GEM PATIENT EDUCATION CENTER

# Bowel, Bladder, Ureter & Diaphragmatic Endometriosis

A patient guide to endometriosis involving organs beyond the usual pelvic surfaces

Version 1.2 · September 2026



**WHY THIS GUIDE MATTERS**

Endometriosis can involve the bowel, bladder, ureters and, less commonly, the diaphragm or chest. Disease at these sites may require specialized imaging, careful surgical planning and collaboration between endometriosis surgeons and other specialists. Symptoms can provide clues, but the severity or location of disease cannot be determined from symptoms alone.

## Bowel endometriosis

**What it is:** Deep endometriosis can infiltrate the bowel wall. Symptoms may include painful bowel movements, cyclical rectal pain, constipation or diarrhea, bloating and pain with sex. Rectal bleeding has several possible causes and needs medical assessment, even if period-related.

**Evaluation:** Expert ultrasound or MRI may help map disease. Colonoscopy may be needed for other bowel diagnoses but does not reliably exclude bowel endometriosis.

**Treatment:** Monitoring, hormonal treatment or surgery may be appropriate. Surgery can involve shaving, disc excision or segmental resection, according to symptoms, extent, safety and your preferences. Discuss benefits, bowel-function effects and complications with an experienced team.

# Bladder Endometriosis

**What it is:** Disease may involve the bladder surface or muscle. Symptoms include cyclical bladder pain, urgency, painful urination and sometimes blood in the urine. Blood in urine needs assessment for other causes too. Expert ultrasound or MRI may help; cystoscopy is useful in selected cases.

**Treatment:** Monitoring or hormonal treatment may be appropriate when there is no urinary obstruction. Persistent symptoms, obstruction or other clinical concerns may lead to surgery. If bladder-wall resection is needed, an experienced team may perform partial cystectomy and repair, aiming to preserve bladder function and protect the ureteric openings. Decisions depend on disease location, symptoms, fertility goals and patient preferences.

**Evidence:** A 2022 review reports recurrent urinary symptoms in 7.34% across mainly case reports and series. This is not a lifetime anatomical recurrence rate and does not prove a definitive cure or the superiority of one operation.

> **GEM SURGICAL POINT**
>
> GEM supports individualized, expert treatment that balances symptom control and kidney protection with surgical risks and bladder function. Removing a bladder lesion does not guarantee that all endometriosis or pelvic pain will disappear. Monitoring or medical care can remain appropriate when there is no obstruction.

# Ureteral Endometriosis

## Why it can be silent



Ureteral endometriosis can compress a ureter from outside or, less commonly, involve its wall. It may cause few or no urinary symptoms even when drainage from the kidney is blocked. A normal urinary history does not exclude significant disease.

Silent obstruction can damage kidney function. When ureteral disease is suspected, kidney imaging is important; assess renal function when indicated. Hydronephrosis, or swelling of the kidney from impaired drainage, needs prompt specialist assessment.

**KEY CLINICAL WARNING**

**A normal urinary history does not rule out ureteral endometriosis. Silent obstruction can be the first clue, sometimes discovered only when hydronephrosis is seen on imaging.**

# Ureteral Endometriosis – When Suspicion Should Be High

## When suspicion should be high



Suspicion is especially important with extensive deep posterior pelvic disease, including rectosigmoid, uterosacral or parametrial involvement. Ureteral disease can coexist with these patterns even without urinary symptoms. Reports from specialist referral populations support careful assessment, but their percentages cannot be applied to every patient.

**GEM CLINICAL PRINCIPLE**

When a patient has advanced or extensive deep endometriosis – particularly rectosigmoid disease or an obliterated/posterior cul-de-sac – the ureters should be deliberately evaluated rather than assumed normal because the patient has no urinary symptoms. Preoperative imaging should assess for hydroureter or hydronephrosis when clinically appropriate, and the surgeon should identify and protect the ureters during complex pelvic dissection.

**Surgical planning:** Treatment may involve ureterolysis when disease is external to the ureter, or removal of an affected ureteral segment with reconstruction/reimplantation when obstruction or intrinsic involvement is more severe. Urologic collaboration is important when significant ureteral disease is suspected.

**GEM KEY MESSAGE**

**IN EXTENSIVE POSTERIOR OR RECTOSIGMOID ENDOMETRIOSIS, THINK ABOUT THE URETERS EVEN WHEN THE PATIENT HAS NO URINARY SYMPTOMS. Silent obstruction can threaten renal function.**

# Diaphragmatic & Thoracic Endometriosis

## Diaphragmatic disease

**Where it occurs:** Lesions may occur on the diaphragm, often on the right side, and can coexist with pelvic endometriosis.

**Possible symptoms:** Cyclical upper abdominal pain, pain beneath the ribs, shoulder-tip pain or pain that worsens around menstruation. Some lesions are asymptomatic and discovered during surgery.

**Important point:** Diaphragmatic disease may be subtle, small, asymptomatic or hidden, particularly on the posterior right diaphragm behind the liver. Careful inspection is therefore important.

**GEM SURGICAL PRINCIPLE: A SAFE, SYSTEMATIC SURVEY**

GEM supports a systematic survey of accessible pelvic and upper-abdominal surfaces after safe entry, including visible diaphragm surfaces where feasible. Visibility can be limited by anatomy or adhesions; not every lesion is visible. Inspection and treatment must stay within consent, safety and available expertise. Incidental asymptomatic diaphragmatic lesions do not automatically require removal.

Document the distribution of visible disease to guide planning. Complex diaphragm or chest treatment may require specialist collaboration or a planned later operation. The aim is useful mapping, without promising that one inspection finds every lesion.

## Thoracic disease



**What patients should know:** Endometriosis involving the chest can present with cyclical chest or shoulder pain, shortness of breath, or catamenial pneumothorax – a collapsed lung occurring in relation to menstruation.

**Evaluation:** Chest imaging and specialist assessment may be needed; imaging may not identify every lesion.

**Team approach:** Suspected thoracic disease may require coordinated gynecologic and thoracic surgical expertise; treatment may involve laparoscopy, thoracoscopy, or both.

**CHEST WARNING:** Sudden chest pain, serious breathing difficulty or collapse needs emergency help now. Call your local emergency number. Do not wait for symptoms to recur with a period.

# Preparing for Complex Endometriosis Care

Current major guidelines recommend specialist imaging to assess the extent of suspected deep endometriosis and referral to specialist endometriosis services when disease involves the bowel, bladder or ureter, or occurs outside the pelvis. Complex surgery may require advanced gynecologic laparoscopic expertise together with colorectal, urologic or thoracic surgical expertise.

## Questions to ask before complex endometriosis surgery



1. Which organs appear to be involved, and how confident are we from imaging?
2. Has my imaging been interpreted by someone experienced in deep endometriosis?
3. Will a colorectal, urologic or thoracic surgeon be available if needed?
4. What type of resection might be necessary and what are the important organ-specific risks?
5. Could surgery affect fertility or ovarian reserve?
6. Will the surgeon systematically inspect the upper abdomen and diaphragm as well as the pelvis?
7. How will disease be mapped, photographed/video-recorded with my consent, described in the operative report and correlated with pathology?
8. If all disease cannot safely be resected, what will the follow-up plan be?

**GEM KEY MESSAGE**

MAP DISEASE AND PLAN SAFELY. GEM supports documenting accessible visible disease and coordinating specialist care. The scope of treatment depends on findings, consent and safety; complex surgery may be staged. Comprehensive records support future care.

**EVIDENCE STATUS**

**Supported clinical points:** Deep disease can involve bowel and urinary organs; ureteral obstruction may be silent and threaten kidney function. Expert assessment and individualized treatment are important.

**Evidence limits:** Much organ-specific surgical research consists of observational studies, case series or technical consensus. Low reported symptom recurrence does not establish a permanent cure. GEM's mapping and documentation preferences are clinical positions, not universal legal requirements.

# Evidence & review

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## Bowel and bladder treatment

Imaging, symptoms, organ function, fertility plans and patient preferences guide treatment. Bowel surgery can range from shaving to disc or segmental resection in selected patients. For bladder disease without obstruction, monitoring or hormonal treatment may be appropriate. Surgery, including partial cystectomy when indicated, requires attention to bladder function and ureteric openings.

## What the bladder review actually reports

Tomasi and colleagues reviewed 28 publications, mainly case reports and series. The abstract reports recurrent urinary symptoms in 7.34%. This is not a lifetime or anatomical lesion-recurrence rate, does not establish that one operation is best, and does not prove a definitive cure. The full paper was not inspected.

## Protecting the kidneys

Ureteral disease can be silent and can obstruct drainage from the kidney. When ureteral involvement is suspected, assess the upper urinary tract with kidney imaging and evaluate renal function when indicated. Hydronephrosis warrants prompt specialist assessment. Published referral cohorts and case reports establish the possibility of silent harm; they do not supply a single risk percentage for every patient.

## Interpreting the removed percentages

The original approximate 70% and 90% figures reflect selected referral-series findings. Alborzi reports 353 enrolled and 326 pathology-confirmed patients, with 70.53% rectosigmoid and 92.9% uterosacral involvement. These are not general-population estimates. The 10-14% statement is background in a case report, not a universal probability. The corrected patient text uses the clinically relevant qualitative warning.

## Diaphragm, chest and safe surgical planning

Assess suspected chest involvement with appropriate specialists. Sudden chest pain or serious breathing difficulty requires emergency assessment regardless of menstrual timing. A safe, systematic survey documents accessible visible surfaces; it does not guarantee that all lesions are visible or require automatic removal of incidental asymptomatic disease. Treatment may be staged according to consent, safety and available expertise.

## Medical information

Seek urgent or emergency assessment for severe or rapidly worsening symptoms.

Version 1.2 · September 2026. Proposed next review: September 2027, or sooner if relevant guidance changes.

## Full references

Numbers correspond to the sources cited in this revised guide. Access notes distinguish relevant full-text inspection from abstract-only checks. No source is presented as an endorsement of GEM.

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  Verification: Relevant full-guideline sections inspected online.

Freely available — https://www.eshre.eu/-/media/sitecore-files/Guidelines/Endometriosis/ESHRE-GUIDELINE-ENDOMETRIOSIS-2022_1.pdf

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