

Discussion: The need for action on endometriosis in Canada



Introduction

EndoAct Canada is an unincorporated not-for-profit organization with the goal of driving action on endometriosis in Canada.

EndoAct Canada was co-founded by The Endometriosis Network Canada (TENC) and the Canadian Society for the Advancement of Gynecologic Excellence (CanSAGE).

TENC is the first patient-led, registered charity in Canada dedicated to raising awareness of endometriosis and providing support and educational resources to those it affects.

CanSAGE is a professional society with a mission to promote and maintain high standards of excellence in the diagnosis and management of complex gynecologic conditions including endometriosis.

By bringing those living with endometriosis together with health care providers and researchers, we represent a collective Pan-Canadian expertise on this disease. Together, we are raising awareness about issues facing the endometriosis community in Canada, as well as solutions to ensure that those in Canada who have endometriosis get the right care, in the right place, at the right time.



What is endometriosis?

- Endometriosis is a chronic inflammatory disease in which tissue similar to the lining of uterus grows on other parts of the body, causing inflammation, scarring, and organ damage.
- Endometriosis affects 1 in 10 women, and unmeasured numbers of transgender, non-binary, and two-spirit people (almost 2 million Canadians).
- Symptoms often begin in adolescence and include severely painful periods, chronic pain, and infertility.
- Endometriosis has no known cause or cure, so it is managed with a combination of specialized surgery, medication, and multidisciplinary care.



State of endometriosis in Canada

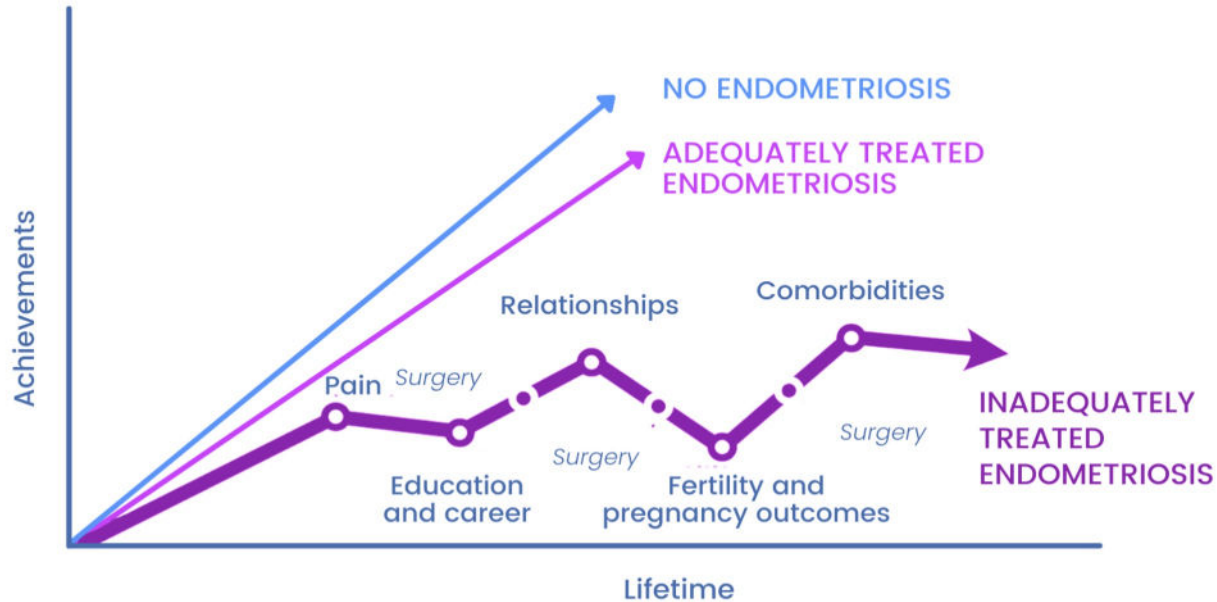
- The average delay to diagnosis in Canada is at least 5.4 years, and can be as long as 20 years.
- Low knowledge and awareness of the disease among health care professionals and the public contributes to delayed diagnosis.
- Wait times for specialised surgical and chronic pain care are 6-24 months or longer.
- Canadians with endometriosis are paying to get the care they need out of country.
- Since January 2019, the Canadian Institutes of Health Research have invested \$8 million in endometriosis (about \$4 per person living with endometriosis).



Consequences of inadequate care

- Adolescents with symptoms are 10 times as likely to miss school.
- Adults with endometriosis lose almost 11 hours of work per week.
- People with endometriosis experience high rates of anxiety, depression, post-traumatic stress, and suicidality.
- Surgically confirmed endometriosis costs \$2.4 billion per year to Canadian society.
- In an article entitled *It Is Time to Treat Endometriosis as if It Were Cancer*, experts agreed, “We, as a medical system, are failing people with endometriosis.”

Consequences of inadequate care



Visit our [patient storytelling platform](#) to learn about living with endometriosis in Canada

Recommendations

- Consult with the Canadian endometriosis community to understand gaps and barriers to endometriosis diagnosis and treatment.
- Develop a comprehensive plan to address endometriosis, in line with commitments made by peer nations and responsive to the priorities of Canadians.
 - For example, the Australian National Action Plan for Endometriosis includes investments in awareness and education, clinical management and care, and research as well as an apology from the Minister for Health “on behalf of the Australian Parliament and medical system for the historic failures that sufferers of endometriosis endured.”
- Support training on endometriosis for health care providers and promote public endometriosis awareness.
- Provide meaningful, sustained, and strategic funding for endometriosis research that focuses on patient-identified priorities across all areas of health research.

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Contacts

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