

Australian Living Evidence Guideline: Endometriosis

Quick Reference Guide for Primary Care

Endometriosis is a chronic, inflammatory, gynaecologic disease marked by the presence of endometrial-like tissue outside the uterus and symptoms may vary significantly in type and severity.

Key highlights:

- At presentation with symptoms suggesting endometriosis, diagnostic tests and treatment may begin at the first consultation
- A normal pelvic exam does not exclude endometriosis
- Hormonal treatment is the first-line management for endometriosis
- Additional use of analgesics, physiotherapy and psychological interventions may be considered
- Imaging (transvaginal ultrasound and MRI) reported by specialists trained in endometriosis have high sensitivity and specificity to identify endometriosis
- Consider laparoscopy to diagnose people with suspected endometriosis preferably after a treatment trial, even if the ultrasound or MRI is normal

Endometriosis is often under-recognised. Diagnostic delay may have a substantial impact on quality of life. Primary care providers are often the first point of contact to the health system for a person with endometriosis. Endometriosis can be diagnosed and managed in a primary care setting, but for some people, referral to secondary care may be beneficial.

The purpose of this quick reference guide is to provide evidence-based information to healthcare practitioners who diagnose and manage people of all ages with suspected or confirmed endometriosis.

These cases can be difficult to define and there is always room for clinical judgment, consideration of trauma-informed care, and decisions about referral.

During history taking, enquire if there is any history of autoimmune disease or if any first-degree relatives have a history or symptoms of endometriosis, as either of these may increase the chance of endometriosis.

What are the symptoms and signs of endometriosis?

Endometriosis diagnosis could be considered in people with the presence of one or more of the following symptoms:

Common symptoms (25 to 70% of cases):

- severe painful periods (dysmenorrhoea)
- pain with sex - during or after intercourse (dyspareunia)
- Infertility
- pelvic pain
- heavy menstrual bleeding

Less common symptoms (10 to 25% of cases):

- bowel symptoms (constipation, diarrhoea, pain with bowel movement (dyschezia))
- severe tiredness
- back pain
- sleep difficulty
- headache
- urinary symptoms (dysuria)
- allergies

Clinical signs that may suggest endometriosis:

Pelvic examination:

- reduced pelvic organ mobility
- pelvic organ enlargement
- posterior vaginal wall nodularity
- pelvic and vaginal tenderness
- visible vaginal endometriosis lesions

Association does not indicate causation, and many symptoms are often found in other conditions. Pain is one of the most common symptoms, but the level of pain (or other symptoms) and extent of endometriosis correlate poorly, and endometriosis may even be asymptomatic.

People with suspected endometriosis may consider keeping a short-term symptom diary which could help the discussion about ongoing management.

How is endometriosis diagnosed?

An earlier diagnosis may reduce pain and distress and could mitigate disease progression. The 'gold standard' for diagnosis of endometriosis has historically been laparoscopy with biopsy and histological confirmation. Emerging evidence suggests that a greater number of cases can be diagnosed using non-invasive techniques such as transvaginal ultrasound (TVUS) and magnetic resonance imaging (MRI).

Clinical Examination

Pelvic examination is not always required but may be useful as part of an initial assessment of endometriosis and to screen for other possible causes of the symptoms. Normal clinical examination does not rule out endometriosis.

Ultrasound or MRI

TVUS is the preferred option as first-line investigation especially to identify endometriomas, or deep endometriosis (including rectosigmoid, pouch of Douglas, bladder or ureters).

If a pelvic ultrasound is not appropriate due to age or sexual history, offer a pelvic MRI. If TVUS, and MRI are not possible then transabdominal ultrasound can be offered.

A normal ultrasound does not exclude endometriosis. If there is any clinical concern, an additional specialist ultrasound may be required and should be performed and/or interpreted by a healthcare professional with specialist expertise in gynaecological imaging.

If ultrasound was inconclusive or negative, or if deep endometriosis involving the bowel, bladder or ureters were suspected, then referral for MRI would be appropriate.

Laparoscopy

A TVUS reported as normal may not detect endometriosis in a small proportion of people with symptoms suggestive of endometriosis and for this reason it is recommended that laparoscopy could also be offered after a trial of treatment.

If endometriosis is diagnosed (or endometrioma) in imaging and no previous surgery, or according to people preferences, a laparoscopy can be considered.

How is endometriosis managed?

Endometriosis does not always need treatment. Explain findings of diagnostic assessment (imaging or laparoscopy) and offer first-line hormonal treatment (see below) and consider additional interventions including analgesics, physical therapy or psychological interventions.

Information and support

People with endometriosis may have psychological, psychosocial, and physical effects and should have timely, appropriate, and evidence-based health information.

Organisation of care

People with suspected or confirmed endometriosis may benefit from coordinated team-based care including: general practitioners and nurse practitioners, nurses (including community nurses, practice nurses and school nurses) and midwives, physiotherapists and other allied health practitioners, psychological support services, gynaecological services (gynaecologists with expertise in endometriosis, including training in laparoscopic surgery, gynaecology specialist

nurses with expertise in endometriosis), fertility services, paediatric and adolescent gynaecologists, multidisciplinary pain management services with expertise in pelvic pain, expertise in gynaecological imaging, specialist surgical services including colorectal surgeons or urologists with an interest in endometriosis, sexual and reproductive health services, First Nations health workers or First Nations health practitioners.

In rural and remote areas, or for people who cannot attend in person, telehealth consultations should be made available, and access to imaging services should be facilitated.

Pain medication

People with endometriosis may experience cyclical pain during menstruation or non-cyclical pain when not menstruating, and effective use of simple analgesics is important. Pain due to painful periods can be alleviated with non-steroidal anti-inflammatory drugs (NSAIDs), however people need to be aware of the risk of side effects.

Consider a short trial of an over-the-counter NSAID alone or in combination with paracetamol, unless contraindicated.

People with endometriosis or suspected endometriosis can consider analgesia to provide relief of pain but should be aware that there is no evidence that analgesics influence disease progression.

Hormone therapy

Hormonal therapies aim to reduce pain and the severity of the endometriosis by reducing the growth and inflammation of endometrial tissue.

Hormone therapy has the best evidence for management of pelvic pain, dysmenorrhoea and dyspareunia. First-line options include combined contraceptives and progestogen therapy (levonorgestrel releasing IUD, implants, MPA, dienogest). Symptoms may return with cessation of treatments. If the first option is not tolerated or was ineffective after three months, an alternative first-line treatment or formulation should be considered.

Second-line hormonal treatments include gonadotropin-releasing hormone (GnRH) agonists and antagonists, and should be offered on specialist recommendation.

Do not offer hormonal treatment alone or in combination with surgery to people with endometriosis who are trying to conceive, because it does not improve unassisted pregnancy rates.

Surgery

There is limited evidence to support laparoscopic surgery (excision or ablation) to reduce pain associated with endometriosis. If endometriosis is suspected, or if a person has not responded to treatment, discuss the role of laparoscopy including:

- what surgery involves
- that it may include treatment of lesions
- that it may or may not improve symptoms
- the possible benefits and harms of surgery
- the possibility for further surgery, if there is bowel, bladder or ureter involvement, or for recurrent endometriosis

For diagnosed endometriomas, surgery is recommended with cyst excision rather than cyst ablation. For deep endometriosis, treatment by a gynaecologist with appropriate surgical expertise or a specialist endometriosis service, if available, is recommended.



There is no evidence to support the benefits of routine repeated surgery for the management of endometriosis. A second surgical procedure may be necessary for specific expertise (e.g. colorectal surgeon or urologist) and the indication should be individually considered, with patients clearly informed about the limitations and potential harms and benefits.

Post-surgery

For people with endometriosis who do not wish to conceive immediately after surgery it is recommended to offer hormonal treatment as this does not negatively impact future fertility and is associated with reduced pain and recurrence of endometriosis.

Hysterectomy

Endometriosis includes tissue outside the uterus, which means that hysterectomy is not always able to improve the symptoms.

It is important that individuals are aware of the inability to carry children after a hysterectomy and the risks associated with early removal of ovaries (cardiovascular disease, osteoporosis and a decrease in cognitive function), the need for hormone replacement therapy, the potential for disease recurrence and the risks of surgery.

Additional therapies

There is no 'cure' for endometriosis so effective self-management techniques and lifestyle changes may have an important role in self-management. Many people want to be more actively involved in their treatment.

Physical therapies

Clinicians may offer a course of pelvic physiotherapy to people with endometriosis as this may be associated with improvements in pelvic pain and pain with sex.

Psychological support

A course of mindfulness classes or psychological interventions may have small improvements in pelvic pain and quality of life, and counselling sessions may be associated with small improvements in quality of life.

Acupuncture

A course of acupuncture may be associated with short term improvements in endometriosis-associated pain and quality of life.

Fertility treatment

Management of endometriosis-related infertility should have multidisciplinary team involvement with input from a fertility specialist and access to fertility services.

Special considerations

Adolescents (10-19 years)

This section intends to highlight what may be different for adolescents compared to other age groups. Adolescent age range has been considered between 10-19 years old according to the WHO definition.

Symptoms

Painful periods during adolescence are very common with a prevalence of around 70%. For heavy menstrual bleeding an underlying bleeding disorder need consideration and exclusion.

Diagnosis

Use transabdominal ultrasound when TVUS is not suitable. MRI, transperineal, or transrectal scan may be considered by a specialist experienced in these modalities and who can interpret the results.

Imaging should be considered earlier for those with significant symptoms to rule out other possible causes (eg 3-6% of adolescents with significant period pain will have an underlying Müllerian anomaly).

Management

All people with symptoms should be reviewed and timely treatment should be offered.

Initial non-invasive treatment should include first-line hormonal treatment and anti-inflammatories. IUD-LNG is safe to use in adolescents and can be inserted under general anaesthetic (if necessary).

Factors that exacerbate pain conditions, including adverse childhood events, poor sleep, and stress, need to be explored and appropriate allied health input sought.

Referral

A referral is recommended to a paediatric and adolescent gynaecologist with experience in pain with periods, persistent pelvic pain and endometriosis.

Laparoscopy

If a laparoscopy is being considered, ideally it should be performed by a gynaecologist with experience in management of endometriosis in young people.

Other treatments should continue whilst awaiting laparoscopy to investigate symptoms.

Cancer risk

For people with endometriosis requesting information about cancer risk in reproductive organs, it is recommended to inform them that although they may have a small increase in ovarian and endometrial cancer, the increase in absolute risk is low compared with women in the general population. As there is no screening test that can accurately detect early ovarian or endometrial cancer, additional testing for people with endometriosis is not recommended.

First Nations people

Clinicians can improve the equity of care for First Nations people by recognising racism (individual bias and systemic racism), intergenerational trauma, and ongoing inequities when assessing people presenting with symptoms suggesting endometriosis. They should be aware of 'women's business' and the wishes of many First Nations people to keep women's health issues private and separate from other health issues.

Regional and remote areas

Many rural patients have difficulty accessing specialised endometriosis care. The challenges include long distances, limited availability of specialists, and extended waiting times for appointments.

Gender identity

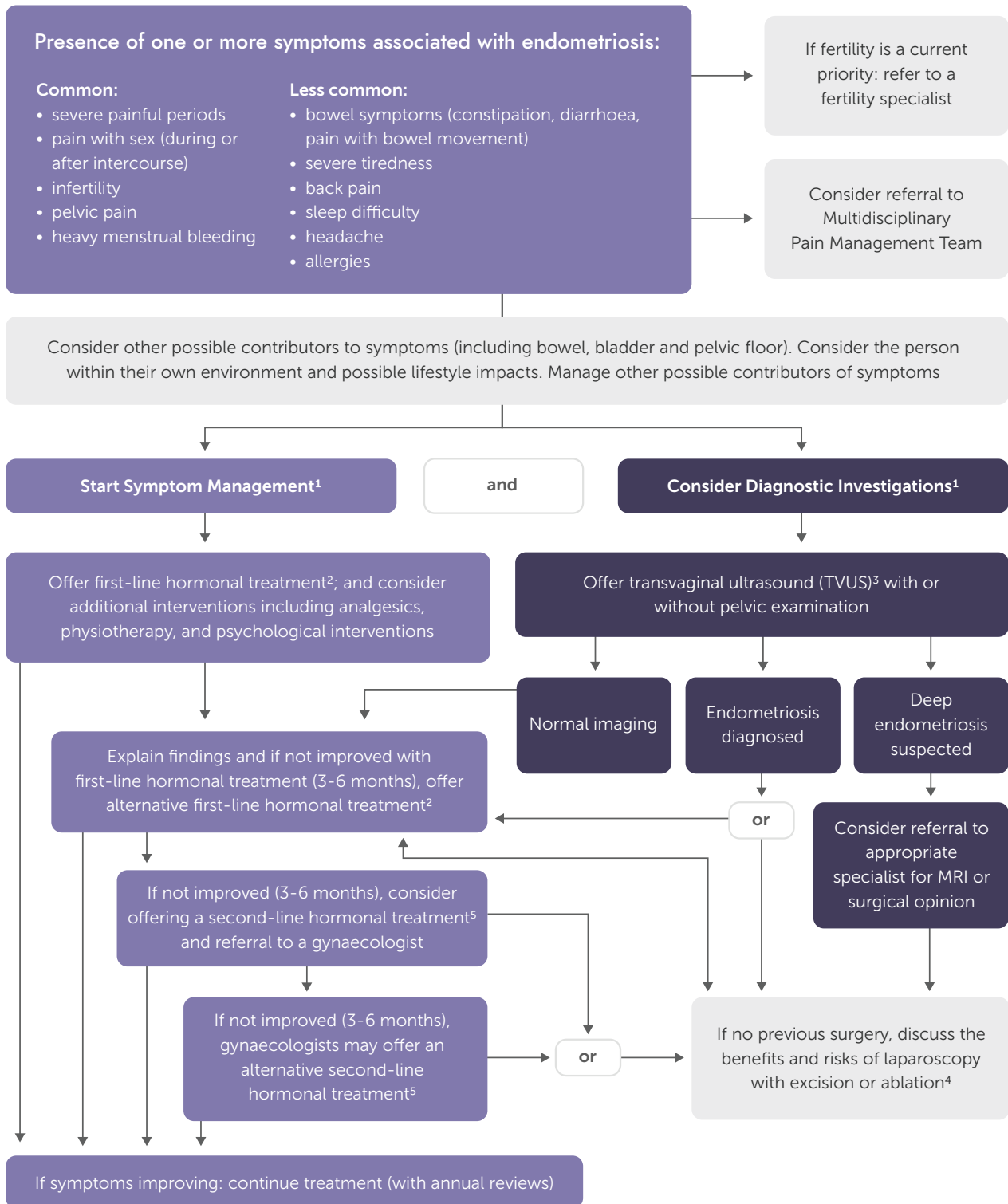
For people who do not identify as cisgender women, endometriosis and endometriosis-associated menstrual symptoms may trigger gender dysphoria as some symptoms can be heightened during menstruation.



For more information and resources, scan the QR code or visit:

ranzcg.edu.au/endometriosis

Summary of diagnosis and management of endometriosis



1. At presentation with symptoms suggesting endometriosis, treatment and diagnosis may begin at the first consultation.

2. Offer hormonal treatment according to patient preferences (including adolescents). First-line treatments are combined hormonal contraceptives and progestogens (oral, injection, implant or IUD).

3. TVUS is the preferred option as first-line investigation, if not possible or appropriate due to age or sexual history, then a transabdominal ultrasound could be suggested. If any clinical concern, an additional specialist ultrasound may be required and should be performed and/or interpreted by a healthcare professional with specialist expertise in gynaecological imaging.

4. In adolescents, laparoscopy should be discussed with a gynaecologist with expertise in young people.

5. Second-line hormonal treatment include gonadotrophin-releasing hormone (GnRH) agonists and antagonists, and should be offered on specialist recommendation.