Primary Care
Women's Health Society

Top tips

Endometriosis

Dr. Nasiha Lindner
GP

This resource has been produced on behalf of the PCWHS. It is for guidance only; healthcare professionals should use their own judgment when applying it to patient care.

For more resources, visit www.pcwhs.co.uk. Date of publication: April 2025. Date of next review: April 2028.
 The PCWHS aims to educate primary care clinicians about women's health, i.e. the health of those who were registered female at birth. Our resources therefore all use the words woman/women and the pronouns she/her. Where patients have a gender identity which is different from their sex registered at birth, communication should be sensitive and respectful of the patient's pronouns.
For further information, or to leave any feedback, please contact admin@pcwhs.co.uk

Endometriosis is a chronic, heterogeneous, systemic condition in which endometrium-like tissue grows outside the uterus, causing scarring, pain and inflammation[1]. It is mostly found within the pelvis, on organs such as the ovaries (endometrioma/chocolate cysts), the bladder and bowel. It can also be found outside the pelvis. Its pathophysiology is still unclear[2].

These tips will help you to spot possible endometriosis, to manage in primary care, and to know when to refer.

1) Be alert to the possibility of endometriosis. It is common!

Endometriosis affects around 10% of women[3] and can occur at any time after the menarche. Surveys continue to show an average length of time from presentation to diagnosis of 8-10 years[4,5].

We should be especially alert to the possibility in teenagers whose 'period problems' may have previously been dismissed and are causing them to miss school. Whilst most endometriosis will improve after the menopause, this is not always the case and so we shouldn't dismiss endometriosis as a possibility in post-menopausal women.

2) Have a symptom checklist.

The hallmark symptoms are pelvic pain and infertility. The extent of disease is not always proportional to the severity of symptoms, which can vary from a localised cyclical picture to more chronic pain, associated with fatigue and depression[6,7].

NICE[8] advise us to suspect endometriosis in women (including those ≤17yo) presenting with ≥1 of:

- Chronic pelvic pain (≥6 months).
- Period related pain (dysmenorrhoea) affecting daily activities and quality of life (QoL).
- Deep pain during or after sexual intercourse (dyspareunia).
- Period related or cyclical gastrointestinal symptoms, e.g. painful bowel movements (dyschezia).
- Period related or cyclical urinary symptoms, e.g. blood in the urine or pain passing urine.
- Infertility in association with one or more of the above.

Be mindful also of rarer symptoms such as cyclical scar swelling and pain, shoulder tip pain, cough and catamenial pneumothorax (pneumothorax occurring within 72 hours of menstruation[9]). Don't forget to ask if any first-degree relatives have a history of endometriosis, as this is a strong risk factor[8].

Endometriosis UK have a pain and symptom diary[10], which can be a helpful diagnostic tool.

For more resources, visit www.pcwhs.co.uk. Date of publication: April 2025. Date of next review: April 2028.

For further information, or to leave any feedback, please contact admin@pcwhs.co.uk

3) Examine, but remember that a normal examination doesn't rule out endometriosis.

Carry out an abdominal and internal vaginal examination (if appropriate) to identify any masses, rule out other differentials and elicit signs that may show more advanced disease, such as[8]:

- Reduced organ mobility and enlargement.
- Tender nodularity in the posterior fornix.
- Visible vaginal lesions.

4) Transvaginal ultrasound (TVUS) is the first-line investigation.

TVUS should be the first investigation, to rule out any other pathologies and potentially detect ovarian endometriomas and signs of deep endometriosis. It is not however very good as detecting superficial endometriosis, thus *do not rule out endometriosis based on a normal scan* and recognise that referral may still be warranted. For those that decline TVUS, consider transabdominal ultrasound of the pelvis[8].

Don't do a CA125 as it's not a sensitive or specific marker, and don't request an MRI from primary care. The latter is used in secondary care to assess the extent of deep endometriosis affecting nearby organs.

5) Don't shy away from making a working diagnosis.

You can make a working/presumptive diagnosis, based on symptoms, signs and ultrasound findings[11], without the need for a diagnostic laparoscopy.

Diagnosis of endometriosis can only be made definitively by laparoscopic visualisation of the pelvis, but it is not essential to make a definitive diagnosis. The European Society of Human Reproduction and Embryology (ESHRE) guidance,[11] (which is much more detailed than NICE guidance) says that laparoscopy should only be considered in those that have had a normal examination and imaging, and where empirical treatment hasn't helped with symptoms.

6) Signpost to support at an early stage.

Endometriosis is a complex chronic condition. It requires a holistic approach, supporting both physical and mental health; providing accurate information is part of that. The resources section has a list of useful patient information.

For more resources, visit www.pcwhs.co.uk. Date of publication: April 2025. Date of next review: April 2028.
 The PCWHS aims to educate primary care clinicians about women's health, i.e. the health of those who were registered female at birth. Our resources therefore all use the words woman/women and the pronouns she/her. Where patients have a gender identity which is different from their sex registered at birth, communication should be sensitive and respectful of the patient's pronouns.
For further information, or to leave any feedback, please contact admin@pcwhs.co.uk

7) You can start treatment in primary care: think pain relief and contraception.

Options depend on the woman's wishes, her symptoms, and whether she wants to conceive. The main aim is to control pain.

First line management as per NICE:

- A short trial (e.g. three months) of pain relief e.g. paracetamol +/- NSAID. If this doesn't help, consider other forms of pain management and referral
- Hormonal contraception to suppress ovarian function e.g.:
  - Combined hormonal contraception e.g. oral, transdermal or vaginal ring. This can be used continuously.
  - Progestogen only methods e.g. oral tablet, levonorgestrel intrauterine device, implant or depot injection. Options for oral progestogens include, medroxyprogesterone acetate, norethisterone or the progestogen only pill. These options have no permanent negative effect on future fertility..

8) Know your guidelines: when to refer

NICE[8] say the following:

- Refer to secondary care gynaecology if:
  - Initial treatment is not effective, not tolerated or contraindicated or
  - Symptoms are impacting daily living or are persistent or recurrent or
  - There are pelvic signs of endometriosis (but deep deposits are not suspected).

- Refer to a specialist endometriosis service if they have suspected or confirmed:
  - Endometriomas, or
  - Deep endometriosis (including bowel, bladder, or ureter) or
  - Endometriosis outside the pelvic cavity

- Refer young women (≤17) with suspected or confirmed endometriosis to a paediatric and adolescent gynaecology service, or specialist endometriosis service.

The NICE guidance on fertility[12] says that investigation should generally be done after one year of trying to conceive, but that referral should happen 'earlier' (timescale not specified) if there is a history of predisposing factors for infertility – this would include diagnosed or suspected endometriosis. The prevalence of endometriosis in women with infertility can be up to 50%[13,14]; women with suspected endometriosis who are trying to conceive are likely to need a multidisciplinary team approach involving gynaecology and fertility services. Most of what we can offer in primary care is contraceptive and therefore of no help to these women.

For more resources, visit www.pcwhs.co.uk. Date of publication: April 2025. Date of next review: April 2028.
 The PCWHS aims to educate primary care clinicians about women's health, i.e. the health of those who were registered female at birth. Our resources therefore all use the words woman/women and the pronouns she/her. Where patients have a gender identity which is different from their sex registered at birth, communication should be sensitive and respectful of the patient's pronouns.
For further information, or to leave any feedback, please contact admin@pcwhs.co.uk

9) Know a bit about secondary care medical and surgical options.

Further medical options in secondary care include dienogest, GnRH antagonists/ agonists and aromatase inhibitors[11].

A diagnostic laparoscopy +/- excision or ablation can confirm the diagnosis and remove deposits and adhesions. Endometriomas may also be surgically treated, which may improve pregnancy rates in endometriosis related infertility. In some cases, and where other treatments haven't worked a hysterectomy may be considered, but women should be counselled that this may not cure all of her symptoms.

10) Don't forget the menopause

For most women, the menopause resolves their endometriosis symptoms, due to an oestrogen deficient state. HRT may theoretically reactive endometriosis, but there is no strong evidence for this[11].

Deciding whether to give HRT is a balance between risks and benefit; keep in mind the important beneficial impact of HRT on bone and cardiovascular health especially in those with premature ovarian insufficiency (menopause <40). ESHRE supports the use of HRT in women with endometriosis.

Those using HRT after a hysterectomy for endometriosis should be given a continuous combined oestrogen and progestogen regime, or tibolone; there is a risk that oestrogen only therapy could reactivate any residual deposits. This may be changed later to oestrogen alone (after the natural age of menopause) but this needs to be balanced with the small theoretical risk of reactivation and malignant transformation[15]. Consider a discussion with her gynaecologist.

Resources for professionals

- NICE guidance.
- ESHRE guidance.
- BMS. Induced menopause in women with endometriosis.
- Endometriosis pathway for Scotland.
- Endometriosis specialist centre search tool.

For more resources, visit www.pcwhs.co.uk. Date of publication: April 2025. Date of next review: April 2028.
 The PCWHS aims to educate primary care clinicians about women's health, i.e. the health of those who were registered female at birth. Our resources therefore all use the words woman/women and the pronouns she/her. Where patients have a gender identity which is different from their sex registered at birth, communication should be sensitive and respectful of the patient's pronouns.
For further information, or to leave any feedback, please contact admin@pcwhs.co.uk

Resources for patients

- Endometriosis UK:
  - Pain and symptom diary.
  - Treatment options.
  - List of support groups.
- The Endometriosis Foundation.
- RCOG patient information.
- NHS website.
- NHS patient information leaflets in different languages.
- Information for those in devolved nations of the UK – Scotland, Wales, NI.
- Fertility network.

References

1) Taylor HS, Kotlyar AM, Flores VA. Endometriosis is a chronic systemic disease: clinical challenges and novel innovations. Lancet. 2021 Feb 27;397(10276):839-852.
2) Ochoa Bernal MA, Fazleabas AT. The Known, the Unknown and the Future of the Pathophysiology of Endometriosis. Int J Mol Sci. 2024 May 27;25(11):5815.
3) World Health Organization. Endometriosis. March 2023.
4) Shim JY, Laufer MR. Adolescent Endometriosis: An Update. J Pediatr Adolesc Gynecol. 2020 Apr;33(2):112-119
5) Endometriosis UK. "Dismissed, ignored and belittled" The long road to endometriosis diagnosis in the UK. March 2024.
6) Facchin F, Buggio L, Roncella E et al. Sleep disturbances, fatigue and psychological health in women with endometriosis: a matched pair case-control study. Reprod Biomed Online. 2021 Dec;43(6):1027-1034.
7) Szypłowska M, Tarkowski R, Kułak K. The impact of endometriosis on depressive and anxiety symptoms and quality of life: a systematic review. Front Public Health. 2023 Sep 6;11:1230303.
8) NICE. NG73. Endometriosis: diagnosis and management. Nov 2024.
9) Visouli AN, Zarogoulidis K, Kougioumtzi I et al. Catamenial pneumothorax. J Thorac Dis. 2014 Oct;6(Suppl 4):S448-60.
10) Endometriosis UK. Pain and symptom diary.
11) ESHRE. Endometriosis. Feb 2022.
12) NICE. CG156. Fertility problems: assessment and treatment. Sept 2017.
13) Van Gestel H, Bafort C, Meuleman C et al.The prevalence of endometriosis in unexplained infertility: a systematic review. Reprod Biomed Online. 2024 Sep;49(3):103848.
14) Bulletti C, Coccia ME, Battistoni S. Endometriosis and infertility. J Assist Reprod Genet. 2010 Aug;27(8):441-7.
15) BMS. Induced menopause in women with endometriosis. Aug 2022.

For more resources, visit www.pcwhs.co.uk. Date of publication: April 2025. Date of next review: April 2028.
 The PCWHS aims to educate primary care clinicians about women's health, i.e. the health of those who were registered female at birth. Our resources therefore all use the words woman/women and the pronouns she/her. Where patients have a gender identity which is different from their sex registered at birth, communication should be sensitive and respectful of the patient's pronouns.
For further information, or to leave any feedback, please contact admin@pcwhs.co.uk