

HOW TO ADVOCATE FOR YOURSELF IN THE MEDICAL SYSTEM WHEN YOU HAVE ENDOMETRIOSIS

CanSage, 2025



Endometriosis is a complex condition that can cause pain, fatigue, and fertility challenges. In Canada, long wait times can make it difficult to get the care you need. Knowing how to advocate for yourself can help you get the right support.

PREPARING FOR APPOINTMENTS

Bringing a few key items can help you feel prepared:

- An overview of your medical history
- Copies of reports from tests or surgeries
- A list of all current medications (including supplements)
- A diary of any symptoms, like pain, bleeding, or cramping
- A list of your top questions or concerns
- A support person who can take notes or advocate for you

REFERRALS & SECOND OPINIONS

In Canada, you have the right to request a second opinion or referral to a specialist at any time.

Questions To Ask:

- "I'd like a second opinion to feel more confident about my next steps. Can you put in a referral?"
- "I'd like to talk to an endometriosis specialist. Is there someone available you can refer me to?"

CLARIFYING GOALS OF TREATMENT

It helps to have a clear idea of what matters to you and what you want to tackle first.

Questions To Ask:

- "I'm not sure what my options are yet, but I'd like to understand what comes next."
- "[Symptom] is my biggest issue right now. What can we do about that first?"
- "What should I expect from the treatment process now and in the future?"

DISCUSSING SURGERY WITH YOUR DOCTOR

Surgery isn't usually the first line of treatment for endometriosis, but it can be an effective solution for some patients and exploring it doesn't mean you have to have a procedure.

Questions To Ask:

- "Is this surgery the best option for treating my endometriosis?"
- "What is the name of the surgery you're recommending, and how does it work?"
- "What are the risks of having surgery for endometriosis?"

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MEDICATIONS & PAIN MANAGEMENT

Some people manage endometriosis with pelvic floor therapy, over-the-counter pain medication, heat or TENS therapy, nerve blocks, or medication.

Questions to Ask:

- "What medications are available to help manage endometriosis pain or control my cycle?"
- "What side effects should I expect in the short term, and what are the long-term risks?"
- "Will this medication affect my fertility now or later?"

LIFESTYLE & COMPLEMENTARY THERAPIES

Lifestyle changes like gentle movement, sleep support, nutrition, and stress management can help reduce flare-ups. Some people also explore acupuncture, massage, mindfulness, or supplements.

Questions to Ask Your Provider:

- "Is there any evidence that [alternative therapy] helps relieve endometriosis pain?"
- "I heard about/read about [option] on social media/in the news. Does it actually work?"
- "Is it safe to combine [herbal therapy or supplement] with my current medication regimen?"

STRATEGIES FOR EFFECTIVE COMMUNICATION

Using clear, collaborative language can help you and your provider work toward effective care together.

- **Be Specific:** "The pain in my lower abdomen makes it hard to stand for more than 10 minutes."
- **Ask Clarifying Questions:** "Can you help me understand why this test isn't recommended?"
- **Bring a Support Person:** "This is my support person. They're helping me take notes today."
- **Ask For It In Writing:** "Can I get a written summary or visit notes to review later?"
- **Use Patient Portals:** "I sent my questions ahead through the patient portal."

WHERE TO FIND ADVOCACY AND SUPPORT

- **Endometriosis Network Canada:** Peer support and resources.
- **CanSAGE:** Patient tools and surgeon directory.
- **ESHRE:** International guidelines for patients.

WORKING WITH YOUR PROVIDER TO ACHIEVE MEANINGFUL CARE

Self-advocacy means preparing thoughtfully, asking questions, and exploring your options. By documenting your symptoms, clarifying your goals, and knowing when to request referrals or second opinions, you can take an active role in your care.