

How to Be Your Own Advocate for Endometriosis Diagnosis and Treatment

If you suspect you have endometriosis, self-advocacy isn't just helpful—it's necessary. Understanding your symptoms, knowing what tests and treatments to ask for, and standing firm when doctors dismiss your concerns can make all the difference in getting the care you need.



4 TO 11 YEARS: AVERAGE TIME BETWEEN SYMPTOM ONSET AND ENDO DIAGNOSIS¹

6 Key Strategies to Advocate for Yourself



Keep track of your symptoms

Since mild to moderate endometriosis can only be definitively diagnosed through surgery, symptoms serve as a crucial guide for doctors. Keeping a detailed record of what you feel, when, and where can speed up diagnosis and treatment. Surgeons even reference these symptom patterns during surgery to locate potential lesions.

Print out the symptom log on page 3 or use a Google Doc or an app on your phone to record:

- ✓ **Pain levels** (1-10 scale) and where you feel it (pelvis, back, bowels, etc.).
- ✓ **When symptoms** occur (before/during periods, after eating, during sex, etc.).
- ✓ **Other issues** (digestive problems, fatigue, infertility, urinary issues).
- ✓ **Treatments tried** (pain meds, birth control, diet changes) and their effects.
- ✓ **Missed work/school days** due to pain.



Prepare for doctor's appointments

Unfortunately, doctors often overlook endo symptoms. Even if you have every textbook symptom, many doctors won't mention the condition unprompted.

Print out page 4 of this guide and bring it to your next appointment.

Pro tip: If dismissed, ask the doctor to document in your chart that they refused to investigate endometriosis. This may make them take you more seriously.

It's vital to go in prepared with the following:

- ✓ A detailed written list of your symptoms and how they impact your life.
- ✓ Specific questions about endometriosis to ask.
- ✓ A list of dismissive comments to watch out for.
- ✓ A supportive person (friend, partner, parent) to back you up and take notes.
- ✓ Printed medical studies or guidelines to reference if the doctor downplays your concerns.

¹Agarwal, S. et al. (2018). Clinical diagnosis of endometriosis: a call to action. American Journal of Obstetrics and Gynecology. 220(4), 354.e1-354.e12.





Know what tests & treatments are (and aren't) effective.

- ✓ **Gold standard for diagnosis** = Minimally invasive laparoscopic surgery (not just an ultrasound or MRI).
- ✓ **Best treatment** = Excision surgery (not ablation, which burns but doesn't fully remove lesions).
- ✓ **Hormonal birth control** can help manage symptoms but doesn't remove or cure endometriosis.
- ✓ **Pelvic floor therapy** may help with secondary pain caused by muscle tension.
- ✓ **Diet changes** can help reduce inflammation but won't cure the disease.



Visit a specialist.

The truth is that few gynecologists are properly trained in diagnosing and treating endometriosis. You can go through countless appointments, treatments, even surgeries, and still never hear the word "endometriosis" unless you're in front of the right person.

Excision specialists can see signs that other doctors might miss. To evaluate a doctor's knowledge about endo:

- Ask about their surgical approach (excision vs. ablation).
- Request a consultation and ask lots of questions.
- Check patient reviews and case studies.



Find support.

A support group can encourage you when you feel defeated, provide ideas for ways to talk to your doctor, and help you feel less alone. That said, be sure to back up any insight you gain from peers with research and information from verified scientific or medical sources.



Trust your body and don't give up.

The most important thing to remember is that you know your body better than anyone else. While doctors generally have good intentions, they are still human. The lack of validation from doctor after doctor can be exhausting and demoralizing, but it's vital to continue fighting for yourself. You deserve to feel better.

Resources for Further Reading

- ESSE Care - <https://esse.care/>
- The Endometriosis Association - <https://endometriosisassn.org/>
- The American College of Obstetricians and Gynecologists - <https://www.acog.org/>
- The Endometriosis Research Center - <https://www.endocenter.org/>
- Endometriosis.org
- *Beating Endo: How to Reclaim Your Life from Endometriosis* by Iris Kerin Orbuch, MD and Amy Stein, DPT
- *It's Not Hysteria: Everything You Need to Know About Your Reproductive Health (but Were Never Told)* by Dr. Karen Tang
- *Endometriosis: A Key to Healing and Fertility Through Nutrition* by Dian Shepperson Mills, MA and Michael Vernon, Ph DCLD



Patient Symptom Log

Name: Age:

Date	Symptom	Location	Severity (1-10)	Notes

Additional notes:

Your Next Doctor's Appointment

Goal of appointment: _____

Questions to Ask:

1. Could my symptoms be caused by endometriosis?
2. What experience do you have diagnosing and treating endometriosis?
3. Do you use laparoscopic surgery for diagnosis? Excision surgery for treatment?
4. If I need surgery, will you remove the lesions completely or just burn them (ablation)?
5. Can you refer me to an endometriosis specialist?
6. What tests can we do to rule out other conditions with similar symptoms?
7. Other:
8. Other:
9. Other:
10. Other: