

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



Overview

Endometriosis affects every aspect of your life. It can interfere with going to school or work, cause difficulties with relationships, negatively impact body image and self-esteem, and limit your ability to carry out daily activities. With this impact on quality of life, your mental health may also suffer.

People with endometriosis often have difficult health journeys. In Canada, it can take at least 5 years to get a diagnosis. Many people find their pain is dismissed by friends, family, and healthcare providers. People with endometriosis may experience social isolation and a lack of support from those around them.

People with endometriosis can seek counselling and support to help deal with mental health and well-being issues. Research shows that people with endometriosis may deal with the following issues:

Depression

Up to 8 in 10 people with endometriosis experience symptoms of depression. If you have depression, you may feel sad and hopeless, have trouble concentrating, lose interest in things that normally make you happy, have trouble sleeping, and feel tired. There are many other difficult things about coping with endometriosis that can lead you to feel depressed.

Anxiety

Up to 8 in 10 people with endometriosis experience symptoms of anxiety. Almost everyone will feel anxious at some point in their life but it can reach a level where being nervous, afraid, or worried disrupts your life. When you have endometriosis, you may feel anxious about your health and how to cope with symptoms like chronic pain.

Loss and grief

Physical pain and chronic illness can lead to a loss of job opportunities, relationships, social activities, and more. When you have endometriosis, you may feel like you've lost the life you hoped to have. If you are having trouble getting pregnant, you may also experience loss and grief because you may not have the family you want.

Challenges with work and school

When you have endometriosis, you may miss school or work because of your symptoms. This makes it hard to keep up with work and school responsibilities.

Problems with relationships and communication

Endometriosis can cause pain and fatigue that can make it hard to do everyday activities and be close to your partner. It can be challenging as a couple when endometriosis causes pain with sexual activity. You might find it hard to talk about your needs or explain how endometriosis affects you. Your partner might find it difficult to understand what you are going through.

Decreased self-esteem and confidence

Living with ongoing pain and other symptoms can make you feel frustrated, helpless, and like you can't do as much as you want to. This can make you feel bad about yourself and not as confident.

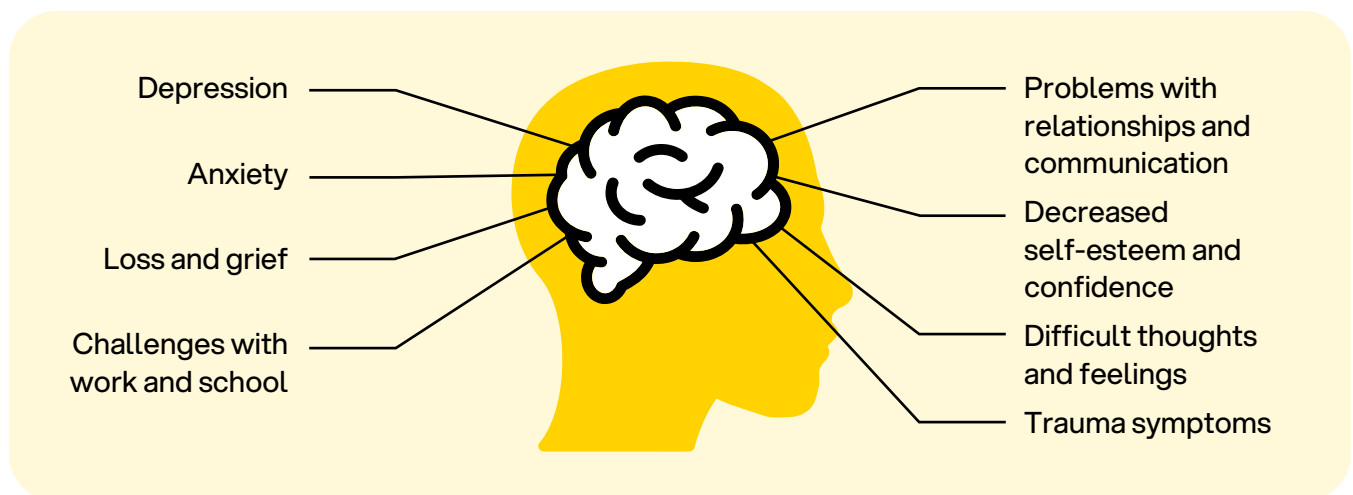
Difficult thoughts and feelings

People with endometriosis might feel frustrated, worried, or sad because of the pain and disruptions to their lives. They may also feel guilty, like they are letting people down or not meeting their expectations.

Trauma symptoms

Trauma symptoms are strong and lasting emotional reactions after something happens to threaten your safety. Many people have experienced trauma. Some people may even experience trauma associated with their endometriosis journey. Trauma can make chronic pain worse. Trauma symptoms include re-experiencing the trauma in the form of nightmares or flashbacks and avoiding places/reminders of the trauma. You may also have negative thoughts and moods like fear, distrust, and self-blame, or feel on edge (feeling on guard or startled easily).

People who have more severe pain because of endometriosis are at higher risk for depression and anxiety than those with less pain. This suggests that getting early, effective treatment for your endometriosis, chronic pelvic pain, and all the impacts of endometriosis on your quality of life could help prevent mental health conditions.



If you have endometriosis and are struggling with your mental health, you are not alone.

If you can't talk about the difficulties of living with endometriosis with people in your life who understand, it can affect your mental health. There are actions you can take to support yourself. Friends and family may be able to offer support. There are endometriosis support groups where you can connect with other people living with endometriosis. And talking to a therapist can help.

Taking care of your mental health

Self-care

Taking care of yourself is important for your mental health when you have endometriosis. Self-care looks different for everyone. Some self-care suggestions like regular exercise and getting enough sleep can be hard for people with endometriosis, but possible. A good place to start is with what feels right to you, and what you can manage. It's all about finding what works best to support your well-being. Self-care is not a replacement for medical treatment or professional mental health help.

Getting support from family and friends

Reaching out for help with your mental health takes courage. You may worry about what people will think of you if you tell them you are struggling with your mental health. If you find it hard to talk about mental health with some friends and family, you can think about who might be a safe support person for you. A safe person is someone that listens kindly to your concerns and supports you in ways you find helpful.

Support groups

Endometriosis support groups provide a chance to meet other people who also have endometriosis. This may help you feel less alone and isolated. Some support groups are moderated by professional facilitators or counsellors, and others are moderated by other people with endometriosis.

If you want to learn more about the support groups offered by The Endometriosis Network Canada, [visit our website](#).

Mental health treatment

If you would like professional help for your mental health, you can make an appointment to talk to a mental health professional who offers counseling or therapy. Therapy is a form of mental health treatment where you have conversations with a trained therapist. Therapy can help you by:

- Teaching you ways to cope with what you are going through.
- Working with you to change behaviours that are not helpful for your situation.
- Providing an opportunity to talk about your feelings.

Research shows that people with endometriosis who go to therapy improve their mental health. They also have better quality of life and better emotional well-being.



Self-care practices to support mental well-being

- Get regular exercise. Even a small amount of exercise can be helpful, like a walk around the block or some gentle yoga.
- Spend time outside in nature.
- Eat regular, healthy meals.
- Get enough sleep.
- Try a relaxing activity, like meditation, muscle relaxation, or journaling.
- Stay connected with family and friends who are supportive and understanding of your needs.

Some ways you can start a conversation about mental health and well-being

If you are struggling with your mental health, you can start a conversation with your friends and family by saying:

- "I've been feeling _____ (overwhelmed, sad, anxious, scared) lately. I thought it might help to talk about it. Would you be open to listening?"
- "I've been struggling with _____ (specific issue). Can I talk to you about it?"
- If you know someone with endometriosis and you think they might be struggling, you can say:
 - "I have noticed that you seem to be feeling _____ (overwhelmed, sad, anxious, scared). Is everything okay?"
 - "I wanted to check in and see how you were doing. Is there anything you'd like to talk about?"

Finding a therapist

There are different types of mental health professionals who offer therapy. These include:

Clinical psychologists

These are mental health professionals who are trained to diagnose and treat mental health conditions using various therapy approaches. They have high-level university degrees in psychology and must be registered with regulatory colleges in each province to practice as psychologists.

Counsellors

Counsellors are mental health professionals with university degrees in providing counselling and talk therapy. They are usually registered with a professional association like the Canadian Counselling and Psychotherapy Association (CCPA).

Social workers

Social workers are also mental health professionals who help people with social concerns like financial and housing problems, and they may provide counselling and talk therapy. Social workers must have a license to practice in the province they work in.



Reach out to a healthcare professional if you are experiencing any of these concerns:

- Trouble sleeping or eating.
- Trouble getting out of bed in the morning.
- Trouble concentrating.
- Loss of interest in things you usually enjoy.
- Inability to manage your usual responsibilities.
- Thoughts of suicide.
- Self-harm behaviours.



Psychiatrists

Psychiatrists are medical doctors who can diagnose mental health conditions and prescribe medicines to treat them. Some psychiatrists may also offer talk therapy.

Different types of therapy have been studied in people with endometriosis

Cognitive behavioural therapy (CBT)

CBT teaches practical skills and strategies to help you change thoughts and behaviours. This can help you cope with hard situations.

Acceptance and commitment therapy (ACT)

ACT helps you accept that you can't control certain things and teaches you how to do things that match what you think is important.

Mindfulness-based stress reduction (MBSR) and other mindfulness-based therapies

Teaches you how to focus in the present moment, and calm your mind and body.

No one therapy works better than another for people with endometriosis. Most important is to find a therapist with whom you feel comfortable and can talk openly.

Here are some points to consider when you are looking for a therapist:

- What kind of therapist would help you feel comfortable (think about their gender, cultural background)?
- Do you want a therapist who has experience working with people with endometriosis, chronic illness, or pain before?
- Do you want someone who uses a certain type of therapy?
- If you have private health insurance, does your therapist have the credentials or training to be covered by your insurance plan?

Many therapists offer a free introductory session to talk about your goals for therapy and how they approach therapy. This can be an opportunity to ask questions and see whether they are a good fit.

You may ask your family doctor if there is any mental health treatment provided through provincial or territorial health care that would be at no cost to you. If you have private health insurance or an employee assistance plan through your employer, some sessions of therapy may be covered. Some therapists have flexible fees (called a "sliding scale") based on your income if you need financial help.



What to do in a crisis

If you are having thoughts of self-harm or suicide, please reach out for help immediately. There are confidential, free services that are available 24 hours a day to help you.

Dial 988 for immediate assistance.

Other crisis phone services include:

- Talk Suicide Canada: 1-833-456-4566
- 1-866-APPELLE (for Quebec residents): 1-866-277-3553
- Hope for Wellness Helpline (for Indigenous people across Canada): 1-855-242-3310

A complete list of crisis resources available in different regions of Canada is available on [this website](#).

Finding happiness while living with endometriosis

Coping with chronic health problems like endometriosis can be very hard. Many people feel upset while dealing with endometriosis. Remember, you are not alone in this. It isn't easy, but there are ways to improve your mental well-being, like self-care, getting support from family and friends, endometriosis support groups, and therapy with a mental health professional. These can help make your life happier and more enjoyable.

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Canadian education and resource websites for depression, anxiety, and pain

[The Centre for Addiction and Mental Health | CAMH](#)

[Home — Anxiety Canada](#)

[Power Over Pain Portal — Power Over Pain](#)

Resources in this series

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

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

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