

FROM SYMPTOMS TO DIAGNOSIS: UNDERSTANDING ENDOMETRIOSIS

This guide explains how doctors diagnose endometriosis and helps you understand what to expect during your appointments.

What is Endometriosis?

Endometriosis is a long-term condition where tissue similar to the lining of the womb grows in other parts of the body.

This tissue lines the inside of your uterus. But with endometriosis, it grows on the outside, usually on your ovaries, fallopian tubes, or the lining of your pelvis. It acts just like the lining of your womb: it thickens and bleeds every month. Because this blood has nowhere to go, it causes swelling, inflammation, and scar tissue.

Where Endometriosis Grows

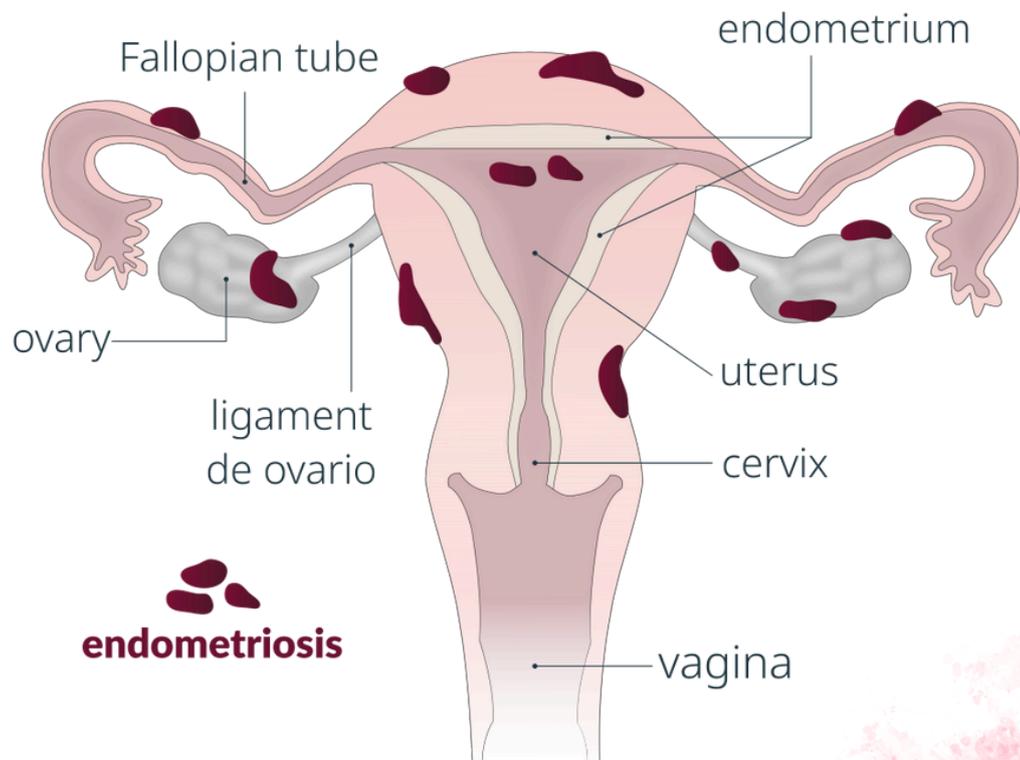


Figure 1. Diagram showing common sites of endometriosis tissue. Adapted from Vega asensio via Wikimedia Commons, CC BY-SA 4.0

<https://commons.wikimedia.org/wiki/File:Endometriosis.svg>

Recognising the Signs

Everyone experiences symptoms differently. Some might feel quite a bit of pain, while others might not notice any.

Common Symptoms

- **Painful Periods:** Severe cramps that prevent you from going to work, school, or completing daily tasks.
- **Chronic Pelvic Pain:** pain in your lower tummy that occurs even when you're not on your period.
- **Pain During Sex:** Pain deep inside during or after sex.
- **Fertility Issues:** Trouble getting pregnant is common. About half of the people struggling to conceive find out they have endometriosis.

Other Signs to Watch For

- **Bathroom Pain:** Pain during bowel movement or urination, especially during your period.
- **Bloating:** Your lower belly may swell up significantly during your cycle (often called "Endo Belly").
- **Rare Signs:** In rare cases, you might feel chest pain or cough up blood during your period.

Important: The amount of pain you feel does not equal the amount of disease you have. You can have a "mild" case and feel terrible pain.

Why does diagnosis take so long?

On average, it takes 7 to 12 years to receive a diagnosis. This delay often occurs because:

- **Pain is dismissed:** Severe period pain is often brushed off as "normal" or "part of being a woman."
- **Confusing Symptoms:** fatigue and stomach pain are often mistaken for IBS (Irritable Bowel Syndrome) or stress.
- **Surgery is required:** The only way to be 100% sure you have it is through surgery, so doctors often wait a long time before suggesting it.

Scans and Tests: What to Expect

Your doctor will likely order tests to check your pelvic area. It is vital to remember that a "normal" test result does not mean you are healthy.

1. **Ultrasound:** A doctor uses a small wand to look at your ovaries and uterus.
 - What it sees: It is good at finding large cysts (called "chocolate cysts").
 - What it misses: It often fails to detect small, flat patches of endometriosis.
2. **MRI Scan** This uses magnets to produce a detailed image of your insides. It is mainly used to plan surgery if doctors suspect deep disease in your bowel or bladder.
3. **Blood Tests:** No blood test can diagnose endometriosis yet. A test called CA-125 is sometimes used, but it is not reliable for diagnosis. It is used to track changes after you have already been diagnosed.

The "Iceberg" Problem

Think of endometriosis as an iceberg. Scans can easily spot the large chunks above water (cysts), but they often overlook the flat, shallow areas hidden below.

- **Fact:** About 80% of endometriosis is "superficial" (small and flat). This means most people with endometriosis will have a normal ultrasound.

The Only Way to Know for Sure: Laparoscopy

Since scans often miss many issues, a laparoscopy (keyhole surgery) is the only definitive way to diagnose the condition.

How it works:

1. **The Incision:** You are put to sleep, and a surgeon makes tiny cuts near your belly button.
2. **The Camera:** They insert a thin camera (laparoscope) to examine your organs directly.
3. **The Biopsy:** If they suspect endometriosis, they remove a small sample for lab testing. This confirms the diagnosis.

What Happens After Diagnosis?

If the surgery confirms endometriosis, your doctor will give it a "Stage."

- **Stage 1 (Minimal):** A few small superficial implants.
- **Stage 4 (Severe):** Many deep implants and scar tissue, possibly sticking organs together.

Remember: Stage 4 isn't necessarily more painful than Stage 1. The stage indicates where the disease is so that the doctor can plan your treatment.

Checklist: When to see a specialist

If you answer "Yes" to any of these questions, see your regular doctor for a referral to a gynaecologist or an endometriosis specialist.

- Is your period pain stopping you from work, school, or social activities?
- Do you experience pain during sex?
- Have simple treatments (like painkillers or the birth control pill) failed to help?
- Did an ultrasound show a cyst on your ovary?
- Are you struggling to get pregnant?

Next Step: diagnosis is just the beginning. Once you know what is happening in your body, you and your doctor can build a plan to manage pain and improve your quality of life.

Further Reading & Patient Resources

- [World Health Organisation \(WHO\)](#): A global overview of symptoms, diagnosis, and the physical and emotional impact of endometriosis.
- [Healthdirect Australia](#): A plain-language guide to understanding your treatment options and when to see a doctor.
- [Mayo Clinic](#): Detailed information on the different stages of endometriosis and standard surgical procedures.
- [Endometriosis Australia](#): Practical advice for daily life, including nutrition, pelvic physiotherapy, and community support groups.
- [Cleveland Clinic](#): A helpful comparison of endometriosis symptoms versus other pelvic health conditions.

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