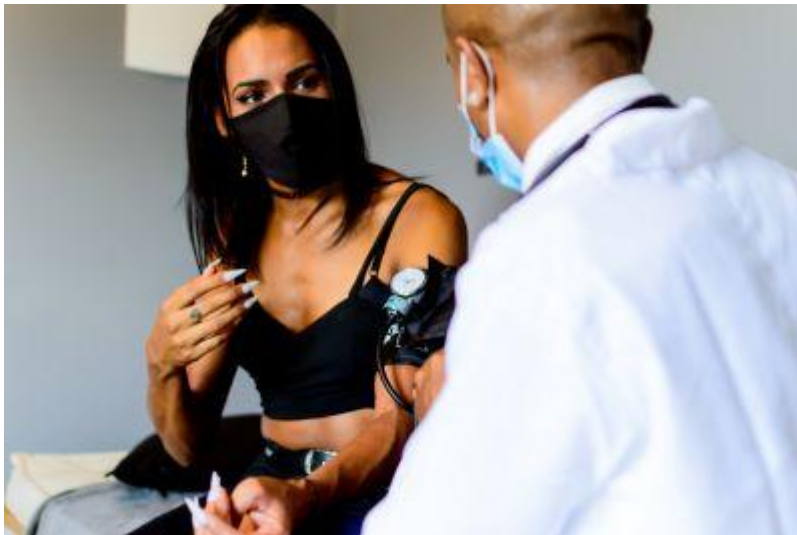


# Endometriosis



## Quick Facts



- 1 in 10 girls and women, and an unmeasured number of transgender, non-binary, and gender diverse people have Endometriosis or a related condition
- On PEI, it is estimated that approximately 9,000 women and gender diverse people could have Endometriosis
- Endometriosis occurs when tissue similar to the lining of the uterus (the endometrium) grows outside the uterus and attaches itself to other organs, causing scarring, lesions, adhesions, and cysts.
- Endometriosis is an extremely painful chronic disease that can impact quality of life
- On average, it takes 7-9 years to obtain a diagnosis of Endometriosis
- The first step to obtaining a diagnosis is to talk to a primary care provider (family doctor, nurse practitioner, or walk-in clinic health professional); it is advised to track symptoms for several months
- Endometriosis can be found in people of all ages and genders
- There is no cure for Endometriosis, only treatment of symptoms (e.g., hormone therapy, lifestyle changes, surgery, physical therapy)

- There are approximately 42 Endometriosis specialists in the entire country, none on PEI; a referral is required through a primary care provider or OBGYN to see a specialist
- An [endometriosis factsheet](#) [PDF] is available for healthcare providers.

## The Longer Story

**More than 1 in 10 girls and women, and an unmeasured number of transgender, non-binary, and gender diverse people have Endometriosis or a related condition.**

This amounts to approximately 1 million people in Canada affected by Endometriosis. Despite this high number, people who have this painful condition often face lengthy diagnosis times, obstacles accessing treatment options, and mental health challenges due to the isolating nature of the condition.

On PEI, based on the national average of people living with Endometriosis, it's estimated that close to 9,000 women and gender diverse people live with the condition.

Traditionally, stigma related to women's health issues has caused a culture of silence around women and gender diverse people's experiences with their menstrual cycles, as well as the various health conditions relating to their cycles. Despite its prevalence, awareness of this disease is low, and many myths and misunderstandings about it, both in the mainstream and within the health care system, make it difficult for patients to get diagnosed and receive appropriate treatment. People with Endometriosis are routinely dismissed as complaining about "normal" period pain or are told that their problems are psychological, rather than physical.

**Endometriosis can be found in people of all ages and all genders.** This includes cisgender women and girls, transgender people, non-binary individuals, and gender diverse people. While Endometriosis primarily affects people with a uterus, in some cases, it can affect people who do not have a uterus. Additionally, Endometriosis can grow and cause scarring and inflammation in other parts of the body, causing symptoms to be felt all over the body, including the lungs and the brain.

## About Endometriosis

Endometriosis occurs when tissue similar to the lining of the uterus (the endometrium) grows outside the uterus and attaches itself to other organs, causing scarring, lesions, adhesions, and cysts. People with this condition often experience distressing symptoms, such as painful menstrual cycles, along with a host of full body symptoms. These symptoms can be exasperated by the menstrual cycle, but can be experienced at any time.

Symptoms vary among individuals, but some of the most common symptoms of Endometriosis include:

- Heavy bleeding during menstruation
- Severe pelvic and abdominal pain that requires more than a low dose pain medication
- Pain or bleeding in between periods
- Periods that last longer than 7 days
- Extreme fatigue
- Lower back pain
- Digestive problems
- Painful bowel movements and/or urination
- Vomiting or passing out during periods
- Missing school or work during a period

Endometriosis isn't the only condition where some of these symptoms are experienced, so individuals trying to pursue a diagnosis are encouraged to track their symptoms and consult with either their family doctor, nurse practitioner, or a walk-in clinic health care professional.

It is estimated that, in Canada, the cost of people missing work due to Endometriosis symptoms is at least \$1.8 billion per year.

To build better awareness among healthcare professionals in PEI, a new resource will soon be available to support diagnosis and treatment of people with Endometriosis:

There are only approximately 42 Endometriosis specialists in the entire country. There is no Endometriosis specialist currently working on PEI, so Islanders seeking care must do so **off-Island**.

Endometriosis is a complex disease that affects both physical and mental health. Research has shown an association with Endometriosis and anxiety and depression. Different people experience the conditions differently; for some, relationships may suffer, and others may find the conditions interfering with work and daily activities.

Anyone who is experiencing symptoms of depression and/or anxiety related to Endometriosis or suspected Endometriosis, **seek help** from a qualified professional.

**Part of the isolation felt by those who have Endometriosis (or symptoms of) is attributed to how difficult it can be to diagnose the condition.**

Often, diagnosis comes after ruling out numerous other health conditions, so the path to diagnosis and treatment can be long. On average, it can take 7–9 years of medical visits to receive a diagnosis; this can leave the person

experiencing painful symptoms feeling hopeless. Some are unable to obtain an official diagnosis and focus on managing each symptom; however, without treating the condition as a whole, the person will likely not be able to achieve sufficient pain relief.

Historically, Endometriosis has been treated as a “woman’s illness,” and, more specifically, a “white woman of childbearing age illness.” Due to the history of medicine often being steeped in racism and sexism, studies have shown that BIPOC individuals are less likely to be diagnosed with Endometriosis. In fact, Black women experiencing symptoms of Endometriosis are 50% less likely to be diagnosed with the condition than white women. Once diagnosed, BIPOC individuals often face more barriers to accessing necessary treatment options due to unconscious biases within the healthcare system. Transgender and other gender diverse individuals face similar barriers to obtaining a diagnosis and treatment plan.

## Getting a Diagnosis on PEI

Individuals who think they may have Endometriosis are encouraged to first consult their family doctor or nurse practitioner. Anyone without a primary care provider can go to a [walk-in clinic](#) or use [Maple](#). It’s a good idea to track symptoms and cycles for several months; however, anyone experiencing severe pain or other concerning symptoms should not wait to consult a health care professional.

If the health care professional thinks Endometriosis is the probable cause of symptoms, they may refer the patient to a specialist. Referrals might include one or more of the following: PEI’s Obstetrics and Gynecology Clinic, the IWK Endometriosis and Chronic Pelvic Pain Clinic (Halifax), or one of the Endometriosis specialists off-Island. Due to the limited number of Endometriosis specialists, wait times can be lengthy.

There is no simple blood test that shows whether a person has Endometriosis. A formal diagnosis stems from a surgical procedure called a laparoscopy. However, current best practice encourages clinicians to counsel toward a diagnosis of Endometriosis and begin a treatment plan when a patient is presenting with symptoms and/or physical signs of the disease.

An [endometriosis factsheet](#) is available for healthcare providers.

## Treatment Plan for Endometriosis

People with Endometriosis (or those who suspect they have the condition) feel genuine pain and deserve proper care and understanding from a health care provider. A caring and holistic (“whole body”) approach to treatment can significantly improve overall well-being and quality of life for those with Endometriosis.

Although there isn't a cure yet for Endometriosis, current treatments focus on managing the disease and its symptoms. Some treatment options include hormone therapy, surgery, lifestyle changes, mental health counselling, and physical therapy.

There is no evidence that removing the uterus cures the condition, but it may relieve symptoms for some, especially for those who also have adenomyosis for which a hysterectomy is a cure.

More research is needed to better understand and identify alternative treatment approaches.

To find out more information, contact:

- The [Endometriosis Network of Canada](#) – which includes a listing of providers in the Maritimes, including:
  - [IWK](#), Halifax , NS
  - Endometriosis and Chronic Pelvic Pain Clinic
  - Saint John Regional Hospital, Saint John, NB
- [PEI Obstetrics and Gynecology Clinic](#)

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