GEM PATIENT EDUCATION CENTER

Understanding Endometriosis

Version 1.2 · September 2026



WHAT YOU NEED TO KNOW

Endometriosis is a **common, chronic and biologically complex disease**. It can occur in several forms and locations, and its symptoms and long-term course vary greatly from one person to another. Understanding the disease is the foundation for informed decisions about symptoms, diagnosis, treatment and fertility.

1. What is endometriosis?



Endometriosis is a chronic inflammatory disease in which **endometrium-like tissue is present outside the uterus**. These lesions are biologically different from normal uterine lining. They can interact with hormones and surrounding tissues and may contribute to inflammation, fibrosis (scarring), adhesions, pain and infertility.

ESTABLISHED EVIDENCE

Endometriosis is a real biological disease. The amount or stage of visible disease does **not reliably predict how much pain a person experiences**.

2. How common is it?

The World Health Organization estimates that endometriosis affects about **10% of reproductive-age women worldwide – approximately 190 million people**. The true number is difficult to measure because symptoms vary, diagnosis is often delayed, and access to expert imaging and surgery differs around the world.

3. What causes endometriosis?

There is **no single proven cause**. Current evidence supports a multifactorial model involving inherited susceptibility, hormones, immune and inflammatory pathways, cell biology and reproductive factors. Retrograde menstruation may contribute, but it does not explain the disease by itself. Environmental exposures are being studied, but they have not been proven to be a single cause of endometriosis.

EVIDENCE EVOLVING

Environmental and endocrine-disrupting exposures are an important research area. Associations have been reported, but current evidence does not prove that pollution or a specific exposure causes endometriosis or determines its severity.

4. Is endometriosis hereditary?

Endometriosis can cluster in families, and inherited genetic susceptibility contributes to risk. However, it is **not inherited as a simple single-gene disorder**. Many genetic variants, each with a small effect, appear to interact with hormonal, immune and other biological factors. Having a mother or sister with endometriosis increases risk, but it does not mean another family member will definitely develop the disease.

5. Where can endometriosis occur?

Endometriosis occurs most often in the pelvis. Common sites include the **pelvic peritoneum, ovaries, tissues behind the uterus, and areas involving or near the bowel, bladder and ureters**. Less commonly, it can occur outside the pelvis, including the abdominal wall and chest. Endometriosis is therefore usually pelvic, but it is not limited to reproductive organs.

6. Different forms of endometriosis

SUPERFICIAL PERITONEAL

Lesions on the pelvic lining. They can be subtle and may be difficult to detect on imaging.

OVARIAN ENDOMETRIOMA

Endometriosis involving the ovary and forming a cyst that often contains old blood.

DEEP ENDOMETRIOSIS

Disease extending beneath the tissue surface. It may involve structures such as the bowel, bladder, ureters, vagina or supporting pelvic tissues. Superficial disease, endometrioma and deep disease can occur alone or together.

IMPORTANT ABOUT STAGING

Stage describes anatomy. It does not reliably measure pain or personal impact, and stage alone cannot predict an individual's fertility.

7. Endometriosis and adenomyosis are different

Endometriosis is endometrium-like tissue outside the uterus. **Adenomyosis** is endometrial-type tissue within the muscular wall of the uterus. They are separate but related conditions and can occur together. Because they may cause overlapping symptoms, identifying both can matter when treatment is planned.

8. Can endometriosis progress?

The course varies: lesions may remain stable, shrink or progress. A 2024 review of deep endometriosis pooled progression estimates of about 21% without treatment and 12% during hormonal treatment. These groups had varied follow-up and were not a randomized head-to-head comparison. The figures are not annual risks or individual predictions.

Current evidence still does not allow clinicians to predict with certainty which individual patient will progress, remain stable, or recur. Symptoms can also worsen without obvious anatomical progression because pain may involve inflammation, fibrosis, pelvic-floor dysfunction and nervous-system sensitization.

ESTABLISHED EVIDENCE + IMPORTANT UNCERTAINTY

Some endometriosis can progress, especially deep disease, but progression is not inevitable and cannot currently be predicted reliably for an individual patient. Follow-up should therefore be individualized.

9. Endometriosis and cancer – putting risk into perspective

Endometriosis is not cancer. It is associated with some ovarian cancers, but absolute risk remains low. ESHRE's 2022 guideline illustrates lifetime ovarian-cancer risk as about 1.3 in 100 among all women and 2.5 in 100 among women with endometriosis. These population estimates do not predict an individual's risk.

Endometriosis alone does not justify extra routine cancer screening or preventive surgery. Follow usual age- and risk-based screening advice. A concerning mass, new symptoms or a strong family/genetic cancer risk needs individualized assessment.

PATIENT TAKEAWAY

The cancer association is scientifically important, but it should not create unnecessary fear. **The great majority of people with endometriosis will never develop ovarian cancer.**

GEM KEY MESSAGE

ENDOMETRIOSIS IS COMMON, COMPLEX AND DIFFERENT IN EVERY PATIENT.

It can range from superficial lesions to ovarian endometriomas and deep disease involving pelvic organs. The amount of disease seen does not necessarily reflect the amount of pain a person experiences. Understanding these differences is the first step toward earlier recognition, individualized treatment and better care.

Evidence & references

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Definitions, frequency and locations

WHO and ESHRE support the core patient description; the international terminology distinguishes the main disease forms. Family clustering is susceptibility, not single-gene inheritance.

Progression and cancer

Bandini's pooled deep-disease estimates have variable follow-up and heterogeneous untreated studies. They do not predict an individual course. The ESHRE cancer table gives illustrative lifetime absolute risks; routine extra cancer screening solely for endometriosis is not recommended.

Full references

- **[S13]** WHO. Endometriosis. Fact sheet, 15 October 2025. Freely available
- **[S01]** ESHRE. Endometriosis guideline. 2022. Freely available
- **[R34693033]** International Working Group of AAGL, ESGE, ESHRE and WES et al. An international terminology for endometriosis, 2021. Hum Reprod Open. 2021;2021(4):hoab029. doi:10.1093/hropen/hoab029. PMID 34693033. Freely available
- **[R38867640]** Bandini V, Giola F, Ambruoso D et al. The natural evolution of untreated deep endometriosis and the effect of hormonal suppression: A systematic literature review and meta-analysis. Acta Obstet Gynecol Scand. 2024;103(9):1722-1735. doi:10.1111/aogs.14887. PMID 38867640. Freely available
- **[R36914876]** Rahmioglu N, Mortlock S, Ghiasi M et al. The genetic basis of endometriosis and comorbidity with other pain and inflammatory conditions. Nat Genet. 2023;55(3):423-436. doi: 10.1038/s41588-023-01323-z. PMID 36914876. Freely available

No listed institution endorses GEM.

Medical information

Do not delay care; seek emergency help for a suspected emergency.

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