Endometriosis: diagnosis and management

First presentation

Suspect endometriosis in women, trans men and non-binary people registered female at birth (including in young people aged 17 and under) who have **1 or more** of:

- chronic pelvic pain
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- deep pain during or after sexual intercourse
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- infertility in association with 1 or more of the above.

Assess individual information and support needs: take into account the person's circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs.

Also:

- discuss keeping a pain and symptom diary
- ask about family history of endometriosis
- take into account that people express pain in different ways
- offer an abdominal and pelvic (internal vaginal) examination to identify abdominal masses and pelvic signs
- offer an ultrasound scan (see **below**).

Initial management

Be aware that endometriosis can be a long-term condition and can have a significant physical, sexual, psychological and social impact. People with endometriosis may have complex needs and may require long-term support.

Carry out additional investigations such as ultrasound, and referral if necessary, in parallel with each other, and in conjunction with initial pharmacological treatment.

Offer initial management with:

- a short trial (for example, 3 months) of paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination
- hormonal treatment (combined contraceptive pill or a progestogen)
- refer to the NICE guideline on neuropathic pain for treatment with neuromodulators.

When fertility is a priority, the management of endometriosis-related subfertility should have multidisciplinary team involvement with input from a fertility specialist. This should include recommended diagnostic fertility tests or preoperative tests and other recommended fertility treatments such as assisted reproduction.

Also see **Fertility is a priority** on **page 2**.

Diagnosis and referral

Do not use pelvic MRI or CA-125 to diagnose endometriosis.

Offer transvaginal ultrasound even if pelvic or abdominal examination is normal to:

- identify ovarian endometriomas and deep endometriosis, including that involving the bowel, bladder or ureter
- identify or rule out other pathology
- guide management and referral options.

Consider a transabdominal ultrasound scan of the pelvis if a transvaginal scan is declined or not suitable.

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Do not exclude the possibility of endometriosis if the abdominal and/or pelvic examinations or ultrasound are normal.

Refer to a gynaecology service:

- if initial management is not effective, not tolerated or is contraindicated, or
- for persistent or recurrent symptoms of endometriosis, or
- for symptoms which impact daily life, or
- for pelvic signs of endometriosis, unless deep endometriosis is suspected

Refer to a specialist endometriosis service (endometriosis centre) if the person has suspected or confirmed:

- endometrioma, or
- deep endometriosis including that involving the bowel, bladder or ureter, or
- endometriosis outside the pelvic cavity.

Refer young people (aged 17 and under) to a **paediatric and adolescent gynaecology service** or **specialist endometriosis service** (endometriosis centre).

Consider laparoscopy to diagnose endometriosis, even if the ultrasound (or MRI, if used after referral to a specialist) was normal.

Discuss surgical management options with people who have suspected or confirmed endometriosis: :

- what laparoscopy involves, and that it may include surgical treatment (with prior patient consent)
- how laparoscopic surgery could affect endometriosis symptoms
- the possible benefits and risks of laparoscopic surgery
- the possible need for further surgery, including the possible need for further planned surgery for deep endometriosis involving the bowel, bladder or ureter.

During diagnostic laproscopy a gynaecologist with training and skills in laparoscopic surgery for endometriosis should perform a systematic inspection of the pelvis and record the findings, including intra-operative imaging.

If a **full systematic laparoscopy** is performed and is **normal**, explain to the person that it is unlikely that they have endometriosis and **offer alternative management of symptoms**.

Ongoing care

If fertility is a priority

Offer excision or **ablation plus adhesiolysis** to people with endometriosis not involving bowel, bladder or ureter.

Offer laparoscopic ovarian cystectomy or **laparoscopic drainage and ablation** to people with endometriomas. Take into account:

- the possible impact on ovarian reserve
- that ablation and drainage may preserve ovarian reserve more than cystectomy

Discuss the **benefits and risks** of **laparoscopic surgery for deep endometriosis** involving the bowel, bladder or ureter. This may include:

- the possible impact of deep endometriosis on pregnancy outcomes
- effect on the chance of future pregnancy
- the possible impact on ovarian reserve
- the effect of complications on fertility
- alternatives to surgery
- other fertility factors.

Do not offer hormonal treatment alone or in combination with surgery to people with endometriosis who want to conceive.

If fertility is not currently a priority

During diagnostic laparoscopy, **consider laparoscopic treatment** of (if present):

- peritoneal endometriosis not involving the bowel, bladder or ureter
- uncomplicated ovarian endometriomas.

Consider excision rather than ablation to treat endometriomas.

For **deep endometriosis involving the bowel, bladder or ureter, consider**:

- pelvic MRI before operative laparoscopy
- a 3-month course of GnRHa before surgery.

Consider hormonal treatment after laparoscopic excision or ablation.

If **hysterectomy** is indicated:

- excise all visible endometriotic lesions at the time of hysterectomy
- discuss with the person what a hysterectomy is, its risks & benefits, related treatments and likely outcome.

Consider outpatient follow-up for:

- deep endometriosis including that involving the bowel, bladder or ureter, or
- 1 or more endometrioma larger than 3 cm.

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