Discussion: The need for action on endometriosis in Canada

ENDOACT 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 more than 1 in 10 women, and unmeasured numbers of Two-Spirit, transgender, and non-binary 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.

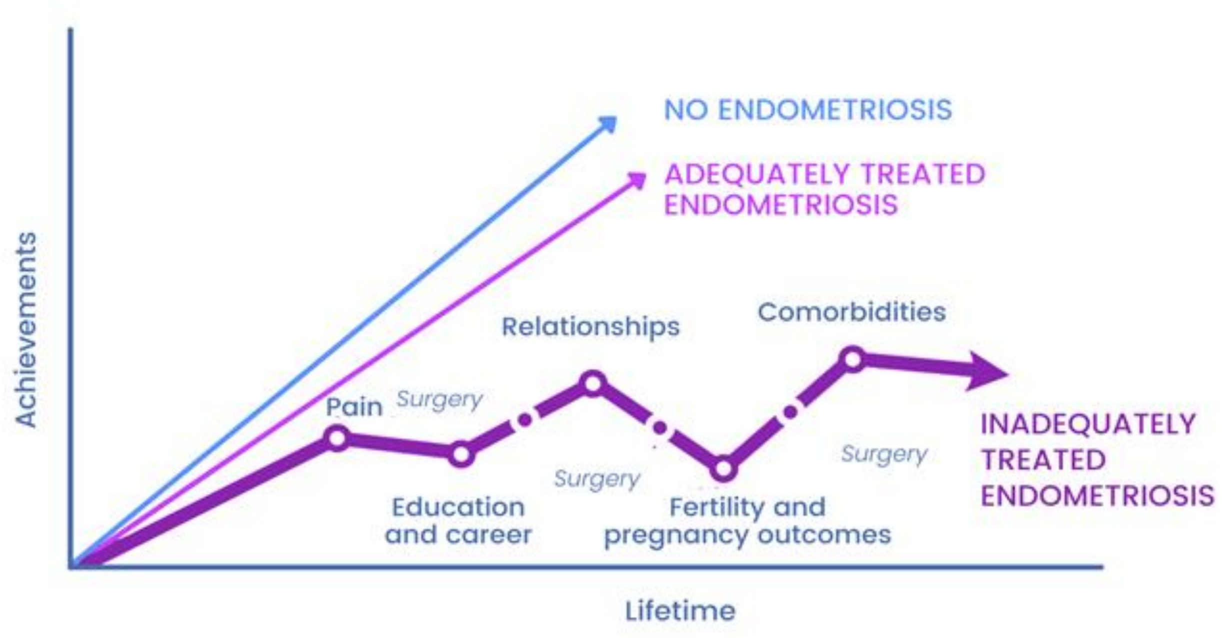
State of endometriosis in Canada

- 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.
- Investments in endometriosis research are low compared to similar chronic conditions.

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 $2.5 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

Enact the endometriosis-related recommendations from the House of Commons Standing Committee on Health report *Women's Health in Canada: Closing the Gender Gap* (November 2025) in a timely and comprehensive way.

Recommendation 1 That the Government of Canada develop a national action plan on endometriosis, in collaboration with provinces and territories and Indigenous governing bodies, as well as people living with endometriosis, clinicians and researchers, to address gaps and barriers that hinder awareness, diagnosis and treatment.

Recommendation 2 That the Government of Canada increase funding for research that supports innovation and discovery with respect to the diagnosis and treatment of endometriosis.

References

Endometriosis & Its Impact

- Singh et al. "Prevalence, symptomatic burden, and diagnosis of endometriosis in Canada: cross-sectional survey of 30 000 women." Journal of Obstetrics and Gynaecology Canada 42.7 (2020): 829-838.
- Wahl et al. "Endometriosis in Canada: it is time for collaboration to advance patient-oriented, evidence-based policy, care, and research." Journal of Obstetrics and Gynaecology Canada 43.1 (2021): 88-90.
- Neustaeter. “'Giving these women their lives back': Canadian starts fund to help those struggling with endometriosis get care abroad.” CTV News. (2021).
- Suvitie et al. "Prevalence of pain symptoms suggestive of endometriosis among Finnish adolescent girls (TEENMAPS study)." Journal of pediatric and adolescent gynecology 29.2 (2016): 97-103.
- Nnoaham et al. "Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries." Fertility and sterility 96.2 (2011): 366-373.
- Estes et al. "Depression, anxiety, and self-directed violence in women with endometriosis: a retrospective matched-cohort study." American journal of epidemiology 190.5 (2021): 843-852.
- Levy et al. "Economic burden of surgically confirmed endometriosis in Canada." Journal of Obstetrics and Gynaecology Canada 33.8 (2011): 830-837.
- Leonardi et al. “It Is Time to Treat Endometriosis as if It Were Cancer.” Journal of Obstetrics and Gynaecology Canada 42(2020):507-509.

Endometriosis Policy in Peer Nations

- Commonwealth of Australia (Department of Health). “National action plan for endometriosis.” (2018).
- Commonwealth of Australia (Department of Health). “Endometriosis progress report.” (2021).
- Commonwealth of Australia (Department of Health). “Australia’s first endometriosis and pelvic pain clinics now available nationally.” (2023)
- République Française (ministre des Solidarités et de la Santé). “Stratégie nationale de lutte contre l’endométriose.” (2022).
- All-Parliamentary Group on Endometriosis. “Endometriosis in the UK: time for change.” (2020).
- UK Government (Department of Health and Social Care). “Women’s health strategy for England.” (2022).
- Scottish Government (Ministry for Minister for Public, Health, Women’s Health and Sport). “Women’s Health Plan: A plan for 2021-2024.” (2021).
- Government of Ireland (Department of Health). “Minister for Health announces development of the National Endometriosis Framework.” (2023).

Contacts

For information about the need for action plan on endometriosis, please contact EndoAct Canada, info@endoact.ca

For information about the endometriosis patient community, please contact The Endometriosis Network Canada, info@endometriosisnetwork.ca

For information about healthcare services for people with endometriosis, please contact the Canadian Society for the Advancement of Gynaecologic Excellence, admin@cansage.org