

The impact of endometriosis in school, work, and life: A guide for people with endometriosis and those who support them



Overview

This resource is for anyone who knows someone with endometriosis, and would like to learn more about the disease, and how to effectively support them at school, work and in daily life.

What is endometriosis?

Endometriosis is a common disease, but many people do not know much about it. It affects at least 1 in 10 girls, women, and unmeasured numbers of two-spirit, transgender, gender-diverse people. This means that almost 2 million Canadians have endometriosis.



Symptoms of endometriosis often start in the teenage years but can begin at any time.

Common symptoms of endometriosis include:

- Pelvic pain
- Period pain
- Bladder symptoms (pain, urgency, frequency)
- Pain with sex or bowel movements
- Fertility challenges
- Gastrointestinal issues (constipation, diarrhea, bloating)
- Fatigue

Endometriosis is a serious, chronic disease. In people with endometriosis, there are abnormal growths of tissue that is similar to the tissue that lines the uterus. These growths are most commonly found in the pelvis—the area of the body between the hips, from the belly button down to the vagina. However, endometriosis growths can be found anywhere in the body. similar to the tissue that lines the uterus. These growths are most commonly found in the pelvis—the area of the body between the hips, from the belly button down to the vagina. However, endometriosis growths can be found anywhere in the body.

Endometriosis is a chronic illness that has no cure. If endometriosis is not treated, serious complications can happen. Once it is diagnosed, the symptoms can be treated, but many people have ongoing symptoms despite treatment.

How does endometriosis impact people with the disease?

Endometriosis affects every aspect of a person's life. The symptoms can make everyday activities challenging, lead to missed school or work, and impact personal relationships. Research shows that teens with endometriosis are 10 times more likely to miss school than healthy teens. Adults with endometriosis lose an average of 11 hours of work time per week.

People with endometriosis often face a lack of understanding from those around them. It is also very common for them to have their symptoms dismissed by friends, family, and healthcare providers. They may be told that the severe pain they are experiencing is normal or that they are just being dramatic.

Endometriosis can make it harder for some people to get pregnant, adding another layer of stress and concern.

All of these difficulties can impact mental health and emotional well-being. For example, symptoms of depression or anxiety are common in people with endometriosis.

Challenges with endometriosis diagnosis and treatment

There is a long delay to diagnosis for endometriosis in Canada, and everywhere else in the world too. People with endometriosis in Canada wait an average of 5 years to be diagnosed, and sometimes much longer. This is partly because of low awareness of the disease. Research shows that many family doctors don't know the main symptoms of endometriosis. People in Canada have to go to an average of 3 doctors before getting a diagnosis.

Endometriosis is usually managed with a combination of surgery, medication, and other supportive care. Wait times in Canada for specialized surgical care for endometriosis can be up to two years or more. Some areas of Canada, like rural, remote, and Northern communities have no access to specialized surgical care without travelling. Other areas of Canada, like the Atlantic provinces and the Prairie provinces, have few expert endometriosis surgeons. There are also long wait times for specialized chronic pain care.



Research shows that even when people get expert medical care for endometriosis, more than half of people still have symptoms that impact their daily lives.

How to support someone with endometriosis

To be a good support for someone with endometriosis, start by learning about the disease and how it impacts people's lives.

Show kindness and understanding when they talk about what they're facing. Each person with endometriosis has their own health story, so avoid comparing one person's experience to another's.

Intersectionality—various aspects of a person's identity—can deeply impact someone with endometriosis. For instance, a person's race, socioeconomic status, gender, sexuality, or cultural background may create barriers to accessing healthcare. Understanding that these differences impact people's experiences is important for supporting people with endometriosis.

It's important to recognize your own needs for self-care while providing support to someone with endometriosis. It's ok to set your own boundaries about how and when you can support someone. It's best to communicate your boundaries clearly but kindly.



A key way to help is by understanding and acknowledging their experiences. Remember, even if you can't see their pain and symptoms, they are real.

School or work accommodations for endometriosis

The first step in accommodating people with endometriosis is to understand that endometriosis is a serious disease that can cause unpredictable pain and other symptoms. This can sometimes make keeping up with school or work responsibilities challenging. Having appropriate accommodations in place will support people with endometriosis to succeed in school or work.



Some possible accommodations and actions that might be helpful include:

- **Educating people in the school or workplace about endometriosis**
- **Having flexible schedules and deadlines**
- **Supporting working from home**
- **Allowing breaks when needed**
- **Providing comfortable seating**
- **Making sure there are accessible restroom facilities**

It's a good idea to have a conversation with each person who needs accommodations and listen to what they feel could be helpful. Everyone's experience with endometriosis is different, and what helps one person might not help another. By paying attention to each person's specific needs, schools and workplaces can give the right kind of help that fits each person.

Resources in this series

[Surgery: A guide for people with endometriosis](#)

[Menopause: A guide for people with endometriosis](#)

[Mental health, well-being, and quality of life: A guide for people with endometriosis and those who support them](#)

[Extrapelvic endometriosis: A guide for people with endometriosis](#)

[Complementary and alternative medicine: A guide for people with endometriosis](#)

[Pelvic health physiotherapy: A guide for people with endometriosis](#)

EndometriosisNetwork.com

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