

Endometriosis is defined as “a systemic, inflammatory disease characterized by the presence of endometrium-like tissue found outside the uterus, usually with an associated inflammatory process. It is a spectrum disease with a variety of subtypes and clinical presentations [1] . . .”

FACTS AND STATISTICS

- On average, it takes **seven to nine years** of discussing symptoms with healthcare providers for a person to be diagnosed with endometriosis [2].
- Endometriosis impacts approximately **1 million people in Canada** and more than 176 million girls, women, transgender, non- binary and gender diverse people worldwide [3]. These numbers suggest that approximately 9,000 individuals could be affected by endometriosis in PEI.
- Endometriosis is a **chronic disease** associated with severe, life-impacting pain and other symptoms. 5 in 10* women and gender-diverse people affected by endometriosis experience **infertility and pelvic pain** [4].
- **Endometriosis can affect people of all genders**, including women, transgender and gender diverse people, and cisgender men (in very rare cases) [5].
- **BIPOC** (Black, Indigenous, and People of Colour) **women and gender diverse people are less likely than White women and gender diverse people to receive an accurate and timely diagnosis** of endometriosis [6].
- People with symptoms often have **decreased social and economic participation** and adolescents with symptoms are ten times more likely to miss school [7,8] .
- Pain and other symptoms with endometriosis and related conditions are not limited to the abdomen/pelvis. **Endometriosis has been found in multiple organs throughout the body** (including lung, diaphragm, bowel, etc.).
- There is **no known cure for endometriosis** (including a hysterectomy). However, symptoms can be managed through pain management, hormone management, and/or surgery [9].

SYMPTOMS

Symptoms may be present at any point during the menstrual cycle, but often worsen during menstruation.

Pain [13]

- Cyclic pain following the menstrual cycle or chronic pain
- Pelvic pain
- Pain during sexual activity
- Back/leg/hip pain
- Disabling and increasingly painful menstrual cycles

Gastrointestinal & Urinary Symptoms [13]

- Constipation or diarrhea (sometimes cycling between the two)
- Abdominal bloating
- Nausea and vomiting
- Painful elimination and urination
- Bladder pain
- Urinary urgency and frequency
- Dysmenorrhea [14, 15]

Fertility Issues [13]

- Infertility
- Recurrent pregnancy loss

Mental Health Symptoms [16,17]

- Depression
- Anxiety

Other [13,17]

- Brain Fog
- Heavy bleeding during menstruation with longer menstruation periods
- Constant Fatigue

SYMPTOM MANAGEMENT OPTIONS INCLUDE:

The first approach to symptom management and treatment is:

- **Menstrual suppression through hormonal management** (symptoms typically recur when hormonal treatment are stopped) [2].

A **multidisciplinary approach can be used** for patients experiencing various symptoms [20]:

- Primary care physician/nurse practitioner
- Allied health professionals such as a pelvic floor physiotherapist, osteopath, registered massage therapist, acupuncturist, and registered dietitian
- Mental health professional, such as a social worker and psychologist
- Medical specialists such as a thoracic surgeon, urologist, colorectal surgeon, gastroenterologist, nephrologist, neurologist, immunologist, physician specializing in pain, etc.

DIAGNOSIS

To decrease the diagnostic/treatment delay and improve patient care, the endometriosis medical community has been moving toward a clinical, rather than solely surgical diagnosis. With imaging advancements, certain phenotypes of endometriosis (e.g. deep and cystic vs. peritoneal) can now be detected and diagnosed via ultrasound or MRI, given a practitioner with advanced training and experience. However, while imaging can now diagnose endometriosis in certain cases, it cannot rule it out. Therefore, given a patient presenting with the symptoms, medical history, and/or physical examination signs of endometriosis, clinicians are encouraged to counsel toward this diagnosis, begin a treatment plan, and make the appropriate referrals for further care [18].



Endometriosis Information Sheet for Health Care Providers

SURGICAL TREATMENT

Some patients with more advanced endometriosis, infertility or pelvic masses may require surgical treatment. There are two main surgical options which are generally offered through a laparoscopic approach including ablation surgery and excisional surgery. The gold standard is now thought to be excisional surgery, which is performed by a gynecologist who has completed appropriate training in this area. More advanced endometriosis may require the care of a MIGS (Minimally Invasive Gynecological Surgery) fellowship trained surgeon who focuses their practice on endometriosis [9]. Presently, patients in PEI must travel off-Island to access advanced MIGS level surgery and may experience lengthy wait times. While excision surgery is the gold standard for endometriosis treatment, symptoms can be managed through hormonal management and pain management. Following surgery most patients will continue to require hormonal management until menopause.

REFERRAL OPTIONS

Local Professionals for Symptom Management

Various allied health professions and medical specialists provide services for endometriosis related symptoms, such as pelvic floor pain, painful urination, and depression. When referring patients to a specialist or allied health professional to support symptom management, ask if the health care professional is trained and regularly provides services for pelvic floor pain and endometriosis symptom management. In more severe cases, a multidisciplinary team including health professionals who specialize in endometriosis care may be required. Currently this service is not available in PEI.

MIGS Fellowship Trained Excision Surgery Specialists

While there are currently no local MIGS fellowship trained excision surgery specialists, to decrease the diagnostic/treatment delay and improve patient care, patients experiencing more severe endometriosis symptoms can be referred to an out-of-province specialist. The Endometriosis Network of Canada has compiled lists of MIGS fellowship trained clinicians who practice excision surgery in Canada by region. These clinicians are also specialists in non-surgical approaches to treating endometriosis and related conditions. Please see the link for the list: <https://endometriosisnetwork.com/finding-a-doctor>. There are surgical subspecialists in NB and NS. Consider the multidisciplinary approach to symptom management if your patients need to be referred to a specialist.

Clinical Practice Guidelines

The Society of Gynecology and Obstetrics Canada produces Clinical Practice Guidelines for endometriosis. Updated guidelines are expected in 2024.

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