



the endometriosis
network **canada**

Thank you for your interest in The Endometriosis Network Canada (TENC).

This little-known disease has big implications, affecting approximately 10% of the female population. We encourage you to review the following information on endometriosis, our awareness activities and the services we offer throughout the year. By publishing an article on endometriosis, you are not only generating awareness through your readers, but providing access to information that could improve quality of life for endometriosis patients.

In the body of this package, you will find:

- Endometriosis Fact Sheet
- Organizational Summary
- Photographs and videos
- Contact information

If you have any questions, or an idea for an expanded piece please do not hesitate to contact us directly.

With regards,

Philippa Bridge-Cook and Erika Myers-Khan
Executive Directors



Endometriosis Fact Sheet

Endometriosis is a common, chronic condition, affecting over 800,000 women in Canada, and even some men. 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.

- Women with this disease wait an average of 7 to 9 years, and see an average of 5 to 7 doctors, before receiving a diagnosis.
- Women 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.

Symptoms of endometriosis vary between individuals, and include:

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

Diagnosis

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.



Treatment

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.

Currently most endometriosis patients struggle to find medical experts in all of the areas they need help with, to coordinate all the care, and to be able to pay for uninsured services.

Personal Impact

Endometriosis also has a significant effect a person's emotional well-being. Studies have shown that this disease impacts the individual's ability to work, socialize, and have intimate relationships. 87 percent of endometriosis patients have depressive symptoms (severe in 33 percent) because of their disease, and 88 percent have anxiety, and research has shown that physical improvement can also bring mental improvement.

Economic Impact

Finally, endometriosis has a significant impact on the Canadian economy. Based on international studies on the cost of endometriosis, in Canada, endometriosis costs \$10.6 billion per year (\$13,413 per patient). This cost is similar to other chronic illnesses such as diabetes and Crohn's disease.



Organizational Summary

The Endometriosis Network Canada (TENC) is the only organization 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, 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. 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.

TENC's **current activities** include:

- interactive educational seminars three times yearly in Toronto
- biennial full day educational symposium
- a professionally-facilitated in person support group in Toronto, and coordinating a network of peer-facilitated support groups across Canada
- online support through a private Facebook group
- organizing awareness activities across Canada
- website and informational brochures

As a result of the support and educational programming TENC has made available, feedback has shown that feelings of isolation and hopelessness can be replaced by empowerment and comfort in knowing that others understand. Willingness to advocate for oneself, and try new streams of treatment often follows.

TENC is entirely run and staffed by dedicated volunteers.

Photographs and Videos

These photographs have been added with the permission of the subjects depicted and/or the photographer. They have been included with the understanding that they may be used in the media.



The CN Tower lit yellow for endometriosis awareness.



Organizers of the 2014 educational symposium in Toronto.



2015 Endometriosis Awareness event in Edmonton.



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2015 Endometriosis Awareness event in Saskatoon



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2015 Endometriosis Awareness event in Toronto.

Living With Endometriosis (Videos)

<http://endometriosisnetwork.com/information/videos/>



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