endometriosis may have a major effect on their personal and social life.

Women shed the lining of their uterus every time they have a menstrual period. This lining is made of endometrial tissue. A woman is diagnosed with endometriosis when endometrial tissue is found in areas of the body where it is not supposed to be. These areas include:

1. The lining of the abdomen - peritoneum (pair' i tuh nee' um) – the tissue shows up as small lesions or spots
2. The ovaries – the tissue attaches to surface of the ovary or forms “chocolate cysts”
3. The ligaments and smooth muscle attachments in the pelvis - scars or “fibrosis” form around the tissue
4. The muscle tissue of the uterus (adenomyosis).



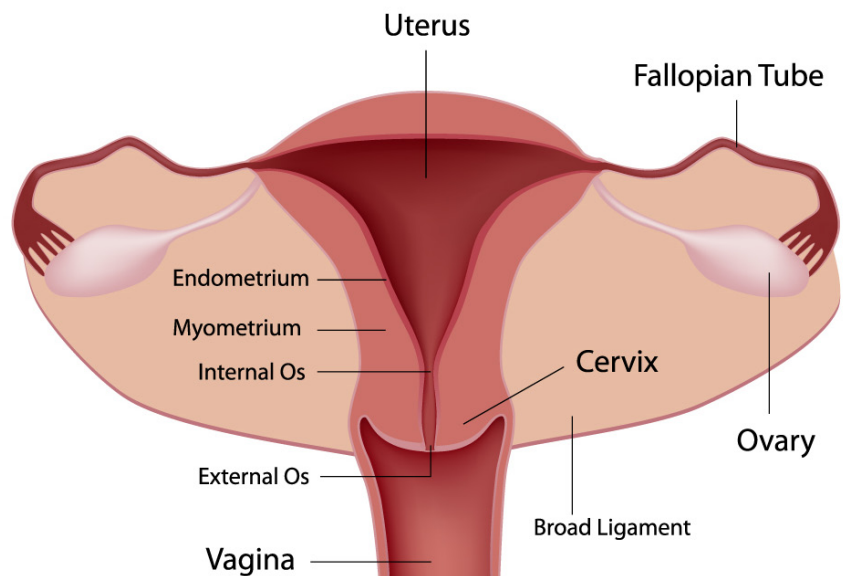
Endometriosis and Pain

Most women with endometriosis have some, or all of the following symptoms:

- Painful cramps with menstrual periods - dysmenorrhea (dis me' or ee' uh) - that cannot be controlled by pain medications or anti-inflammatory medications.
- Chronic pain between the umbilicus (belly button) and the pubic bone. May be worse from the time of ovulation through the



Female Reproductive System



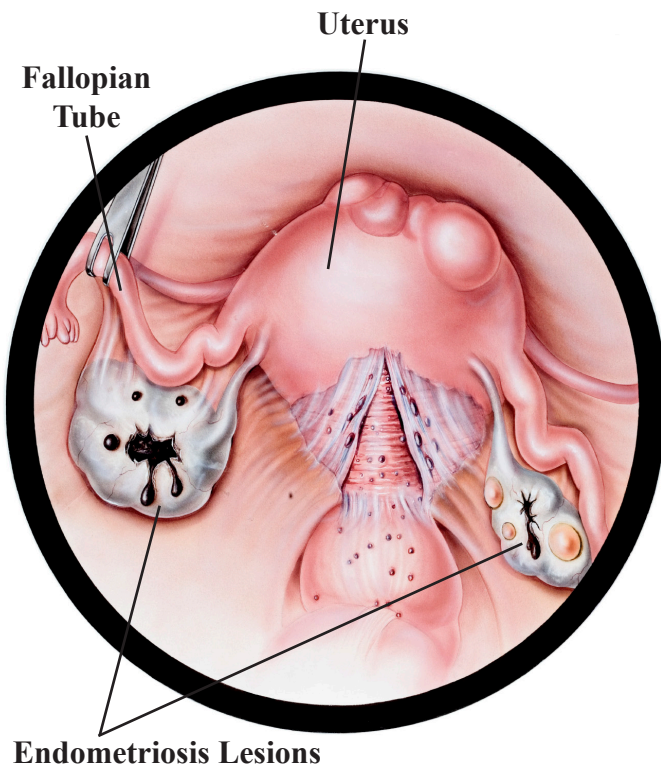
menstrual period. The pain may be felt toward the sides, in the middle or very deep within the pelvis.

- Pain during sexual intercourse - dyspareunia (dis puh roo' nee uh) - that can feel like something being hit at the back of the vagina.
- Painful bowel movements - dyschezia (dis kee' zee uh) - during menstrual periods or all of the time.

The pattern or type of pain can differ greatly in women. If the ovaries are affected, the pain can be worse during ovulation. Sometimes the pain can feel as severe as appendicitis.

Women with endometriosis often have bowel problems such as bloating, diarrhea or constipation. They may get severe cramps in the pelvic or upper abdominal area. It is also possible to have pain and problems with the bladder. The type of pain and where and when it occurs can help with the diagnosis.

The degree of pain a woman feels is not related to the size or number of endometriosis lesions she has. This has puzzled doctors for a long time. Another puzzle is that some women who are seeking help for infertility will have large non-painful nodules or adenomyosis that they are not aware of.



There is now research that shows why a woman with mild endometriosis may experience severe pain. Some of these reasons are:

- A. The uterus behaves differently in women with endometriosis. It produces a greater amount than normal of a substance called prostaglandin. This causes cramping of the muscle in the uterus, where there are many pain nerves.
- B. The lesions of endometriosis can produce substances that cause inflammation and pain. The effects of these substances can vary from woman to woman.
- C. The lesions can cause referred pain, called **trigger points**. These are specific areas of tenderness on the muscle wall of the abdomen. We have nerves that carry signals from the internal organs through the spinal cord to the brain. The nerves connect to the spinal cord at the same place as other nerves which carry signals from our skin and muscles. When endometriosis is not treated, the nerves may be stimulated over a long period of time. As a result, some of the pain sensation can “spill over” and be felt in the muscles and skin (referred pain).

Also, in the pelvis there are many connections with the nerves in other organs such as the uterus, ovaries, bladder and peritoneum. Pain can “spill over” into those organs and cause problems in the bladder (interstitial cystitis) and the bowel (irritable bowel syndrome).

Endometriosis can also cause extra nerve tissue to form. These nerves may be more sensitive and result in increased pain through a process called **sensitization**.



We are committed to on-going research into how and why endometriosis causes pain, and we will continue to look for the best treatments. Women who attend our Centre are asked to participate in studies to help us develop better ways to help women with chronic pelvic pain and endometriosis.

Stages of Endometriosis

The stages are a way of showing the degree of scarring or adhesions. They can indicate how likely it is a woman can become pregnant. But the stages are not very helpful for predicting a woman's degree of pain. It is also important to note that most women stay at the same stage of endometriosis all of their lives. It is rare for a woman to progress from stage I to stage IV.

Stage I: Small areas of endometriosis mainly on the surface of the lining of the pelvis. The ovaries, fallopian tubes and bowel are not involved.

Stage II: Larger areas of endometriosis on the ovaries with significant adhesions (organs or tissue connected abnormally by scar tissue).

Stage III: Ovarian chocolate cysts of more than 3 cm. with significant adhesions.

Stage IV: The rectum has become attached to the cervix so the cul de sac is not present. Stage IV usually also includes ovarian cysts and significant adhesions.

The first Appointment:

There are a few steps to take before your first appointment at our Centre. After we receive your doctor's referral, we will mail you a package of questionnaires. Please complete and return them to us before your appointment. Your answers will help us to find the best treatment options for you. A nurse may contact you to go over the questionnaires and answer any questions you may have before your visit.

Please make a list of any treatments or surgeries you've had for pelvic pain. It would also be very helpful if you request the records for these treatments from the hospital, family doctor, or specialist. Bring these records and your list to your first appointment.

During your first visit, the doctor will go over your records and medical history with you. You will also have a **pain-mapping** examination. First, the doctor will palpate (touch) your abdomen to find and map the tender areas. This will show the areas where the nerves are affected in your skin and muscles (somatic nerves). Then you will have a pelvic exam and ultrasound to find internal areas that are affected such as the uterus and ovaries.

Pain mapping is very useful for finding the sources of pain caused by endometriosis. It can clearly show the trigger points and tender areas in the uterus, ovaries, bladder or peritoneum. Pain mapping also helps to assess pain that is caused by something other than endometriosis (adhesions, cysts, hernias, irritable bowel syndrome, and interstitial cystitis).

Next, the doctor will talk to you about the cause of your pain and explain what treatment options are available. We want to be sure that you have all the information you need and enough time to make a decision. It can be helpful to have a partner, close friend or relative help you consider your choices.

If you are having a lot of spill over pain or the pain is affecting your ability to function, you may also wish to consider other resources. These could include pelvic floor physiotherapy or cognitive-behavioural therapy or mindfulness therapy.

Deciding on Treatment:

If your history, symptoms and examination show that you might have endometriosis, there are a number of ways to deal with the problem. The only reasons to treat endometriosis are:

- to relieve pain
- to treat infertility (if present)
- to remove ovarian cysts.

Endometriosis does not get worse over time so there is no need for surgery to "stop progression." And there is no need for surgery to help with pregnancy later on, since many women who have pain do not also have problems with infertility. Our doctors will help you explore your options based on your individual situation.

Treatment Options:

Pain control:

The first line of treatment for all women is anti-inflammatory medication (Ibuprofen-like drugs). These drugs help to control the pain and are often combined with other pain medications such as Tylenol or narcotics.



Life Style changes:

It is important to eat a healthy diet. Many women find it helpful to follow the Canada Food Guide at

<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>

“Anti-inflammatory” foods such as Omega-3 fatty acids (in many types of fish), legumes, nuts, seeds, and avocados are also helpful as is avoiding processed foods.

Limit red meats, fat and refined sugars to help reduce weight. Women who are overweight produce more of the hormone estrogen which can lead to more pain.

A healthy diet also decreases the inflammation in the uterus and pelvic deposits of endometriosis

Regular exercise is also very important. The body produces endorphins during intense activity that are very effective at reducing pain.



Medical Treatment:

Hormones are another form of treatment. These medications stop ovulation and control the ups and downs in your own hormone levels that happen in a normal menstrual cycle. Women respond to hormone treatment in very individual ways. Some of these medications are expensive

and every medication has some side effects. Your doctor needs to carefully monitor hormone treatment and make changes if needed.

Medical treatments can be very effective in controlling pain due to endometriosis.

Possible medical treatments include:

- The birth control pill, patch, or vaginal ring (estrogen-progesterone therapy). These can be used as a three week on/1 week off schedule to stop ovulation and still have periods. If this does not control pain, they can be used without the break to stop the periods.
- IUD (intra-uterine device): The Mirena® IUD releases low doses of progesterone in the uterus.
- Progesterone only therapy: Lowers estrogen levels and stops ovulation and menstrual periods. This is called second line therapy and might be more effective for pain control. These medications are taken orally (Provera®, Megace®, Norlutate®, and Visanne®) or by injection (Depo Provera®).
- Gonadotropin releasing hormone (GnRH) agonists are one step further in treatment. They dramatically lower estrogen levels. They may be given by injection (Lupron®) or by inhaler (Synarel®). Danazol, a testosterone derivative, may be given by mouth or vaginally.

Women who do not plan to become pregnant in the near future will probably benefit from pain medication along with hormonal treatment to stop ovulation.

A treatment to de-sensitize the nerves may be used if pain is related to the forming of trigger points and sensitization. These medications include:

- Tricyclics: Nortriptyline, desipramine, and amitriptyline
- Others: gabapentin, pregabalin (Lyrica®), bupropion, etc.

If medical treatment is not successful, surgery may be an option.

Surgical Treatment:

In most cases laparoscopy is used for surgical treatments. It is done through a set of small cuts or incisions in the abdomen. We have found that removing the lining of the abdomen where the endometriosis lesions are, has been successful. A small number of women will need repeat surgery when lesions reappear.



Who is likely to benefit from surgery?

When making a decision about your treatment, it is important to consider:

- your symptoms
- your plans for pregnancy
- the stage of your endometriosis.

Surgery is an ideal option for women with ovarian cysts or those who are infertile.

Women with endometriosis related pain who have completed their family have many options.

These include:

- removal of the uterus – hysterectomy
- removal of one or both ovaries, in addition to removal of the endometriosis.

Painful periods (dysmenorrhea) respond best to medical treatment. Painful intercourse (dyspareunia) and painful bowel movements respond best to surgery (80% of cases) but may also respond to medical treatment.

Fortunately, most young women with stage III and IV endometriosis respond very well to medical treatment and can usually avoid surgery. In difficult cases, In Vitro Fertilization can help a woman to become pregnant, and is sometimes the first choice.

The Good News:

In our experience, women can be very successfully treated with a combination of medication and surgery. A healthy life style, a strong support system, and understanding the state of your endometriosis are all very important. All of these steps along with a strong relationship with your health care providers will help you to live a healthy happy life. We, at the BC Women's Centre for Pelvic Pain and Endometriosis believe in, and work hard to provide you with patient-focussed care.

There is a great deal of research interest in endometriosis around the world. We are hopeful that in the near future we will understand more about the cause and progression of endometriosis. That will lead to new and better forms of treatment.

In the meantime we encourage women to support each other in dealing with this challenging condition. Share information with each other, take part in research, and when you are feeling better, lobby for more funding for research in this important area of women's health.