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FAMILY MEDICINE

PATIENT RESOURCE

Endometriosis

What every woman should know — symptoms, diagnosis, fertility, treatment, and living well.

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🇨🇦 Based on Canadian and international evidence. General information only — not personal medical advice. Discuss your symptoms with your physician.

Content curated and designed by Mohammadreza Torbatimoghaddam, Clinical assistant

1 What is endometriosis?

Endometriosis is a chronic, inflammatory condition where tissue similar to the lining of the uterus (the endometrium) grows outside the uterus — on the ovaries, fallopian tubes, pelvic lining, bowel, and sometimes elsewhere. This tissue responds to hormones, causing inflammation, pain, and scarring.

Endometriosis is **not** an infection, **not** sexually transmitted, and **not** caused by anything you did or didn't do.

2 How common is it in Canada?

~1 in 14
Canadian women of reproductive age diagnosed (survey of 28,000+ women)

~1 in 10
Women of reproductive age worldwide — about 190 million people

Up to 28%
Of women with chronic pelvic pain have endometriosis

~25%
Of women with infertility are affected

True rates are likely higher — many women go undiagnosed for years.

3 What are the symptoms?

Symptoms vary widely — some women have severe symptoms; others have few or none:

- **Pelvic pain** — hallmark; ~90% report it
- **Painful periods** — beyond "normal" cramps (~70%)
- **Pain with sex** — during or after (~53%)
- **Pain with bowel/bladder** — especially on periods
- **Pain outside periods** — ~50%
- **Infertility** — ~22% report difficulty conceiving
- **Fatigue** — common but often overlooked
- **Bloating / digestive symptoms** — can mimic IBS
- **Heavy or irregular bleeding**

Important: Pain severity does not always match how much disease is present. Small amounts of endometriosis can cause severe pain; extensive disease can cause little pain.

4 Why does diagnosis take so long?

In Canada, women wait an average of **5.4 years** from first symptoms to diagnosis — about 3 years before seeing a doctor, then another 2.3 years to diagnosis. Internationally, delays of 5–12 years are common; most women see 3 or more providers first.

This happens because pain is often dismissed as "normal," symptoms overlap with IBS or bladder issues, there is no simple blood test, and surgery was historically required to confirm the diagnosis.

Good news: Current guidelines support a **clinical diagnosis** based on symptoms, exam, and ultrasound — without requiring surgery. Treatment can start sooner.

5 How is it diagnosed?

Approach	What it means for you
Clinical diagnosis	Based on symptoms and exam — enough to start treatment
Ultrasound	First imaging test; can find ovarian cysts (endometriomas) and some deep disease
MRI	Used when more detail is needed (bowel, bladder, deep lesions)
Laparoscopy	Camera surgery to see/biopsy tissue — no longer required before treatment
Blood tests	No reliable diagnostic blood test; CA-125 alone is not enough

6 What causes it — and who is at higher risk?

The exact cause is not fully known. Factors include retrograde menstruation, genetics (risk ~5× higher if your mother or sister has it; ~50% of risk may be inherited), immune factors, and estrogen fueling growth.

Risk factors

- Periods starting before age 12
- Short cycles (< 28 days)
- Never having been pregnant
- Lower body mass index
- Family history of endometriosis

Remember

- You did not cause this condition
- It is not an STI or infection
- Severe period pain that limits life deserves evaluation

7 Does it affect fertility?

Endometriosis can affect fertility, but **most women can still become pregnant** — sometimes with help. About 30–50% experience some infertility. Miscarriage risk is about 1.5× higher and ectopic pregnancy about 2.5× higher.

- **IVF** is the most effective option · **IUI** can help milder disease · Talk to your physician early if planning pregnancy

Myth: Pregnancy is sometimes suggested as a "treatment." Research does **not** show that pregnancy reliably reduces endometriosis or prevents it from returning.

8 Does endometriosis increase cancer risk?

About a **2-fold higher relative risk** of ovarian cancer (clear cell ~3.4×; endometrioid ~2.3×), but the **absolute risk stays low**: lifetime risk ~1.1% overall vs about **1.9%** with endometriosis.

- Routine preventive ovary removal is **not** recommended for endometriosis alone
- Long-term combined birth control pills can **reduce** ovarian cancer risk
- Extra cancer screening beyond standard guidelines is usually not needed

9 Does it go away after menopause?

Most women improve significantly after menopause as estrogen falls. About **2–4%** of postmenopausal women still have symptoms. Hormone therapy (HRT) can sometimes reactivate symptoms — discuss carefully. Any new pelvic pain after menopause should be checked promptly.

10 What are the treatment options?

There is no cure yet, but treatments can manage pain and improve quality of life. Care is tailored to your symptoms, pregnancy plans, and response.

Option	Notes
NSAIDs	May help mild pain; evidence specifically for endometriosis is limited
Birth control pills	Often continuous; first-line, effective, low-cost
Progestin options	Pills, hormonal IUD, or injection
GnRH agonists / antagonists	Stronger suppression; often with "add-back" hormones
Laparoscopic surgery	When meds fail or for large cysts/deep disease
Hysterectomy	Last resort when pregnancy not desired; ~25% still have some pain

- First-line hormones reduce pain similarly — choice depends on side effects, cost, and preference
- ~11–19% do not get enough relief; ~25–34% have pain return within a year of stopping

11 Can diet and lifestyle help?

These are complements to — not replacements for — medical care:

- **Anti-inflammatory / Mediterranean-style eating** — fruit, vegetables, whole grains, fish, healthy fats; limit red/processed meat
- **Low-FODMAP** for bloating · **Omega-3s** · **Exercise, yoga, mindfulness, CBT** · **Pelvic floor physiotherapy**

12 How does it affect mental health?

Women with endometriosis have about a **1.5–2× higher risk** of depression and anxiety. Chronic pain, fatigue, relationship impacts, fertility worries, and delayed diagnosis all contribute.

> Seeking support matters. Talk to your physician about counselling or medication. Multidisciplinary care — medical plus mental health — is recommended.

13 What should I do if I think I have it?

1. **Track symptoms** — pain timing/severity, periods, bowel/bladder, daily impact
2. **See your physician** — severe period pain that limits life is not something to dismiss
3. **Ask about treatment** — care can start on clinical diagnosis; you don't need to wait for surgery
4. **Share fertility goals early** · **Find support** — The Endometriosis Network Canada (endometriosisnetwork.com)

14 Key takeaways

1. Affects about 1 in 10 women of reproductive age — common in Canada.
2. It is a real chronic condition — not "just bad periods."
3. Diagnosis no longer requires surgery; treatment can start sooner.
4. Hormones and surgery help; finding the right plan may take time.
5. Fertility can be affected, but most women can still become pregnant.
6. Cancer risk is slightly higher but absolute risk stays low.
7. Mental health matters — ask for support.
8. You are not alone — advocacy and multidisciplinary care help.

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