

EndoAct Canada Press Kit

March 24, 2022

Thank you for helping to support EndoAct Canada!

About EndoAct Canada

- The 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.
- Envisions a Canada in which all people with endometriosis receive the right care, in the right place, at the right time. Their vision of success is that people with endometriosis can thrive in life, work, and play.
- Aims to generate high-quality evidence that advances solutions for the problems that matter most to the Canadian endometriosis community.

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.
- Affects approximately 1 million people in Canada -- 1 in 10 women and unmeasured numbers of transgender and gender diverse people.
- Symptoms often begin in adolescence and may include severe menstrual cramps, chronic pelvic pain, pain during sex, fatigue, and infertility.
- There is neither a definitive cause nor a known cure for endometriosis – symptoms are managed using a combination of surgical, medical, and supportive care.
- Despite the burden of endometriosis, awareness of this disease is low because of menstrual stigma and taboo.

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.

- Average delay to diagnosis in Canada is 5.4 years, but can be as long as 20 years.^(1,2)
- Adolescents with symptoms are 10 times as likely to miss school.⁽³⁾
- Adults with endometriosis lose more than 10h of work weekly.⁽⁴⁾
- People with endometriosis experience high rates of anxiety, depression, post-traumatic stress, and suicidality.⁽⁵⁾
- Estimated cost of at least \$1.8 billion per year to Canadian society.⁽⁶⁾

How have peer nations mobilized on endometriosis?

Canada has not taken comprehensive action on endometriosis to date, creating knowledge and practice gaps. Peer nations have:

- Australia: In 2018, the Australian government published a National Action Plan for Endometriosis with the objectives of 1) increasing awareness and education about endometriosis, 2) improving clinical management and care, and 3) driving research.⁽⁷⁾ The government has invested more than \$22 million to advancing these objectives,⁽⁸⁾ and in March 2022 committed an additional \$58 million including to funding to establish new specialised endometriosis and pelvic pain clinics in each state and territory.⁽⁹⁾
- France: In 2022, the French government announced a national endometriosis strategy addressing awareness and education, diagnosis and treatment.⁽¹⁰⁾ As part of the strategy, the government will invest 20 million euros in endometriosis research over the next 5 years, prioritize endometriosis education for health care professionals and the public, and establish a network of health care professionals dedicated to the diagnosis and management of endometriosis in every region of France by 2023.⁽¹¹⁾
- United Kingdom: In 2020 an All-Party Parliamentary Group recommended a commitment to drive down diagnosis time, access to appropriate care, awareness, and investment in research.⁽¹²⁾ Endometriosis is a priority in the UK Government's vision for a women's health strategy.⁽¹³⁾
- Scotland: Endometriosis is a priority in the Women's Health Plan for 2021-2024.⁽¹⁴⁾
- United States: In 2020, the U.S. House of Representatives passed an amendment doubling annual federal research funding for endometriosis from \$13 million in 2019 to \$26 million.⁽¹⁵⁾

How will EndoAct Canada make a difference?

- On January 14, 2021 EndoAct Canada launched their website [endoact.ca](https://www.endoact.ca) and social media channels on [Facebook](https://www.facebook.com/endoactcanada/) <https://www.facebook.com/endoactcanada/>, [Instagram](https://www.instagram.com/endoact) <https://www.instagram.com/endoact> and [Twitter](https://twitter.com/endoactcanada) <https://twitter.com/endoactcanada>.
- On January 28, 2022 EndoAct Canada launched the #ActOnEndo #ACTIONSURLENDO toolkit and campaign to support people with endometriosis and their allies to demand federal action on endometriosis.
 - People who are interested in contacting their Member of Parliament can do so by visiting the [toolkit webpage](#)
- Individuals touched by endometriosis can [share personal stories](#) EndoAct website about what it's like to live with the disease.
 - By sharing these stories, EndoAct will help bring greater understanding of endometriosis to an essential audience and connect those living with the disease across Canada.
 - By collecting these stories, EndoAct will provide government, stakeholder and the public with a better understanding of the impact of Endometriosis across the country.
 - People who are interested in sharing their endometriosis story can do so by visiting [EndoAct's stories webpage](#).

What is EndoAct Canada's goal?

By investing in a national action plan on endometriosis, Canada will advance patient-centered and evidence-based solutions for the impact of this disease, take a leadership position on gendered health issues, and support the equal and full participation of all people in Canadian life.

Quotes

Philippa Bridge-Cook, patient, Board Chair at [The Endometriosis Network Canada](#) and EndoAct Canada Co-Chair, states “As a public health and social justice issue, endometriosis has been ignored for too long. People with endometriosis in Canada need patient-centred policy that is informed by evidence, which requires collaboration combining the expertise of patients with that of clinicians, researchers, and government stakeholders.”

Dr. Catherine Allaire, former President of [CanSAGE](#) and EndoAct Canada Co-Chair, states “As a clinician who has been treating patients with endometriosis for 25 years, I have heard so many stories of traumatic experiences of pain being normalized and dismissed, diagnostic delays, inadequate treatments, and lives derailed by this disease. Though we have made progress in understanding and managing endometriosis, we can do so much better as a nation to improve access to timely and evidenced-based care. EndoAct was created to drive this change through collaboration with all stakeholders toward a national action plan on endometriosis.”

Kate Wahl, EndoAct Canada Executive Director, states “There is a lot we don’t know about endometriosis and its impact on people in Canada. EndoAct is doing research that is led with people who have endometriosis and is focused on patient-identified priorities. The goal of this work is to support evidence-informed, patient-centered policy and practice.”

Denise Campbell, EndoAct Volunteer Member, believes Strong Black Woman stereotypes have significantly impacted her medical treatment. “Sometimes I feel that because I push through my struggles with a lot of positivity and I do my best to present well, my doctor just does not believe me,” she says. “Just because I don’t present my debilitating pain to doctors’ standards doesn’t mean I don’t deserve compassion and understanding. For some reasons, maybe because I’m Black, my doctors just don’t believe that I’m in pain and struggling. We need safe spaces for conversations around race and endometriosis.”

Katie Luciani, Executive Director at [The Endometriosis Network Canada](#) and EndoAct Canada Volunteer Member, states “Living with endometriosis causes immeasurable suffering and pain. One thing I have learned is that our community always rises to the challenge, meeting our pain with strength and perseverance. We will not give up! Endometriosis has stolen numerous hours, days, months and years from those living with the disease - myself included! Now is the time for action from our government! It’s time for Canadians to acknowledge our fight, to join us in our fight, and to take immediate action in how to understand, treat and support those of us living with endometriosis.”

Marie-Josée Thibert, patient, founder of [Endométriose Québec](#) and EndoAct Canada Volunteer Member, states “Endometriosis is so much more than having a painful period. It can have major physical, psychological and emotional consequences on those affected. In addition to significant repercussions on their private, social and professional lives, patients across Canada need access to a multidisciplinary approach that addresses all the angles of the disease.

How can folks support EndoAct Canada?

1. [Write to your Member of Parliament](#) to demand a national action plan for endometriosis
2. If you have a story about how endometriosis has affected your life, share it on [EndoAct Canada's stories page](#)
3. Follow [@endoactcanada](#) on [Facebook](#), [Instagram](#) and [Twitter](#) - Like and share their social media posts
4. Use the hashtag [#EndoActCanada](#)

Social media posts

[Social media images and video Dropbox link](#)

Suggested social media posts

Here are some sample posts that you can use or feel free to write your own:

1. INTRO ENDOACT CANADA

[Suggested image](#)



FACEBOOK

Introducing EndoAct Canada!

- #EndoActCanada goal: To drive policy action on endometriosis in Canada.
- How? By bringing together people living with endometriosis, health care professionals, and researchers, EndoAct Canada represents Pan-Canadian expertise on endometriosis. Together, EndoAct is raising awareness about the problems faced by the endometriosis community and solutions to ensure that everyone in Canada who has this disease gets the right care, in the right place at the right time.
- Wanna help? Head over to www.endoact.ca to take action today by submitting your story on endometriosis, become a member, and/or sign up for their newsletter.

INSTAGRAM

Introducing #EndoActCanada ca

- Their goal : To drive policy action on endometriosis in Canada.
- How? By bringing together people living with endometriosis, health care professionals, and researchers, EndoAct Canada represents Pan-Canadian expertise on endometriosis. By raising awareness about the problems faced by the endometriosis community and solutions EndoAct Canada works to ensure that everyone in Canada who has this disease gets the right care, in the right place at the right time.
- Wanna help? Go to @endoactcanada to take action today by submitting your story on endometriosis and/or sign up for their newsletter.



TWITTER

Introducing @endoactcanada The mission of #EndoActCanada 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.



@endoactcanada / #EndoActCanada

info@endoact.ca

endoact.ca

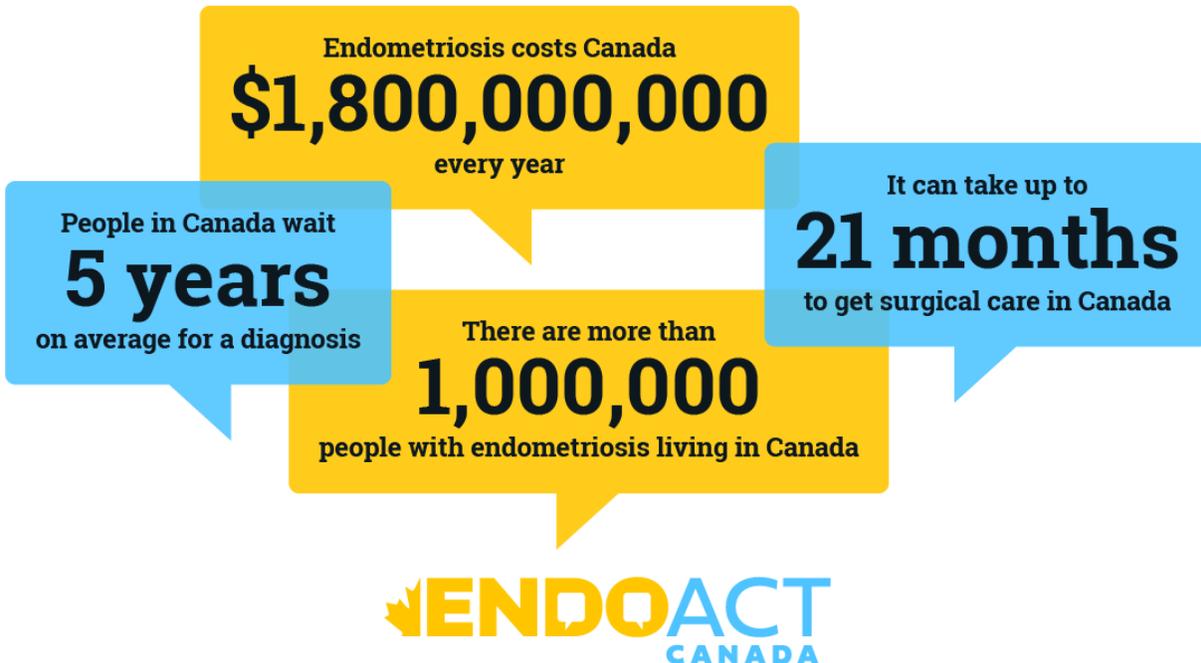
2. STATISTIC POST

[Video Dropbox link](#)

STAT GIF LINKS

[HTML5](#)

[Giphy link](#)



[Twitter Image](#)

INSTAGRAM

Did you know:

- Endometriosis costs Canada \$1,800,000,000 every year?
- There are 1,000,000 people with endometriosis living in Canada?
- Canadians wait for an average of 5 years for an endometriosis diagnosis?
- To get surgical care for endometriosis in Canada can take up to 21 months?

Has endometriosis affected your life? Share your story @EndoActCanada to help other people in Canada, including elected officials and policymakers, understand the impact of endometriosis across the country. Let's roll back these stats together!

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Has endometriosis affected your life? Share your story to help other people in Canada, including elected officials and policymakers, understand the impact of endometriosis across the country. Let's roll back these stats together!

www.endoact.ca/stories/

TWITTER

Choose your stat:

Did you know that #endometriosis costs Canada \$1,800,000,000 every year? Head over to www.endoact.ca or @endoactcanada to learn more about how #EndoActCanada is working to roll this stat back!

Did you know that there are 1,000,000 people with #endometriosis living in Canada? Head over to www.endoact.ca or @endoactcanada to learn more about how #EndoActCanada is working to roll this stat back!

Did you know that Canadians wait for an average of 5 years for an #endometriosis diagnosis? Head over to www.endoact.ca or @endoactcanada to learn more about how #EndoActCanada is working to speed up care!

Waiting up to 21 months for #endometriosis in Canada is too long a wait. Head over to www.endoact.ca or @endoactcanada to learn more about how #EndoActCanada is working to reduce wait times.

Contact Information

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If you have any questions related to social media posts, contact
Sarah Lett
Mass Velocity Media
hello@massvelocity.ca

Partners and members

EndoAct's work is currently being supported by:

- [The Endometriosis Network of Canada](#)
- [Endométriose Québec](#)
- [Canadian Society for the Advancement of Gynecologic Excellence](#)
- [University of British Columbia Office of Community Engagement](#)
- [Mass Velocity Media](#)

[Volunteer Members](#) include both medical professionals and patients across Canada. Follow the link for an up-to-date list of volunteers.

References

Endometriosis & Its Impact

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Endometriosis Policy in Peer Nations

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