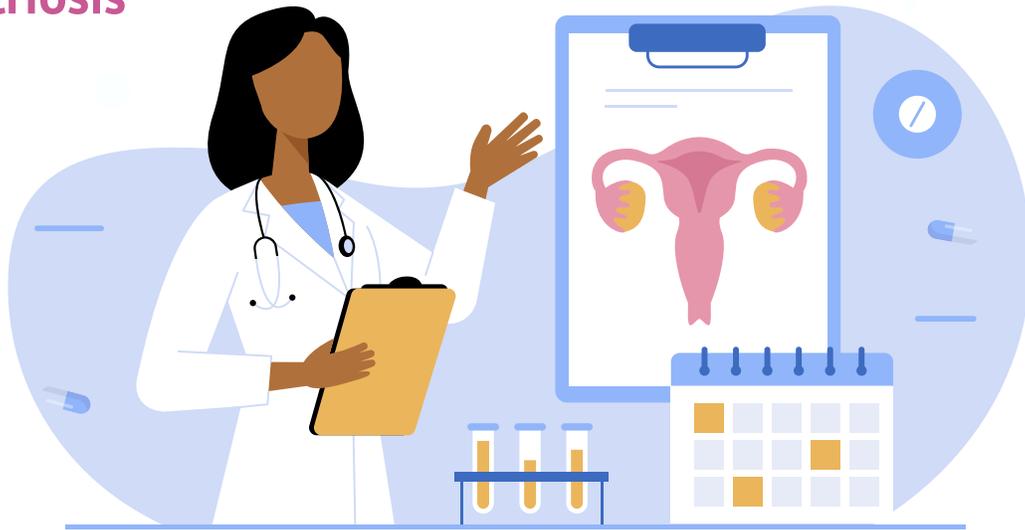


Diagnosing Endometriosis



Patients with **endometriosis** often face challenges on the path to diagnosis. Preparing in advance for your health care appointments and advocating for your own health may help you overcome potential hurdles.



3 OUT OF 4 PEOPLE
experience a misdiagnosis



3+ PHYSICIANS VISITED
before endometriosis diagnosis



6.7 YEARS
average delay in diagnosis

Because of the **stigma** around menstruation, some women find it difficult or embarrassing to initiate conversations with their health care provider about period-related symptoms like pelvic pain and heavy bleeding. It is often only when the pain becomes severe or when infertility occurs that women consult their providers about a diagnosis and treatment. **Open communication with your health care provider is the best way to ensure you get a timely diagnosis.**

How Is Endometriosis Diagnosed?

Your health care provider will ask for you to describe your symptoms and may perform a **pelvic exam** and/or an imaging test, such as an **ultrasound** or **MRI**, to look for endometrial **lesions**. However, these methods are unlikely to find lesions unless they have developed into large cysts.

Traditionally, the primary method to diagnose endometriosis is through **laparoscopy**, a surgical procedure that allows the surgeon to view the organs inside your abdomen and collect tissue samples for pathological evaluation. However, most experts agree that a definitive diagnosis through laparoscopy is not necessary to treat presumed endometriosis with medical management.

Surgical Stages of Endometriosis

The American Society of Reproductive Medicine classifies endometriosis into the following disease stages, based on the number, depth, and size of the **implants**.

It is important to note that the disease stage does not necessarily reflect the severity of a person's symptoms or the impact on their quality of life. For example, a person with stage 4 endometriosis may experience fewer life-disrupting symptoms than a person with stage 1.

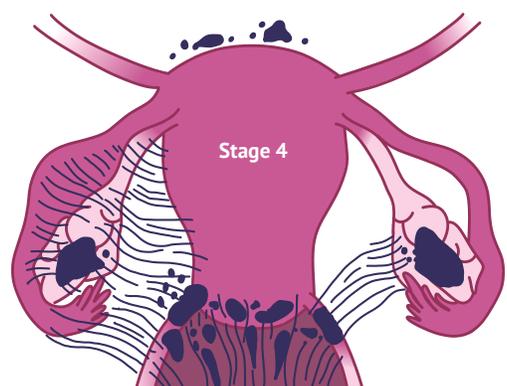
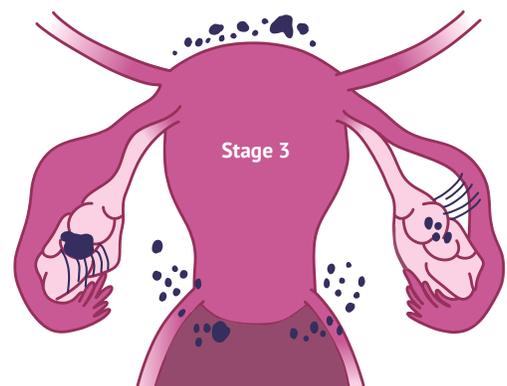
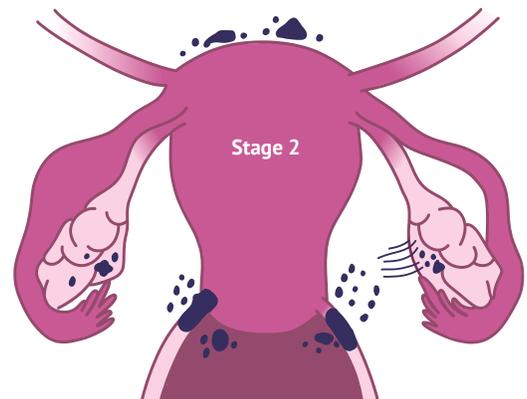
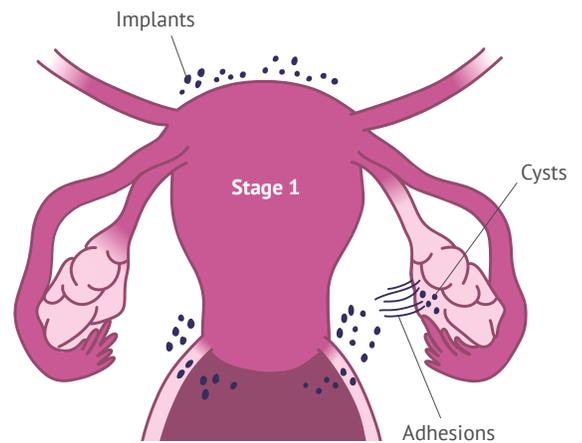
Each stage can present itself in so many variations that additional classification systems for endometriosis have been developed to describe lesion location, fertility index, and pain.



What Is Adenomyosis?

Lesions can also occur in the muscle of the uterus (the myometrium), causing a related condition called **adenomyosis**, with some symptoms similar to endometriosis. Adenomyosis is not as well understood, but has been shown to also be present in up to 42% of women with endometriosis.

Ask your doctor about evaluating your symptoms for the presence of adenomyosis too.



Talking With Your Health Care Provider

Endometriosis and its symptoms can manifest differently for each individual. Make sure to communicate to your health care provider which aspects of your disease are most burdensome to you.

Be graphic and descriptive about the frequency and severity of your pain. Give examples of activities that your pain prohibits you from doing and remedies you have tried to manage your symptoms. If you are uncomfortable verbalizing your experience, try to write it down in advance and share it with your provider.

How to Prepare for Your Doctor Visit

To help your provider better understand your experience, consider bringing the following information to your appointment:



A record of your menstrual cycle and related symptoms (such as in a journal or an app)



Your history of symptoms and, if applicable, past diagnoses or misdiagnoses



A record of past gynecological surgeries, tests, and treatments



A list of your current medications



Family history of endometriosis or undiagnosed symptoms



A support person (such as a spouse, family member, or friend) who can help you take notes and advocate for you



Names and contact info for other health care professionals who provide you with care

Questions to Ask Your Health Care Provider



Researching and compiling a list of questions to ask your health care provider may help you to feel more prepared to engage in discussion around your diagnosis and treatment.

Questions may vary depending on whether you are being evaluated for the first time or receiving ongoing treatment, as well as whether you are seeing your primary care physician, gynecologist, or other specialist.

- How can I know if what I am experiencing is endometriosis?
- What else could it be? What other conditions cause similar symptoms?
- Do I need to have a **laparoscopy** to fully diagnose what is going on with my body, or is there strong enough evidence based on my history and symptoms to start treatment?
- Would additional testing, like an **ultrasound** or **MRI**, be helpful in my case?
- Could any of my current medications make my endometriosis worse? (Have a list of medications and doses prepared to share with your provider.)
- What treatment options are available to me, and what are the risks and benefits of each of these treatments?
- Which treatment option or plan do you recommend that I try first? Why?
- What alternative treatments (e.g., acupuncture, yoga) might be worth trying?
- Are there any helpful strategies or practices I can do at home to assist with managing my symptoms?
- Would physical therapy for my **pelvic floor** potentially benefit me?
- What kind of surgical options are available? Can you recommend a skilled surgeon trained in minimally invasive procedures?
- Can you provide me with additional resources to learn more about endometriosis and similar diseases?
- Could you recommend resources to help me educate my family, friends, and employer about endometriosis?

You can help foster clear communication with your doctor by asking direct and specific questions. Don't be afraid to restate what your doctor has told you or to ask clarifying questions to ensure that you understand the answers.