

—◆ A to Z of —◆

Endometriosis

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Adenomyosis

An evidence-based glossary



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with reference to peer-reviewed and
clinical guideline sources

A

Adenomyosis

Adenomyosis is a condition in which endometrial-type cells and tissue grow within the muscular wall of the uterus (the myometrium). It causes an enlarged, tender uterus, heavy periods and worsening period pain, and is confirmed on ultrasound or MRI rather than by symptoms alone (Rees et al., 2021). It commonly occurs alongside endometriosis but is a distinct disease, defined by where the tissue sits in the muscle rather than outside the pelvis (Wang et al., 2025).

B

Bowel Involvement

When endometriosis infiltrates the bowel wall, most often the rectum or sigmoid colon, it is classed as deep infiltrating disease. It can cause cyclical pain on opening the bowels, bloating, constipation, or bleeding around menstruation, and is frequently mistaken for irritable bowel syndrome, which delays diagnosis further. Severe cases occasionally need bowel resection alongside excision of pelvic disease (Becker et al., 2022).



CA-125



CA-125 is a blood protein that can be raised in endometriosis, particularly with ovarian endometriomas, but it is not a diagnostic test on its own. It lacks the sensitivity and specificity to confirm or rule out the disease, since it also rises with fibroids, pelvic infection and several unrelated conditions, so clinical guidelines do not recommend it as a standalone screening tool (Hirsch et al., 2016).



Diagnostic Delay



Across UK studies, the average time from symptom onset to a confirmed endometriosis diagnosis has consistently sat between eight and ten years, and recent charity survey data puts it at over nine years, a figure that has risen rather than fallen over the past decade (Manchester University NHS Foundation Trust, 2026; De Corte et al., 2025).

Contributing factors include normalisation of period pain by patients and clinicians, symptom overlap with other conditions, and long waits for gynaecology referral and laparoscopy (Karavadra et al., 2025; Li et al., 2025).

This delay is not shared equally: a 2026 UK report on ethnically diverse communities found an average wait of around 11 years, over twice as long between seeing a gynaecologist and receiving a diagnosis as the national average, despite these patients typically seeking help from a GP sooner after symptoms began (Harris, S., 2026). Comparable or greater disparities are documented for Black and Hispanic women in the US, where delays can run to roughly double the general average, pointing to structural bias in how pain is heard and believed rather than any difference in underlying disease (American Journal of Managed Care, 2023).



Endometriosis

Endometriosis is increasingly understood not as a purely gynaecological condition but as a systemic inflammatory and neuro-inflammatory disease, one that involves the whole body rather than staying contained to the pelvis. Misplaced tissue similar to the lining of the womb, most often found on the ovaries, fallopian tubes, and pelvic lining, responds to the hormonal changes of the menstrual cycle, triggering local inflammation and scarring, but it also promotes the coordinated growth of new nerve fibres and blood vessels directly into the lesions, a process called neuroangiogenesis that helps explain why the pain is so often disproportionate to the amount of visible disease (Morotti et al., 2014).

Lesions also aren't simply at the mercy of the ovaries: they can carry their own aromatase enzyme, letting them manufacture oestrogen locally and fuel their own growth largely independent of the menstrual cycle (Mori et al., 2019).

It affects an estimated 2 to 10 percent of women and those assigned female at birth of reproductive age (Becker et al., 2022), and how much disease is visible often bears little relation to how severe someone's symptoms are.



Fertility

Endometriosis is found in roughly 1 in 3 to 1 in 2 women investigated for infertility, far higher than the 2 to 10 percent estimated in the general population, through mechanisms including distorted pelvic anatomy, inflammation, and effects on egg quality and implantation (Wang et al., 2025).

Adenomyosis is separately linked to lower IVF implantation rates in some studies, particularly where imaging shows a significantly thickened or irregular junctional zone, though many people with either condition conceive without assistance (Rees et al., 2021).



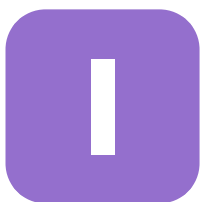
GnRH Agonists and Antagonists

Gonadotropin-releasing hormone (GnRH) agonists and antagonists work by suppressing the body's own hormone signalling to the ovaries, inducing a temporary, reversible menopause-like state that starves oestrogen-sensitive tissue. They are used for a limited period, often alongside low-dose hormone add-back therapy, to control pain while limiting bone density loss and menopausal side effects (Becker et al., 2022).



Hysterectomy

Removal of the uterus is considered a definitive treatment for adenomyosis, since the disease is confined to the womb itself. It does not, however, address endometriosis growing outside the uterus, so for people with both conditions, ovarian conservation, incomplete excision of pelvic disease, or continuing oestrogen exposure can mean symptoms persist afterwards (Rizk et al., 2014).



Inflammation



Both endometriosis and adenomyosis involve a chronic local inflammatory response: immune cells and inflammatory mediators accumulate around misplaced tissue, contributing to pain, scarring and adhesion (bands of scar-like tissue) formation, and to the fatigue and whole-body symptoms many people describe alongside pelvic pain. This inflammatory picture is a growing focus of research into non-hormonal treatments (Simancas-Racines et al., 2026).



Junctional Zone



The junctional zone is the innermost layer of the myometrium, visible on MRI, and its thickness has long been used as a key imaging marker for adenomyosis, with a thickness above roughly 12mm widely cited as supportive of the diagnosis. A systematic review and meta-analysis pooling data across dozens of studies found this measurement gives reasonable but imperfect accuracy (pooled sensitivity around 72 percent, specificity around 86 percent), and some individual prospective studies have since found thickness alone correlates poorly with a confirmed diagnosis, meaning irregular borders, myometrial cysts and other structural features are increasingly weighted alongside, rather than instead of, a single thickness cutoff (Rees et al., 2021).



Kissing Ovaries

This is the descriptive clinical term for a pair of ovaries that have become fused together in the midline by adhesions, usually from bilateral ovarian endometriomas, so that they sit pressed against each other behind the uterus. It is regarded as a marker of more severe, deeply infiltrating pelvic disease and typically makes surgery more technically demanding (Becker et al., 2022).



Laparoscopy

Laparoscopic surgery, keyhole visualisation of the pelvis often with tissue biopsy, has long been the reference standard for confirming endometriosis. Updated international guidance now also accepts a clinical diagnosis based on history, examination, and imaging in many cases, so that treatment does not always need to wait for surgical confirmation, though laparoscopy remains central for more complex or surgical cases (Becker et al., 2022).



Myometrium



The myometrium is the thick muscular wall of the uterus. In adenomyosis, endometrial-type glands and stroma become embedded within this muscle, provoking local muscle overgrowth and thickening, which is why the uterus in adenomyosis often feels bulky, boggy, and tender rather than being defined by a single mass, as fibroids are (Rees et al., 2021).



NICE Guidance and New Diagnostics



The UK's National Institute for Health and Care Excellence (NICE) updated its endometriosis guideline in late 2024 to sharpen symptom recognition and referral pathways, and has since been assessing two non-invasive tests, a saliva-based microRNA test and an abdominal electrical-signal test, for earlier detection in primary care. These sit alongside, rather than replace, surgical diagnosis while further evidence is gathered (National Institute for Health and Care Excellence, 2026; Manchester University NHS Foundation Trust, 2026).





Ovarian Endometrioma



Often called a chocolate cyst for the dark, tar-like old blood it contains, an endometrioma is a cyst that forms when endometriosis implants and bleeds within the ovary. Larger or bilateral endometriomas are associated with reduced ovarian reserve, both from the disease itself and from the effect of surgical removal, which is weighed carefully in people wishing to preserve fertility (Moreno-Sepulveda et al., 2022).



Progesterone Resistance



Many people with endometriosis show reduced tissue sensitivity to progesterone, the hormone that would normally counterbalance oestrogen's effects on the womb lining. This progesterone resistance helps explain why the disease can behave abnormally in its response to hormonal contraceptives and why treatment often needs individualising rather than following a single standard protocol (Zhang and Wang, 2023).





Quality of Life



Global burden-of-disease modelling shows disability-adjusted life years attributable to endometriosis have been rising in absolute terms even as age-adjusted rates decline (Yu et al., 2025), reflecting chronic pain, fatigue, mental health impact, and effects on work, education and relationships. Both endometriosis and adenomyosis are increasingly recognised as needing multidisciplinary, whole-person management rather than pain relief alone (Yu et al., 2025).



Retrograde Menstruation



First proposed by John Sampson a century ago, this theory suggested that menstrual blood and endometrial cells flow backwards through the fallopian tubes into the pelvis instead of leaving the body, implanting there to become endometriosis. It dominated thinking about the disease's origins for decades, but it is now widely regarded as an outdated theory that has been debunked as a standalone explanation. Research shows that around 90 percent of menstruating people experience retrograde flow, yet only a small minority ever develop endometriosis, and the theory cannot account for rare cases in men, in people who have never menstruated, or for lesions found in the lungs, brain and other sites away from the pelvis (Morotti et al., 2014).

Current research instead points to endometriosis as a disease rooted in genetics, immune dysfunction, and altered cell biology, with retrograde flow, where it happens at all, unable on its own to explain who develops the disease and who does not.



Staging and Superficial Disease

Endometriosis is commonly staged from I to IV using American Society for Reproductive Medicine criteria, based on the location, depth and extent of lesions and adhesions found at surgery. Superficial peritoneal disease, shallow implants on the pelvic lining, is generally considered the mildest form, though stage does not reliably predict how much pain a person experiences (Ashkenazi et al., 2023).



Transvaginal Ultrasound



A transvaginal ultrasound scan, performed by an experienced sonographer, is usually the first imaging test offered when endometriosis or adenomyosis is suspected. It can identify ovarian endometriomas, features of adenomyosis, and some deep infiltrating nodules, though its accuracy depends heavily on operator expertise, which is part of why diagnostic delay persists in areas with limited specialist access (Karavadra et al., 2025).



Uterine Artery Embolisation



This is a minimally invasive procedure that blocks blood flow to the uterus, used as an alternative to hysterectomy for symptomatic adenomyosis, particularly in people who wish to preserve their uterus. Studies show it can reduce uterine volume, junctional zone thickness and reported symptom scores, though outcomes for future fertility are less well established than for hysterectomy (Turtóczki et al., 2024).





Vaginal Nodules



Deep infiltrating endometriosis can form firm nodules in the rectovaginal septum, the tissue between the vagina and rectum, which may be felt on internal examination and are associated with deep pain during intercourse. These nodules are a marker of more extensive disease and often need specialist, multidisciplinary surgical planning (Becker et al., 2022).



Womb Lining



Both endometriosis and adenomyosis involve tissue **similar** to the womb lining behaving abnormally: in endometriosis it grows outside the uterus, and in adenomyosis it grows into the uterine muscle wall itself. Patient organisations such as the World Endometriosis Research Foundation work to standardise definitions like this across research and clinical care so that studies and treatments can be compared consistently (World Endometriosis Research Foundation, n.d.).





eXcision Surgery



Excision surgery removes endometriosis lesions, cutting out the abnormal tissue, as distinct from ablation, which burns only the visible surface. For deep infiltrating disease in particular, excision is associated with more durable pain relief and lower recurrence, though it is technically demanding and best performed by surgeons experienced in complex pelvic disease (Manu et al., 2026).



Young-Onset Disease



Endometriosis can begin in adolescence, with a scoping review of diagnostic delay finding a mean symptom onset around 14 years old in adolescents, years before diagnosis is typically reached. Period pain that stops a young person attending school or normal activities is not something to dismiss as ordinary, and earlier recognition in this age group is a growing focus of clinical guidance (Fryer et al., 2024).





Zoladex

Zoladex, the brand name for goserelin, is a GnRH agonist given by injection to suppress oestrogen production and shrink endometriosis and adenomyosis activity. It is typically used for a defined course of months, often alongside add-back hormone therapy, to manage side effects such as hot flushes and bone density loss during treatment (Becker et al., 2022).

A Note on the Evidence

Figures and clinical criteria in this guide draw on sources including the ESHRE Guideline for the Diagnosis and Treatment of Endometriosis, NICE guideline NG73 and 2026 draft diagnostics guidance, Global Burden of Disease modelling studies, MRI and ultrasound diagnostic literature on the junctional zone, and UK charity and parliamentary survey data on diagnostic delay. Prevalence and delay statistics vary between studies depending on population and methodology, and are presented here as ranges reflecting that uncertainty.

“Awareness grounded in evidence is what turns years of dismissed pain into a recognised diagnosis.”

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