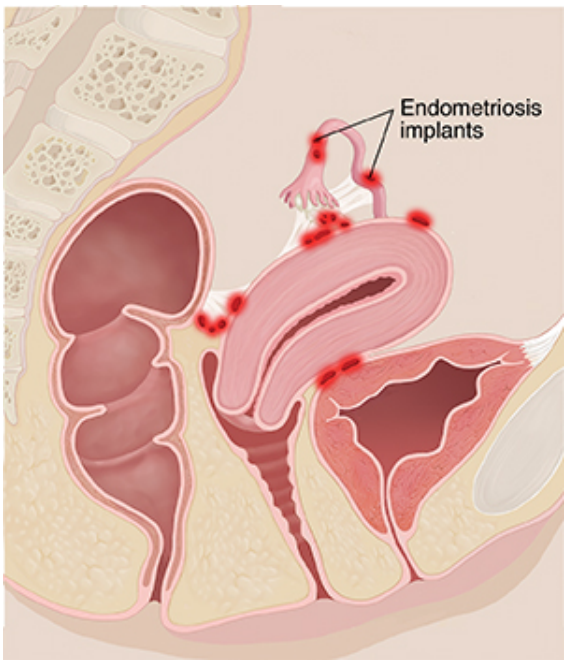
ENDOMETRIOSIS AND YOU

WHAT IS ENDOMETRIOSIS?

Endometriosis is a condition in which the cells that are normally found within the uterus (lining the cavity) are also found in other parts of the body, such as on the ovaries or in the pelvis. Although these "endometrial cells" can be found in many different organs in someone with endometriosis (such as on the bowel, bladder, diaphragm, liver, and even the lungs), they are most commonly found in the pelvis and on the ovaries.



HOW COMMON IS ENDOMETRIOSIS?

It is estimated that one in every 10 women has endometriosis, and it is found more commonly in women having difficulty conceiving (approximately 50%). While endometriosis is relatively common, it is often asymptomatic (meaning women may not know they have it, because it isn't causing any problems).

WHAT ARE THE SYMPTOMS OF ENDOMETRIOSIS?

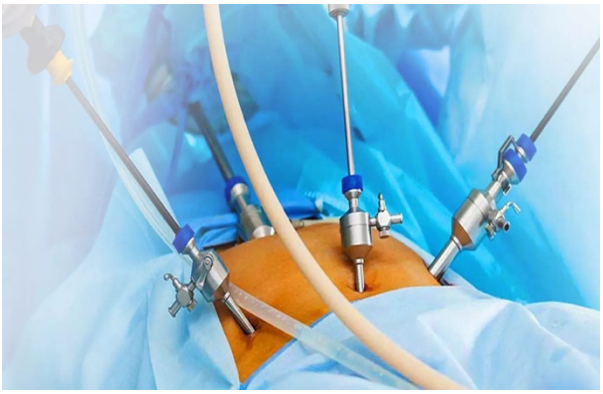
Endometriosis can cause a range of symptoms, from very mild to very severe. Typically, the following symptoms are described by patients with endometriosis:

- Very painful periods (dysmenorrhea)
- Pain with intercourse (dyspareunia)
- Pain with bowel movements (dyschezia)
- Ovarian cysts of endometriosis (chocolate cysts, or endometriomas) causing bloating or pain

In some severe forms, endometriosis can affect the bowels or bladder and result in cyclic rectal bleeding or blood in the stools or urine. Finally, patients with endometriosis may have a harder time conceiving than women without endometriosis.

HOW IS ENDOMETRIOSIS DIAGNOSED?

In the past, surgery was recommended in order to diagnose endo ("diagnostic laparoscopy") however all major gynecologic societies around the world agree that this is no longer necessary. Presence of symptoms, physical exam findings, or ultrasound/MRI findings are used to make a presumptive diagnosis and begin management.



IS ENDOMETRIOSIS DANGEROUS?

The main features of endometriosis are pelvic pain, ovarian cysts, and impaired fertility. It is considered a benign (non-cancerous) disorder that primarily affects quality of life. However, there is a very small increased risk of certain subtypes of ovarian cancer in women with endometriosis, compared to those without (about 1 – 2.5% increased risk over a lifetime). Endometriosis is not considered a precancerous condition, and there is no screening recommended for ovarian cancer at this time.

HOW IS ENDOMETRIOSIS MANAGED?

Management is tailored to every unique woman's needs, keeping in mind her symptoms and plans for childbearing. Unless childbearing is desired immediately, the mainstay of endometriosis treatment is medical suppression with some form of hormonal agent. The reason for this is because even with surgery, there is an up to 30-50% chance of endometriosis coming back. The chance of recurrence after surgery can be significantly decreased by taking medication for endometriosis after surgery, until pregnancy is desired.

One of the first steps in managing your endometriosis will be deciding on whether you would like to focus on symptom management or fertility, since all of the medications for endometriosis prevent or do not allow for pregnancy. You can revisit this decision at any point along the way during your treatment.

The next two pages provide an overview of the medical and surgical treatment options.

If you would like to discuss with us further, ask your family doctor to send a referral to: 514-843-2888 (fax) or endocares@muhc.mcgill.ca

WHAT ARE THE MEDICAL OPTIONS FOR ENDOMETRIOSIS?

There are many medical options for endometriosis, each with its own unique benefits and limitations.

- **NSAIDs (non-steroidal anti-inflammatories)**

  These are medications like ibuprofen and naproxen, which decrease inflammation associated with endometriosis, and can help relieve period pain (dysmenorrhea) and also lessen bleeding. While they help with symptom control, they do not address the underlying endometriosis. Main side effects include stomach upset.

- **Birth control pill, patch, or ring**

  Taking continuous birth control (meaning without a sugar-pack/placebo week) works very well to suppress endometriosis and decrease pain. These options have both estrogen and progestin in them and are effective as contraception and also to manage endo. Main side effects include abnormal spotting (improves with time), mood changes, and possibly water retention.

- **Dienogest (Visanne®)**

  Dienogest is a pill taken daily that contains only one hormone, a unique progestin. This medication is very effective at suppressing endometriosis and can significantly shrink endometriomas (chocolate cysts) over time. It is not a birth control pill and it is possible (although unlikely) to become pregnant while taking it. Main side effects include abnormal spotting, breast tenderness, and mild sleepiness (advisable to take before bed). With long-term use, there can be a slight, reversible decrease in bone density that has not been associated with increased fracture risk or osteoporosis.

- **Mirena® or Kyleena® IUD (intra-uterine device)**

  The Mirena® and Kyleena® deliver a continuous dose of levonorgestrel, a progestin that suppresses endometriosis activity and make periods lighter and less painful. They last for 5 years after insertion and are considered among the best options for contraception. Main side effects include mild pain with insertion (1-2 days), abnormal spotting (improves with time), and possibly acne.

- **Depo-Provera (depo-medroxyprogesterone acetate, DMPA)**

  DMPA is an injectable medication given every 12-13 weeks containing a single hormone. This medication is very effective as birth control and works well to control endometriosis. Main side effects include abnormal spotting (improves with time), possible weight gain, and with long term use it may cause reversible decrease in bone density. However it has not been associated with increased risk of fractures or osteoporosis.

- **Elagolix (Orilissa®)**

  This medication is a pill taken twice daily that works on receptors in your brain to simulate menopause. By decreasing your body's hormone levels similar to menopause, the endometriosis is effectively suppressed. This medication is not considered birth control. Main side effects include abnormal bleeding, mood changes, and hot flashes.

- **Leuprolide Acetate (Lupron®)**

  Lupron is an injectable medication that works similarly, but more effectively, than elagolix. Injections are given every 12 weeks (a 4 week formulation also exists), and it also causes a reversible, medical menopause. This medication is not considered birth control. Main side effects include abnormal bleeding, mood changes, difficulty sleeping, and hot flashes. Oftentimes, a small dose of hormone replacement therapy (called "add-back") is given to counteract the side effects of Lupron, especially if it will be used for more than 6 months.

- There are other medications which are rarely used nowadays (danazol, aromatase inhibitors) because there are better options with fewer side effects available.

WHAT DOES SURGERY FOR ENDOMETRIOSIS MEAN?

Surgery for endometriosis will depend on each patient's symptoms and priorities. Based on a discussion with your doctor, the right surgery for you can be determined.

There are many important questions to consider:

1. Is this primarily for pain or fertility?
2. Is there an endometrioma present?
3. Have you had surgery before?
4. Have you completed your childbearing?

Generally speaking, surgery for endometriosis is done laparoscopically, with a goal to remove scar tissue and any implants of endometriosis. This can include removing cysts from ovaries, removing deep disease from the peritoneum and the supporting structures around the uterus, shaving lesions off of the surface of the bowel or bladder, and the ureters, which are the connecting tubes between each kidney and the bladder.

WHAT ARE THE RISKS OF SURGERY?

General Anesthesia

All laparoscopy is done with general anesthesia, which means being put to sleep and using a breathing tube to help you breathe.

Infection

Generally a small risk for this kind of surgery, however antibiotics may be given intravenously while you are asleep, according to the surgeon's discretion

Bleeding

All patients must be aware of a risk of excessive bleeding and potentially requiring a blood transfusion before surgery. While this is considered a low risk surgery for transfusion, we require signed consent or refusal for blood products prior to surgery.

Injury to other organs

Other organs or structures may be injured during surgery including, but not limited to:

- Bowel (small and large intestine)
- Bladder
- Ureters (connecting tubes from kidneys to bladder)
- Blood vessels
- Nerves

If an injury occurs and is identified at the time of surgery, any necessary repairs will be done at the same time.

If a bladder injury occurs, you may be required to go home with a urinary catheter for one week.

Blood clots

Walking after surgery is very important to decrease this risk. Additionally, you may be given a dose of anticoagulation during surgery to reduce this risk.

This may seem like an intimidating list – while surgery usually goes very well, without any complication, it is important to be aware of all the risks involved.