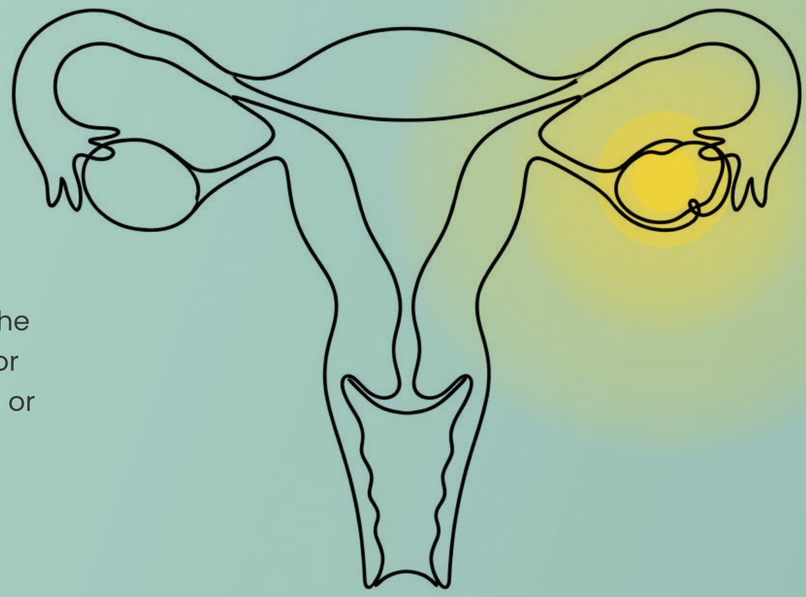
From Reactive to Proactive: Your Endometriosis Diagnostic & Management Toolkit

Reducing diagnostic delay through early recognition & coordinated care.



Identify and Intervene: Designed to address the critical diagnostic delay in endometriosis care, this toolkit is an actionable, evidence-based resource to empower Primary Care Providers (PCPs) and Emergency Medicine Physicians (EMPs) to bridge the gap between symptom onset and specialized management through early recognition and empiric therapy.

Navigate Your Toolkit: Access foundational tools and resources to guide the care team through every stage of the endometriosis diagnostic process, including role-specific guidance where applicable. You can print this toolkit for physical reference or download the digital version to use the interactive checklists—simply click the white circles or squares to track your progress as you go.

Support Your Practice: Explore more insights and resources through the CanSAGE Endometriosis Care Education Program (ECEP) with advanced education in imaging interpretation and surgical management pathways.

CanSAGE | ECEP

The Cost of Delay & Why Early Recognition Matters[1,2]

A “normal” or negative imaging result is not a clean bill of health—diagnostic delay causes physical and psychological harm.

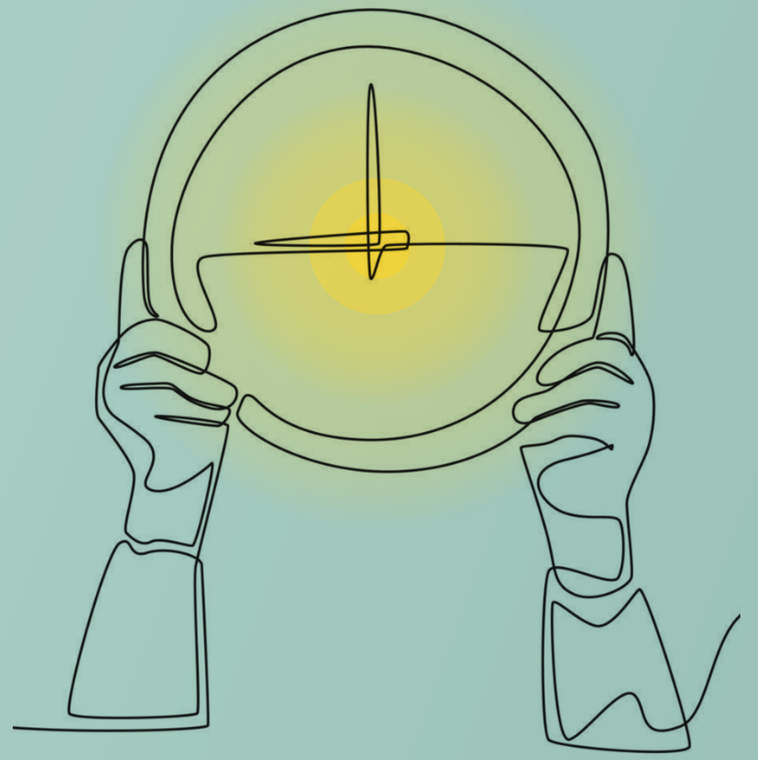
Endometriosis affects one in ten individuals, impacting almost two million Canadians, yet patients often face significant diagnostic and treatment delays of 5+ years.

Recognize the Burden

Persistent, unmanaged symptoms contribute to physical impairment, psychological distress, and substantial socioeconomic costs, including lost productivity.

Reframe the Goal

Shift the clinical objective from “waiting for surgical confirmation” to initiating empiric therapy based on clinical suspicion.



Cycle of Fragmented Care[1,2]

System-level gaps compound delays in diagnosis and treatment, resulting in lasting harm.

Onset & Normalization of Pain

Symptoms often begin before age 20. Adolescent pain is frequently minimized, resulting in missed opportunities for early intervention.

Fragmented Care

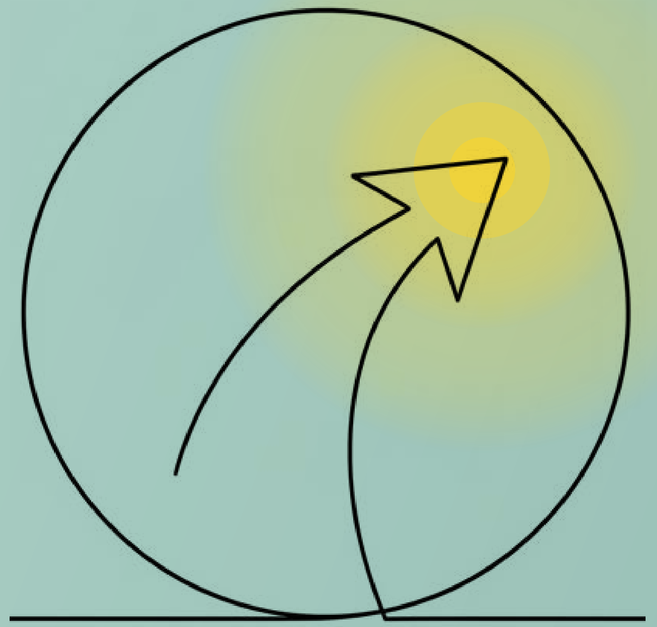
Patients cycle through the system without a long-term plan due to systemic barriers in accessing specialized diagnostics, challenges in the clinical recognition of complex symptoms, and the need for more integrated, collaborative care models.

The Emergency Pivot

Intolerable pain leads to ED visits. Without targeted follow-up, this becomes a cycle of repeat visits and perceived dismissal.

The Outcome

Undiagnosed endometriosis leads to progressive, multi-system complications that can be detrimental to productivity, social life, intimate relationships, and mental health.



Step 1 — Recognizing Endometriosis: Building Clinical Suspicion[1–5]

Endometriosis is a systemic inflammatory disease often presenting with cyclic and acyclic symptoms and requiring a high index of suspicion for both pelvic and extrapelvic patterns.

The evaluation of a patient with suspected endometriosis begins with a complete history including a review of symptoms, related medical history, previous therapies, impact on quality of life, and goals of care.

Use the screening checklist on the next page to validate clinical suspicion.

History

When investigating possible endometriosis, screen for the following:

Core Symptoms (Cyclic or Acyclic):

- **Chronic pelvic pain (>3 months)**
- **Common symptom cluster (4 "D"s):** Dysmenorrhea, dyspareunia, dyschezia, dysuria
- **Infertility**

System-Specific Symptoms (Often catamenial):

- **Genital**: Post-coital bleeding
- **Urinary**: Dysuria, hematuria, flank pain
- **Gastrointestinal**: Dyschezia, bloating, diarrhea, constipation, nausea/emesis
- **Diaphragm/chest**: Shoulder or subcostal pain, pneumothorax, hemothorax
- **Skin, muscle, fascia**: Painful mass with catamenial exacerbation at site of previous incisions, umbilicus
- **Nerve involvement**: Sciatica

Additional Considerations:

- **Adolescent onset:** Severe dysmenorrhea starting at menarche, obstructive anomalies (e.g., very light/absent menses with severe pain)
- **Impact on function**: Frequent absenteeism from school or work
- **Resistance to treatment**: Pain unresponsive to NSAIDs
- **Other risk factors**: Family history (first-degree relative), early menarche, short menstrual cycles, heavy menstrual flow, and Mullerian anomalies

Note: Gastrointestinal symptoms and acyclic pain are common, particularly in adolescents.

Pre-exam Consultation

Before initiating physical assessment, utilize the trauma-informed protocol below to establish patient safety, consent, and control:

- ○ **Validate and acknowledge patient experience**
- ○ **Assess clinical utility of a bimanual/internal exam:** Contraindications: Adolescent patient, no history of penetrative sexual activity, or patient declines due to discomfort/trauma. A clinical diagnosis can be made, and empiric therapy initiated, based on history and/or imaging alone.
  - ☐ **IF CONTRAINDICATED:** Defer internal exam. Proceed to clinical diagnosis & empiric therapy
  - ☐ **IF INDICATED:** Proceed with trauma-informed protocol below.
- ○ **Establish patient autonomy and empower informed decision-making**: Communicate to the patient that they are in control of their body and can pause/stop the exam and ask questions at any time. Ensure the results from any procedure or examination are discussed in full with the patient to empower informed decision-making and respect patient autonomy.
- ○ **Obtain and maintain consent:** Obtain ongoing, explicit consent for each step of the examination or any diagnostic procedure. Be mindful that some patients, particularly Indigenous women, girls, Two-Spirit, transgender, and gender diverse people, may feel pressured to comply with medical recommendations due to power imbalances and historical traumas, such as forced sterilization. Ensure patients clearly understand that no procedure will be completed without their full consent, and that they have the right to pause or stop at any moment.
- ○ **Offer chaperone**

Note: A bimanual examination should be performed after the myofascial assessment. The clinician should use the vaginal digit to palpate genital structures before depressing the abdominal wall with the external hand. Diagnostic caveat: Many patients will have a completely normal bimanual and speculum exam, including a normal posterior vaginal fornix. A normal physical exam does not rule out endometriosis.

Physical Examination

If a targeted physical examination is indicated, examine the following:

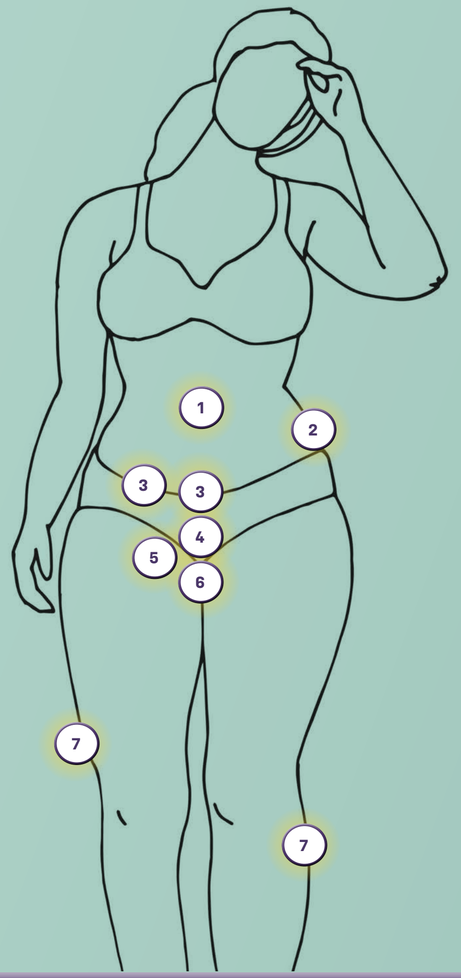
- **General well-being:** Vital signs in acute presentations (to rule out emergencies or other pathologies) Mental status and BMI
- **Myofascia/abdominal wall (superficial, deep, and low abdominal wall, including scars)**: Evaluate tone, tenderness, allodynia, or hyperalgesia for signs of central sensitization
- **Neurological patterns (pain or sensory deficits)**
- **Pelvic exam & suggestive clinical signs:** The following clinical signs may suggest the presence of endometriosis:

  - ☐ Uterosacral tenderness
  - ☐ Fixed retroverted uterus
  - ☐ Ovarian masses
  - ☐ Cyclic scar swelling/pain
  - ☐ Nodularity along the vaginal fornices or cul-de-sac
  - ☐ Vaginal lesions of endometriosis
  - ☐ Hematuria/hematochezia

  ☐ **IF POSTERIOR COMPARTMENT YIELDS ABNORMAL FINDINGS:** Consider a rectovaginal exam and kidney imaging to rule out rectal involvement and hydronephrosis

Note: A bimanual examination should be performed after the myofascial assessment. The clinician should use the vaginal digit to palpate genital structures before depressing the abdominal wall with the external hand. Diagnostic caveat: Many patients will have a completely normal bimanual and speculum exam, including a normal posterior vaginal fornix. A normal physical exam does not rule out endometriosis.

1. **Abdomen and Umbilicus:** Assess for bloating, myofascial tenderness /tone in the abdominal wall, and painful masses at the umbilicus or previous surgical scars.
2. **Flank and Kidneys:** Assess for flank pain and potential hydronephrosis.
3. **Pelvic Organs (Uterus and Ovaries):** Assess for tenderness, fixed mobility, size, and texture anomalies via bimanual exam.
4. **Bladder:** Assess for dysuria, hematuria, and tenderness in the anterior compartment.
5. **Bowel and Rectum:** Assess for dyschezia, constipation, diarrhea, and nodules in the posterior compartment or rectovaginal septum.
6. **Vagina:** Assess for dyspareunia, post-coital bleeding, and visible lesions in the posterior vaginal fornix.
7. **Lower Back and Legs:** Assess for sciatica and neurological patterns of pain or sensory deficits.



PCP Considerations:

- [ ] Distinguish cyclic vs. acyclic pain patterns
- [ ] Screen for gastrointestinal or other pathology that may mimic IBS

EMP Considerations:

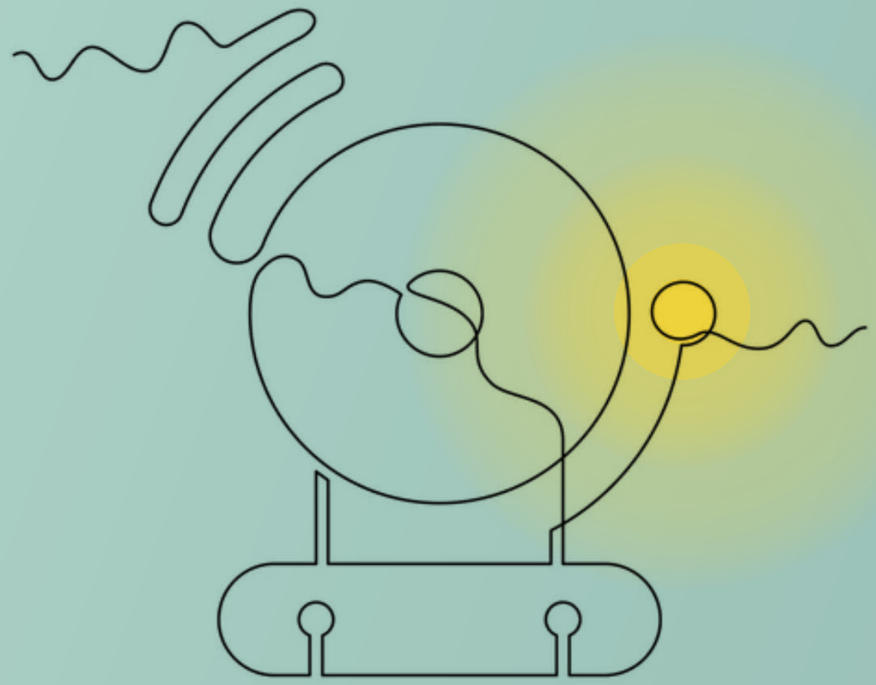
- [ ] Differentiate acute exacerbations of chronic pathology from acute surgical emergencies like adnexal torsion or appendicitis

Next Step: Determine the appropriate diagnostic actions and therapy initiation

Step 2 — Diagnostic Action Plan: Clinical Diagnosis Enables Action[1–3,6,7]

A clinical diagnosis is sufficient to initiate triage and treatment.

Establish clinical diagnosis: A presumptive clinical diagnosis can be made based on history and physical findings to initiate empiric medical therapy.

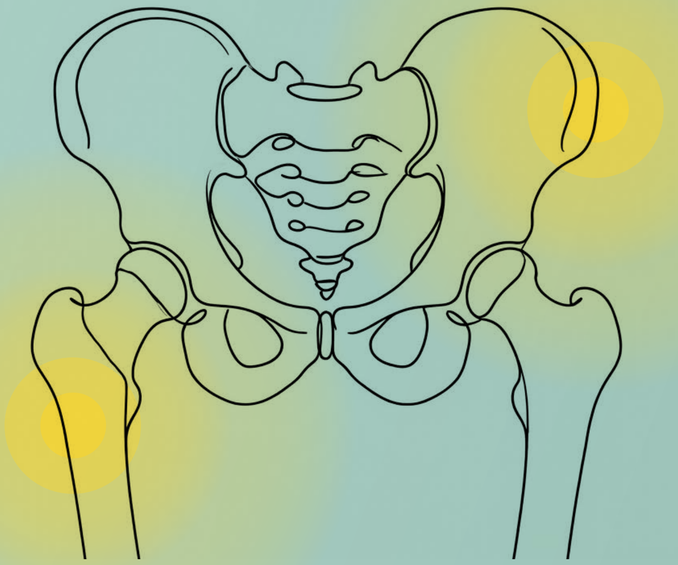


Do not

- Use biomarkers (e.g., CA-125) for diagnosis (low diagnostic utility)
- Delay treatment for surgical confirmation

Order Targeted Imaging

Order basic imaging to assess ovaries/uterus and rule out alternatives; order advanced imaging to map the disease and detect deep disease or multisystem involvement[a]



- ○ **Order a basic abdominal and pelvic ultrasound** as first-line investigation for all patients presenting with pelvic pain to assess symptoms suggestive of endometriosis, identify ovarian endometriomas, and exclude non-endometriosis pelvic pathologie[b].
  - ☐ **IF NORMAL WITH NO SIGNS OF DEEP ENDOMETRIOSIS:** Initiate empiric therapy
  - ☐ **IF DEEP ENDOMETRIOSIS IS SUSPECTED (e.g., basic ultrasound reveals an endometrioma, or the patient exhibits severe symptoms like deep dyspareunia, painful bowel/bladder habits, or a fixed/nodular uterus):** Order an advanced abdominal and pelvic ultrasound for endometriosis and explicitly request 'assessment for deep endometriosis/sliding sign' (or MRI if advanced ultrasound expertise is unavailable) to diagnose ovarian endometriomas and deep endometriosis[b,c]
  - ☐ **IF OTHER PATHOLOGY:** Treat accordingly

Note: A basic ultrasound assesses the uterus, ovaries, and rectouterine pouch for fluid or mass. A normal/negative basic ultrasound result does not rule out superficial endometriosis (lesions on the surface of the peritoneum) or deep endometriosis (lesions extending beyond the peritoneum). An advanced ultrasound includes components of the basic ultrasound as well as assessment of the anterior compartment (bladder and ureters to assess for hydroureter), posterior compartment (bowel, uterosacral ligaments, parametria, vagina, rectovaginal septum, rectouterine pouch peritoneum), soft markers (ovarian mobility, site-specific tenderness), rectouterine pouch obliteration state (sliding sign), and kidneys (to assess for hydronephrosis).

[a] Transvaginal scans may not be appropriate for all adolescents or non-sexually active patients. Transrectal or limited abdominal ultrasound may be used as alternatives to ensure patient comfort and appropriateness. CT scanning is not recommended as a primary investigative tool for pelvic endometriosis but may be indicated for acute abdominal pain or suspected thoracic endometriosis.
[b] Detection of endometriomas with basic or advanced ultrasound has a sensitivity of 93% (95% CI 87%–99%) and specificity of 96% (95% CI 92%–99%).
[c] Detection of deep endometriosis with advanced ultrasound has a sensitivity of 79% (95% CI 69%–89%) and specificity of 94% (95% CI 88%–100%).
Consult How To Perform an Ultrasound to Diagnose Endometriosis for a practical guide on basic versus advanced endometriosis ultrasound.

PCP: Longitudinal Management & First-Line Therapy

Goal: Suppress symptoms early to reduce disease progression.

- **Confirm patient does not have immediate fertility goals**
- **Initiate First-Line Therapy:** NSAIDs for symptom relief combined with hormonal suppression. Options include:
  - Continuous Combined Hormonal Contraceptives (continuous use preferred)
  - Progestogens
  - GnRH antagonists, GnRH agonists, and aromatase inhibitors may be considered if first-line is ineffective or is contraindicated

    Consult Diagnosis and management of endometriosis, published in CMAJ, for a summary of hormonal therapies for endometriosis including their dosage, adverse effects and special considerations, and relative costs.
- **Fertility Considerations:** Do not prescribe hormonal suppression to treat infertility (as it prevents conception). However, treating symptoms early is vital to prevent disease progression.
- **Monitor & Adjust:** Follow up at 3 months. If pain persists:
  - Trial a different hormonal class
  - Refer to Gynaecologist/Minimally Invasive Gynecologic Surgery (MIGS) for surgical assessment
  - Refer to Pelvic Health Physiotherapy for early and concurrent multidisciplinary management

    Consult Pelvic Health Physiotherapy: A Guide for People With Endometriosis for patient-focused information on pelvic health physiotherapy and how it can be used to help manage symptoms of endometriosis and other pelvic conditions.

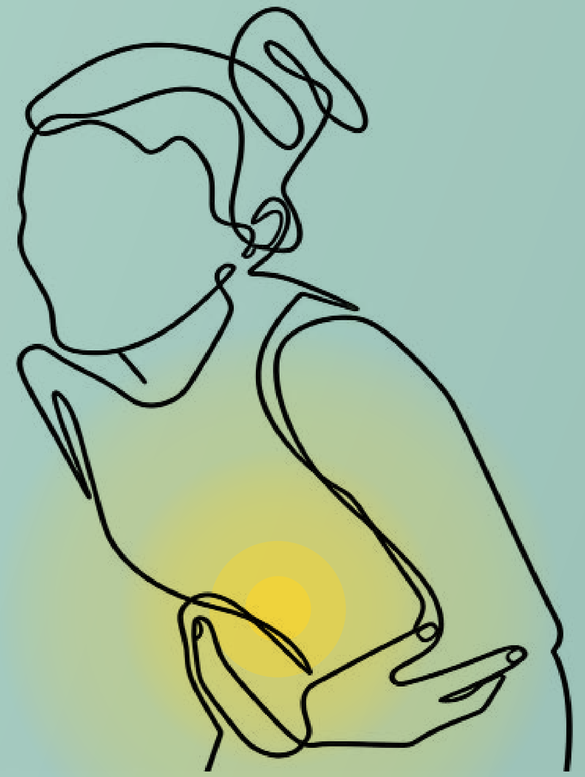
Note: Access to advanced ultrasound expertise, pharmacotherapy costs, and insurance coverage vary significantly across provinces/territories and private plans. Please verify local formularies and eligibility criteria as coverage policies are subject to change.
Next Step: Determine whether escalation or referral to specialist care is required.

→ Proceed to the next page for EMP considerations

EMP: The Emergency Room Pivot

Goal: Rule out the acute, validate the chronic, and bridge to care.

- **Differentiate and Triage:** Rule out surgical emergencies (e.g., adnexal torsion, tubo-ovarian abscess, appendicitis, ruptured or hemorrhagic ovarian cyst) and non-endometrial causes of pelvic pain versus acute exacerbation of chronic endometriosis.
- **Check Extrapelvic Signs**: If a patient presents with catamenial (cyclical) chest pain or shortness of breath, investigate for catamenial pneumothorax. pollakiuria, flank pain
- **Provide a Clinical Bridge**: Document ‘suspected endometriosis’ to validate the patient experience. Prescribe bridging analgesia and consider initiating hormonal suppression if no surgical emergency exists. Advise patients of available options to discuss with their primary care providers and ensure referral for outpatient follow-up.



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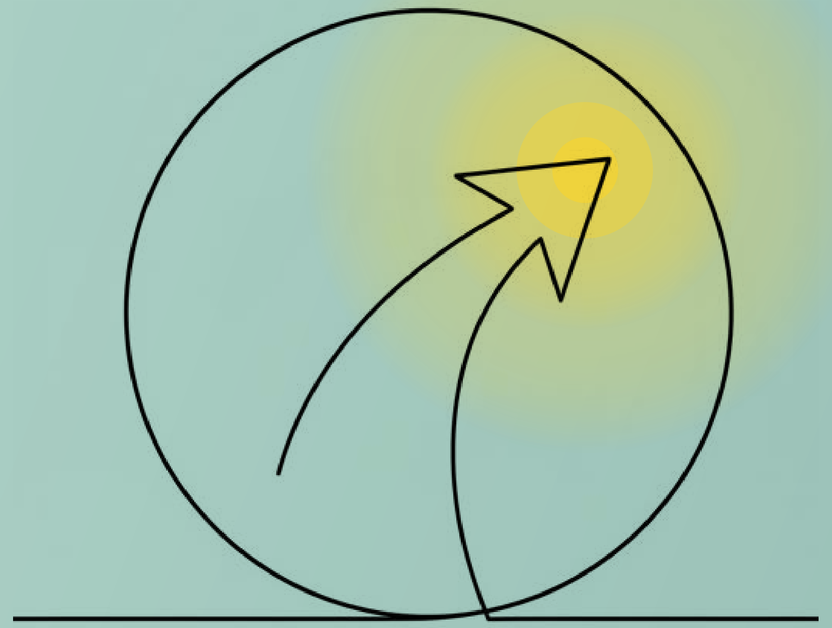
Next Step: Determine whether escalation or referral to specialist care is required.

Step 3 — Escalation and Referral[1–3,8]

Timely referral to specialized care prevents disease progression, manages symptoms, and supports fertility preservation for interested patients.

Note: Referrals can be concurrent (e.g., to gynaecology, fertility, and/or pain specialists simultaneously) to minimize delays and address complex needs.



Referral Checklist & Decision Algorithm

A referral is indicated if the patient meets any single criterion below.

Surgical Indications

- Imaging confirms deep endometriosis (bowel, bladder, or ureter involvement)
- Persistent ovarian endometrioma (regardless of size) or complex ovarian cyst
- Hydroureter or hydronephrosis detected on imaging (once acute causes like kidney stones are ruled out)
- Requiring histologic confirmation (e.g., exclusion of malignancy or complex pathology)
- Symptomatic despite medical or surgical management

☐ **Refer to Gynaecologist/MIGS**

Refractory Pain

- Symptoms of endometriosis and other pelvic conditions are persistent and function-limiting
- Contraindications to hormonal therapy

☐ **Refer to Multidisciplinary Pain Support**

Mental Health

- Patient desires pregnancy and has known endometriosis

☐ **Refer to Mental Health Specialist**

Fertility Priority

- Patient desires pregnancy and has known endometriosis

☐ **Refer to Reproductive Endocrinologist Infertility Specialist (REI)**

Note: Referrals can be concurrent (e.g., to gynaecology, fertility, and/or pain specialists simultaneously) to minimize delays and address complex needs.

When making a referral, ensure the following criteria are met:

- ○ Imaging and previous operative reports included
- ○ Disease extent and symptom burden clearly documented
- ○ Prior medical therapies summarized
- ○ Fertility considerations noted
- ○ Request specialist with advanced endometriosis surgical expertise
  If a local specialist is unavailable, consider utilizing virtual consults, referring to a regional centre, and offering information on travel assistance programs.

See a sample referral form from the BC Women's Hospital + Health Centre for more details on relevant information when making a referral.

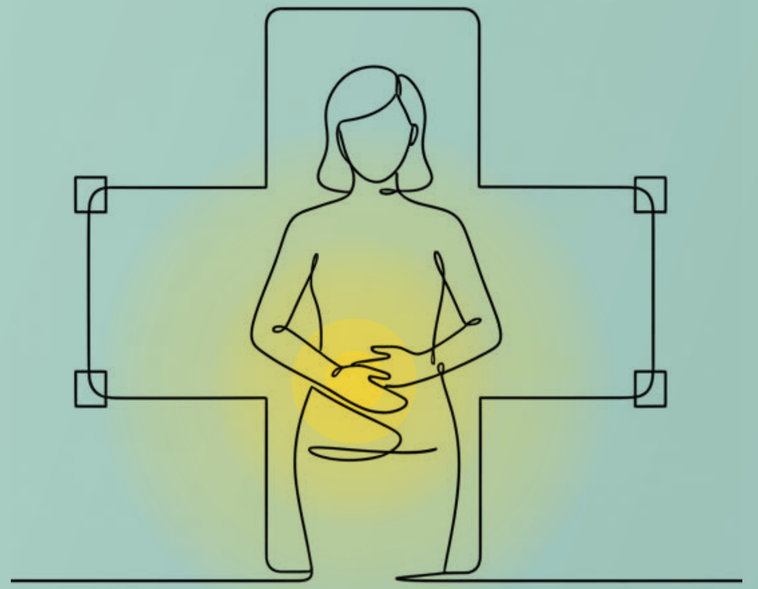
Endometriosis Diagnostic & Action Checklist[1–5]

Timely referral to specialized care prevents disease progression, manages symptoms, and supports fertility preservation for interested patients.

Step 1 – Recognizing Endometriosis

Step 2 — Diagnostic Action Plan

Step 3 — Escalation and Referral



Step 1 — Recognizing Endometriosis

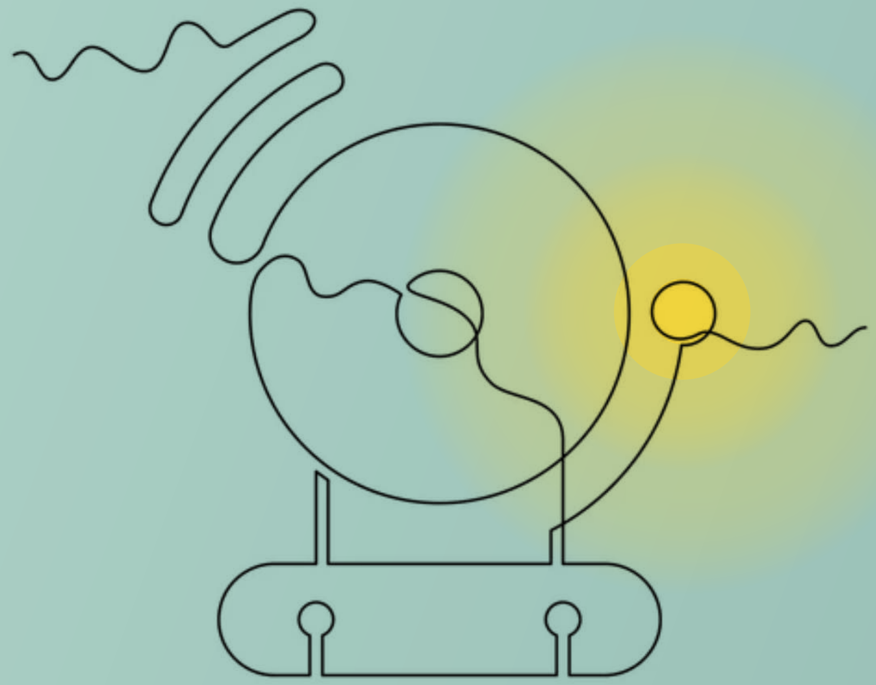
Goal: Validate clinical suspicion using a trauma-informed approach.

- [ ] **Take Detailed History:** Actively screen for chronic pelvic pain (>3 mos), dysmenorrhea, dyspareunia, dyschezia, dysuria, and infertility.
- [ ] **Review Systems:** Check for catamenial (cyclic) symptoms in other systems: GI (bloating, diarrhea), Urinary (hematuria, flank pain), Neurological (sciatica), and Abdominal Wall (pain/mass at umbilicus or surgical scars).
- [ ] **Identify High-Risk Profiles:** Note adolescent onset, significant absenteeism, resistance to NSAIDs, or family history.
- [ ] **Apply Trauma-Informed Protocol:** Validate patient experience and establish patient safety and autonomy. Defer internal exams for adolescents or those without penetrative sexual history; rely on imaging instead.
- [ ] **Perform Physical Exam:** If appropriate and consented, inspect vaginal mucosa, palpate abdominal myofascia/scars for tenderness, and perform bimanual exam to check for nodules, fixed mobility, or mass.

Step 2 — Diagnostic Action Plan

Goal: Establish a clinical diagnosis and initiate therapy without a surgically confirmed diagnosis, positive imaging, or abnormal physical exam findings.

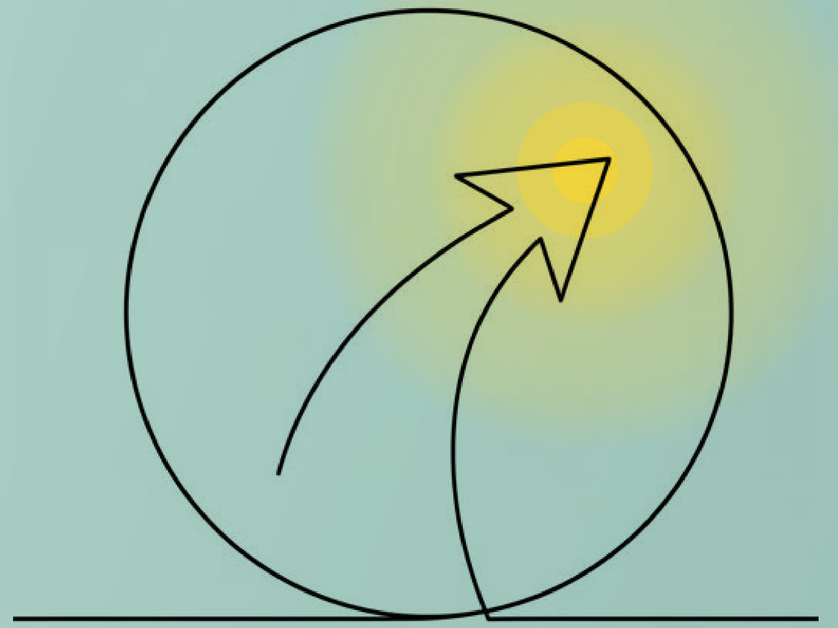
- **Diagnose Clinically:** Make a presumptive diagnosis based on history and physical findings to start treatment. Do not delay for surgical confirmation or use biomarkers (e.g., CA-125).
- **Order Imaging:** Start with basic ultrasound to rule out other pelvic pathologies. Order advanced ultrasound (or MRI) if deep endometriosis is suspected or to map disease.
  Tip: Explicitly request 'assessment for deep endometriosis/sliding sign' on the requisition.
- **PCP Considerations — Initiate Therapy:** If pregnancy is not an immediate goal, prescribe NSAIDs for pain relief combined with hormonal suppression (e.g., continuous combined contraceptives or progestogens) to stop disease progression. **A confirmed diagnosis is not required to initiate therapy**.
- **EMP Considerations — Manage Acute Episodes:** Rule out surgical emergencies (torsion, appendicitis). If stable, provide bridging analgesia and refer for outpatient management.
- **Monitor & Adjust:** Follow up at 3 months. If pain persists, trial a different hormonal class or escalate care.



Step 3 — Escalation and Referral

Goal: Timely triage to prevent progression and protect fertility.

- **Refer to Gynaecologist/MIGS:** Deep endometriosis, hydronephrosis/hydroureter, persistent/complex adnexal masses, or if medical management is ineffective.
- **Refer for Multidisciplinary Pain Support:** Pain is function-limiting after 3 months of first-line therapy or if hormonal therapy is contraindicated or not tolerated.
- **Refer for REI/Fertility Specialist:** Known/suspected endometriosis with immediate fertility goals.
- **Refer for Mental Health Support:** Signs of depression, anxiety, or isolation.
- **Prepare Referral Package:** Ensure referral includes imaging reports, documentation of disease extent/symptom burden, summary of prior medical therapies, previous operative reports, and fertility goals.



The Future of Endometriosis Care[1–3]

Proactive and continuous care leads to early action and definitive surgical management, significantly improving long-term outcomes.

Early Detection

Symptom onset,
Validation by PCP,
Clinical diagnosis.

Personalized, Patient-Centered Care

Empiric medical management,
Advanced imaging if needed,
Continual multidisciplinary support.

Surgical Precision

Comprehensive surgery by a specialist rather than repetitive diagnostic laparoscopies.

Fertility Preservation

Early counseling on fertility preservation for those at risk of ovarian damage who desire future pregnancy.

Note: Approximately 30–50% of patients with endometriosis may experience infertility

Additional Resources

Support your practice with Canadian clinical standards.

- **Clinical Algorithms:** Access the diagnosis and management of endometriosis flowchart (Figure 2), published in CMAJ.
- **Expert Resources:** Leverage CanSAGE tools developed by Canada's leading gynecologic experts.
- **Continuing Education:** Enroll in the CanSAGE ECEP to advance diagnostic and management expertise.
- **Support for People With Endometriosis:** The Endometriosis Network Canada (includes community support and resources on pelvic health physiotherapy and surgery guides)
- **Indigenous Health & Trauma-Informed Care:** Access resources such as the Trauma-Informed Care Fact Toolkit and the Guide to Disclosure of Harm with Indigenous Patients and Families to better understand the impacts of colonization, including forced sterilization and intergenerational trauma, and to build culturally safe, empowering healthcare environments for Indigenous communities

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