

Thank you for your interest in The Endometriosis Network Canada!

This little-known disease affects about 1 in 10 women and unmeasured numbers of transgender, non-binary and gender-diverse people. We urge you to review the information on endometriosis in this kit and feel free to reach out to our team if you have any questions.

By publishing an article about endometriosis, you are both generating awareness through your readers and providing access to information that could improve the quality of life for people living with endometriosis.

What is Endometriosis?

Endometriosis is a complex and debilitating chronic disease that occurs when tissue similar to the lining of the uterus implants outside of the uterus to form lesions, cysts, and deep nodules, affecting over one million people in Canada. Despite its prevalence, awareness of this disease is low, and many myths and misunderstandings about it confound the patient's path to receiving diagnosis and effective treatment.

People with endometriosis are routinely dismissed by many physicians as complaining about normal period pain or are told that their problems are psychological rather than physical.

Signs & Symptoms of Endometriosis

Symptoms of endometriosis vary between individuals, and include but are not limited to:

- Pelvic pain - can be extremely debilitating, and constant
- Bowel issues including diarrhea and constipation Nausea
- and vomiting
- Bladder pain, urinary frequency/urgency
- Infertility and recurrent pregnancy loss
- Fatigue

About The Endometriosis Network Canada

The Endometriosis Network Canada (TENC) is the first registered charity in Canada dedicated to providing education, support, and awareness, to those living with endometriosis nationally. TENC was incorporated as a not-for-profit in November of 2012 by a group of people with endometriosis, who met through a Toronto-based endometriosis in-person support group.

This group of individuals recognized the great need to provide Canadians with resources to help improve their quality of life with this chronic disease. In 2016, TENC became a registered charity. TENC has had the opportunity to draw upon top medical experts in the country and internationally, as well as networking across Canada with endometriosis patients.

The mission of TENC is to promote awareness while providing education, support, and resources nationally, for people with endometriosis and those whose lives it touches.



EndoAct Canada

The Endometriosis Network Canada is a founding organization of EndoAct Canada, a representation of Pan-Canadian expertise on endometriosis. Their mission is to improve the lives of people with endometriosis in Canada by driving policy action that is based on science and grounded in the needs of the endometriosis community. They envision a Canada in which all people with endometriosis receive the right care, in the right place, at the right time.

What is the Impact of Endometriosis?

Long waits for diagnosis and difficulties accessing effective treatment lead to years of suffering for many people with endometriosis in Canada, impacting their ability to thrive in life, work and play.

- The average delay to diagnosis in Canada is 5.4 years, but can be as long as 20 years.
- Adolescents with symptoms are 10 times as likely to miss school.
- Decreased social and economic participation as well as mental health concerns.
- Estimated cost of at least \$1.8 billion per year to Canadian society.
- To get surgical care for endometriosis in Canada can take up to 21 months?

Diagnosing Endometriosis

Endometriosis can only be definitely diagnosed through laparoscopic surgery, although it can be suspected based on clinical history, and/or imaging results such as ultrasound or MRI.

Once diagnosed, patients in many areas of Canada cannot access laparoscopic excision surgery, which is one of the most effective treatments for endometriosis, or any specialized care for their disease.

Even patients who do receive specialized care often continue to have significant symptoms:

- 59% continue to have painful periods
- 56% continue to have painful intercourse
- 60% continue to have chronic pelvic pain

However, appropriate multidisciplinary care can help alleviate the symptoms of endometriosis. This can include expert surgery, identification, and treatment of other conditions that commonly are found coexisting with endometriosis, pelvic physiotherapy, pain management, nutritional strategies, and emotional support.



TENC's current activities include:

- Facilitating twice-per-month virtual, Canada-wide endometriosis support groups; in-person support groups were held monthly prior to the pandemic
- Enhancing education about the disease through a resource-rich website, bi-weekly blog posts, periodic educational events, and community engagement over social media
- Hosting annual endometriosis awareness events including the Virtual EndoMarch Canada as well as our annual fundraising event, The Endo Network's Run To End Endo™, which aims to raise awareness while bringing the endo community together across Canada and around the world
- Facilitating two private, online Facebook support groups; one dedicated to endometriosis patients and one dedicated to supporting people caring for those living with the disease
- Hosting educational webinars and town hall meetings to educate the public and connect people navigating endometriosis with expert clinicians in Canada several times per year
- Providing monthly, virtual wellness workshops (i.e. Restorative Yoga, Qigong, Endo Eats Baking Social) for the community, free with a suggested donation or a Pay What You Can structure to ensure accessibility for all.

Contact List

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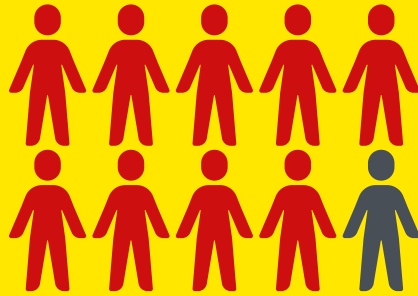
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Endometriosis Facts & Stats

5.4

The average delay to diagnosis endometriosis in Canada is 5.4 years, but can be as long as 20 years



1 in 10 women and unmeasured numbers of transgender and gender-diverse people



Estimated cost of at least \$1.8 billion per year to Canadian society

5 - 7

The number of doctors the average person sees before being diagnosed with endometriosis

