Endometriosis

Health professional tool

Assessment, investigations & management
Women with dysmenorrhoea often visit their GP multiple times before they are referred to a specialist. GPs are in a strong position to advocate for women with suspected endometriosis, helping to reduce the average seven-year delay in diagnosis.

**Epidemiology & prevalence**

Endometriosis is an oestrogen dependent inflammatory condition, defined by endometrial cells found outside the uterine cavity. It is a progressive, recurrent and often debilitating condition.

- High prevalence - estimated to affect 5% to 10% of women, including adolescents
- More common than diabetes or breast cancer, yet has no known cause or cure
- Probability is 3 to 10 times higher if 1st-degree relative has the condition
- Diagnosed in 20-50% of women undergoing laparoscopy for assessment of chronic pelvic pain (CPP) or infertility

**Pathogenesis**

The aetiology of endometriosis is unknown but retrograde menstruation is the leading theory for pelvic endometriosis. This however does not explain all forms of endometriosis.

**Key message:** Dysmenorrhoea that impairs quality of life (QoL) is not normal – first referral should be to a gynaecologist

**Presenting symptoms**

**Pain:**
- severe dysmenorrhoea that gets progressively worse, impacting on quality of life (lost productivity, days off work/school)
- recurring or persistent pelvic pain with duration of >6 months
- worsening dysmenorrhoea whilst taking hormonal contraceptives
- ovulation pain
- deep dyspareunia
- pain during internal examination
- back or leg pain

**Bowel and bladder symptoms:**
- cyclic bladder or bowel symptoms
- pain before or after opening bowels
- pain before, during or after urination
- bleeding from the bowel
- blood in the urine
- irritable bowel syndrome (IBS) type symptoms – constipation, diarrhoea or colic

**Other symptoms:**
- chronic fatigue, weariness, bloating or pain not during period or ovulation
- infertility
- fainting during period or feeling faint
- nausea
- depression

**Bleeding:**
- heavy, irregular, extended or post-coital bleeding with or without clots
- dark or old blood being passed before or at the end of period

**Note:** A possible diagnosis of endometriosis should be considered in adolescents presenting with: persistent pelvic pain (cyclic and/or non-cyclic), severe dysmenorrhea, dysmenorrhea resistant to non-steroidal anti-inflammatory drugs (NSAIDs) and the oral contraceptive pill (OCP), and pain interfering with daily activity.
Possible sites of endometriosis

- Peritoneum, ovaries and fallopian tubes
- Uterosacral ligaments and Pouch of Douglas
- Bladder and bowel
- Recto-vaginal septum
- Abdominal surgery scars and rarely in other organs outside the pelvic cavity

Several potential sites of endometriosis are illustrated in the diagram below.

Early diagnosis is important

Normalisation of pain, lack of suspicion by women and health professionals about dysmenorrhoea, diversity of symptoms and lack of clinical knowledge are barriers to diagnosis.
- Women face an average 7-8 year delay for surgical diagnosis and up to 13 years for deep infiltrative disease (DIE)
- Endometriosis is usually progressive, even in the asymptomatic patient
- Where DIE and endometriomas exist, more complex management is required

Key message:
Delayed diagnosis can lead to infertility, debilitating pain and reduced QoL

Assessment
Assessment should include:
- **history**
  - present and past menstruation
  - family history (1\textsuperscript{st} and 2\textsuperscript{nd} degree relatives)
- **examination**
  - palpation of abdomen for areas of tenderness or guarding
  - vaginal exam (\textit{only} in sexually active women) for tenderness, uterine size, nodules, ovarian cysts
  
  \textbf{Note:} Examination during menses may increase chance of detecting DIE.
- **imaging** (pelvic/abdominal ultrasound)
- exclude other causes of lower abdominal pain e.g. sexually transmitted infection (STI), ectopic pregnancy, pelvic inflammatory disease (PID), ovarian torsion, IBS
**Key message:**

The combination of laparoscopy and histological verification is considered the gold standard for the diagnosis of endometriosis.

**Investigations**

**Ultrasonography is the first-line investigative tool**

1. Abdominal/transvaginal ultrasound (TVUS)
   - may be negative
   - may detect endometriomas
   - if ultrasound is performed by gynaecologist trained in advanced ultrasound, it may detect DIE of the bowel, bladder or rectovaginal septum
2. MRI (mainly specialist use)

**Referral**

When to refer patient for confirmation of diagnosis and/or treatment of endometriosis to specialist gynaecologist:

- severe dysmenorrhoea (any woman presenting with dysmenorrhoea, regardless of age, should be investigated)
- period pain that is not managed by either NSAIDs or OCP
- presents with a complex of symptoms including dysmenorrhoea

After referral to gynaecologist arrange 3 month follow-up, with longer appointment time to review.

**Post-diagnosis management**

- Liaise with treating gynaecologist and other health professionals
- Ongoing management depends on treatment response, persisting symptoms, and expected health outcomes

**Managing pain**

**Endometriosis-associated pain may be:**

- recurrent endometriosis
- recurrent pelvic pain and/or
- related to chronic pain syndrome

**Multidisciplinary pain management:**

- analgesics including NSAIDs
- endometriosis pain suppression:
  - OCP (continuous or conventional), NuvaRing™
  - Implanon™ +/- Mirena™, or individually
- gynaecologist may prescribe:
  - GnRH agonists (lead to low oestrogen, add back HRT/MHT, maximum use 6 months)
  - progestogens and anti-progestogens
  - aromatase inhibitors

**Patients with persistent or severe pelvic pain are at increased risk of depression and anxiety; routine screening is recommended.**

- Patients with persistent pelvic pain should be taken seriously to assist early diagnosis and symptom control
- Suggesting the pain is psychosomatic/psychological can disempower the patient and lead to reduced QoL
- Refer to a pain clinic, pain specialist and/or psychologist at the earliest opportunity

**30% of women with endometriosis will experience infertility**

- refer to fertility specialist after 6 months of trying to conceive or >35 years of age

See multidisciplinary management section.
Multidisciplinary management plan

Create a management plan with a multidisciplinary team to help address symptoms. Include the patient in the decision-making process, informing her of all side-effects and benefits of treatment. Encourage a healthy lifestyle and a strong support network to address both the physical and mental aspects of endometriosis to improve QoL.

### Physical activity

Regular physical activity may reduce pain and improve wellbeing.

### Pelvic floor physiotherapy

- Treatment of pelvic floor muscle dysfunction, persistent pelvic pain and dyspareunia
- Rehabilitation of associated muscles of the pelvic and abdominal region

### Complementary and alternative medicine

Women may seek and feel benefits from complementary therapies in the management of dysmenorrhoea and pain. According to the European Society of Human Reproduction and Embryology (ESHRE) guidelines evidence for the following is not well established:

- acupuncture
- transcutaneous electrical nerve stimulation (TENS)
- magnesium, vitamin B1 and B6 (B6 – concern over safety of high doses)
- fish oils (omega-3 fatty acids)

### Mental health

Endometriosis can negatively impact QoL and have a detrimental effect on physical, emotional and mental wellbeing. Early diagnosis and treatment may reduce this effect. Discuss the management plan with the patient. Consider referral to a counsellor or psychologist.

Ask your patient the questions below. If any responses are positive, further exploration is required.

During the last month, have you:

- often been bothered by feeling down, depressed or hopeless?
- often been bothered by having little interest or pleasure in doing things?
- been bothered by feeling excessively worried or concerned?

**Key message: assess mental and emotional health**

**Flowchart informed by:**


Putting it into practice

**Case study 1**
Teenager with primary/secondary dysmenorrhoea:
- NSAIDs then review at 3 months (book long appointment)
If no improvement:
- prescribe OCP:
  - cyclic with follow up in 3 months – if patient is in last few years at school and pain free
  - if persistent pain – continuous OCP until end of school + refer to gynaecologist
  - if breakthrough pain on continuous OCP - refer to gynaecologist (preferably with advanced laparoscopic skills) for assessment and laparoscopy
- tests (heavy bleeding): FBE, iron studies, thyroid function tests (TFTs), Von Willebrands
- ultrasound, abdominal or TVUS if sexually active

**Case study 2**
Patient returns after laparoscopy:
- monitor patient response to treatment
- continue prescribed management
- refer back to gynaecologist if pain recurs

**Case study 3**
Patient returns after 14 months trying to conceive, without success. Is depressed and struggling with recurrent pelvic pain:
- refer to fertility specialist
- review with operating gynaecologist
- assess mental health and refer if required

Seek out health professionals with endometriosis experience including:
- general practitioner
- gynaecologist with advanced laparoscopic skills (who may also refer to colorectal surgeon and/or urologist)
- psychologist/pain specialist
- fertility specialist
- community health nurse
- pelvic floor physiotherapist
- dietitian
- accredited exercise physiologist
- sex therapist
- naturopath

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