

Consider Endometriosis

Think you may have endometriosis? It is important that you not feel embarrassed or afraid to let your school nurse, OB-GYN, your guardian, or another trusted adult know what you are feeling. Having these discussions doesn't have to be scary or overwhelming!

Early detection and treatment are crucial and can prevent years of unnecessary pain, suffering, and potential infertility. Although pelvic surgery is the only way to confirm a true diagnosis, certain symptoms can lead health care providers to suspect endometriosis. **Use this tool to record and share symptoms with your doctor.**

1. Do you experience pain in your pelvic region (the lower part of your belly) during your period, which is unresolved with over-the-counter medications such as ibuprofen (Advil, Motrin, etc.)?

- Yes
- No

2. Is it difficult to participate in everyday activities such as sports or social time with friends because of excessive pain, exhaustion, or weakness?

- Yes
- No

3. Have you ever been diagnosed with ovarian cysts?

- Yes
- No

4. Has a close, female relative ever been diagnosed with endometriosis? (Mother, grandmother, sister, or aunt, for example).

- Yes
- No – If no, have any female relatives ever experienced the symptoms mentioned in this survey?
- Unknown

Please check any or all symptoms you experience monthly during your period (check all that apply):

- Cramping – Very painful, unresolved with rest or over the counter pain relievers. This pain may make you curl your body up into a ball or double over.
- Digestive Problems / Gas
- Nausea / Vomiting
- Diarrhea / Constipation
- Excessive bloating (water retention)
- Very heavy bleeding and/or clotting
- Irregular periods
- Bleeding between periods
- Painful bowel movements
- Severe migraine headaches
- Sudden mood swings / Uncontrollable crying
- Lower back pain and/or leg pain
- If you are sexually active – Painful sex



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Endometriosis Treatment: Finding a Doctor That's Right For You

If you think you may have endometriosis, finding an endometriosis specialist is crucial to getting proper treatment for the disease. Finding the right doctor can be tricky, but arming yourself with research and good information can help simplify the process. Begin by reviewing your symptoms with your family doctor, or another trusted medical professional, so they can assist you with recommendations, referrals, and follow up care.

The proper specialist is one who has thorough knowledge of endometriosis, including: *exceptional* surgical skills and training, access to the most modern surgical equipment and techniques, current understanding of various treatments, and openness to complementary approaches. They should listen to you patiently and have compassion for what you are going through.

Preparing Yourself For An Appointment

- Before seeing a specialist, it is important to gather as much information and medical history as possible.
- If you have medical records from previous physicians throughout your treatment, bring them to the appointment.
- **Also bring the "Consider Endometriosis" survey and the "Personal Pain Profile" to your appointment.** These worksheets will help you speak with your doctor about the symptoms you're experiencing.
- Think about other ways to describe your symptoms, concerns, and fears – be specific. How much pain do you have on an average day, and how often? Is there a time of day that the pain is worse? Does the pain come and go? What helps alleviate the pain? How upsetting and disrupting is the pain to you? Do specific activities trigger your pain? Does pain interfere with your daily activities or personal routine?
- Don't be afraid to ask questions!

What To Consider When Seeking A Specialist

- Does the doctor specialize in the treatment of endometriosis / adolescent endometriosis?
- What percentage of their patients are young women and girls?
- Does the doctor have experience with related conditions?
- What is the doctor's attitude about your role in your health care? Is he or she willing to receive input from you?
- Do they allow ample time for thorough conversation and examination, or do they rush?
- Are they able to explain surgical procedures and treatment options clearly and in terms you can understand?
- What is the doctor's belief on different hormone therapies (oral contraceptives, IUD, etc.)? Can they discuss their reasons for prescribing certain medications, as well as the associated pros & cons?
- What does your intuition say? Are you comfortable speaking with them? Do they listen to, acknowledge, and address your concerns? *This must be someone you can trust and talk to openly!*
- Does the doctor work cooperatively with other specialists who have a history of caring for endometriosis patients (ex. GI doctors, pediatric gynecologists, psychotherapists, etc.)?

What To Consider When Discussing Treatment Options

- Always ask about all available treatment / management options – surgical and medical - and choose the approach you feel most comfortable with and is best suited to your lifestyle.
- When discussing medications, ask the doctor to explain exactly what they are for. For instance, is it for pain relief, or for hormonal suppression? Also ask about risks, side effects, and drug interactions. Be certain to understand the duration of intended treatment and schedule follow up appointments to monitor results.

What To Consider When Discussing Surgical Treatment

- How does the doctor plan to use surgery to treat endometriosis? Do they specialize in laparoscopy? Does the surgeon plan to use laser (burn), or surgically excise (cut out) endometriosis tissue?
- Will your surgery be documented with images?
- How clearly are they able explain the procedure? What exactly will be done during the surgery? For example, will endometriosis be removed? Or, will it be an exploratory (look-only) surgery – if so, why?
- Is the doctor affiliated with a hospital that regularly treats endometriosis? Do they have a "team" of surgeons established to address different elements of surgical treatment? Will your doctor have other surgeons (general, colorectal, etc.) in the operating room with them?
- What can be expected after the surgery? How much pain can you expect post-operatively? How can you lessen the pain? What are post-op restrictions for going back to school, activities and your normal routine? Learn how you can help to prepare yourself and your body for the surgery.
- Be sure to ask your doctor's office for a pre-op and post-op routine to assist in your healing process.

Never rule out a second opinion...or a third!