

Do you see female patients? Do they have painful periods? Pain pre or post their periods? Painful sex? Do they suffer chronic pelvic pain, which



Endometriosis UK  
[endometriosis-uk.org](http://endometriosis-uk.org)

- **One in 10** women of reproductive age (between puberty and menopause) are affected by endometriosis.
- **10%** of women with endometriosis are infertile. **190 million worldwide.**
- The prevalence of endometriosis in women with infertility is as high as 50%.
- Endometriosis is the second most common gynaecological condition, after the commonest, the menstrual cycle.
- Endometriosis affects **1.5 million women**, a similar number of women are affected by diabetes or asthma.
- On average it takes **8 years** from onset of symptoms to get a diagnosis.
- Endometriosis costs the NHS **£8.2bn** a year in treatment, loss of education, work and health care costs.
- The cause of endometriosis is unknown, but there are many theories.



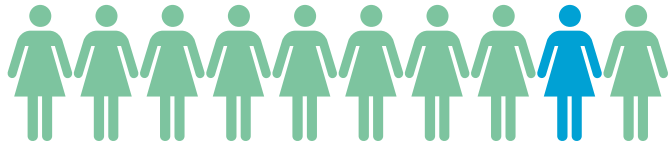
Women of any age can be affected by endometriosis but it is rare for the

Teenagers who suffer with painful periods, experience fainting or collapse when having a period, or who miss school because of their period problems should be considered as possibly suffering from the condition.

Symptoms may vary from woman to woman and some women may experience no symptoms at all (or may not recognise their symptoms as abnormal).

Typical endometriosis symptoms include:

- painful periods
- deep pain during sex
- chronic pelvic pain
- painful bowel movements, painful urination and blood in urine
- cyclical or premenstrual symptoms with or without abnormal bleeding and pain. Heavy periods are not a symptom of endometrisois, although a lot of women with endometriosis also have heavy periods.
- chronic fatigue
- depression (depression is not a direct symptom , however may be a side effect of the long diagnosis, or having a chronic condition and infertility.
- a family history of endometriosis
- infertility
- painful caesarean section scar or cyclical lump
- back, legs and chest pain.



Endometriosis should be considered early in young women with pelvic pain as there is often a delay of between seven and 12 years from the

Suspected endometriosis may be managed in primary care but consider referral to gynaecology or a specialist endometriosis centre if there is any suspicion or uncertainty over the cause of pain or if women are presenting with fertility issues. Women with suspected deep endometriosis involving the bowel, bladder or ureter must be referred to a specialist endometriosis service. All women should have as a minimum an abdominal examination and if appropriate a pelvic examination (NICE 2018 quality standard), and should be informed that endometriosis is being considered.

Treatments that can be tried in primary care include:

- **analgesics** (NSAID); these can be used in combination and especially around the time of the period
- **oral hormonal treatments** taken conventionally, continuously without a break, or in a tricycling regimen (three packs together); if women cannot have estrogen then the progesterone-only pill (eg, cerazette) could be used but it is important to remember that not all women will experience amenorrhoea so pain may persist; other alternatives include a course of medroxyprogesterone acetate (MPA), norethisterone or Dienogest (MHRA to approve this drug for use in England is awaited and it is now available to prescribe for endometriosis). If the initial course of hormonal treatment does not manage symptoms, the woman should be referred to a gynaecologist (NICE 2018 quality standard)
- **intra-uterine hormones** may provide relief from pain and is also a long-term treatment.

If you see a woman with the above symptoms, encourage her to see her GP or consider a referral to gynaecology. Be aware of local arrangements and seek advice from an endometriosis clinical nurse specialist (this may not be available in all areas, alternatively refer to local gynaecology department):

- if there is uncertainty over the diagnosis
- if a woman requests referral



- if the woman has fertility problems
- if surgical and medical management of endometriosis is required
  - endometriomas or where endometriosis is affecting the bowel (NICE 2018 quality standard)
- if initial hormonal treatment for endometriosis is not effective, not tolerated or contraindicated (NICE guidelines 2017 and Quality Standard 2018).

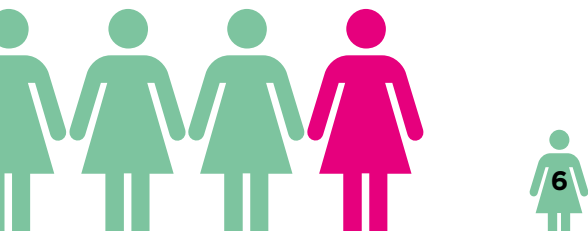
Please note, a six-month timescale can be used to decide whether initial hormonal treatment is effective however a referral should be made before six months if it becomes clear that treatment is not effective.

Women with endometriosis often need referral to secondary care for the diagnosis and treatment of the condition.

The investigations offered include ultrasound scan, although a negative scan or MRI does not rule out endometriosis, therefore the gold standard for diagnosis is laparoscopy with biopsy. Laparoscopy can be diagnostic but more often this is combined with operative surgical procedures to remove the endometriosis. Investigations offered should include a pelvic ultrasound scan, MRI scan, laparoscopy with biopsy, laparotomy, and laparoscopic assisted vaginal hysterectomy.

Cases of severe endometriosis (or suspected severe endometriosis) should be sent to a specialist BSGE (British Society for Gynaecology Endoscopy) accredited endometriosis centre where women can access specialist gynaecologists and a clinical nurse specialist (CNS) who work in conjunction with general surgeons and urologists. These specialist centres also liaise with pain management teams and have links with a local fertility team.

A list of BSGE accredited endometriosis centres can be found online at the BSGE website at: [bsge.org.uk](https://www.bsg.org.uk)



NICE (2017) **Endometriosis: diagnosis and management NICE guideline** [NG73]. Available at: [nice.org.uk/guidance/ng73](https://www.nice.org.uk/guidance/ng73)

NICE (2018) Endometriosis Quality standard [QS172]. Available at: [nice.org.uk/guidance/qs172](https://www.nice.org.uk/guidance/qs172)

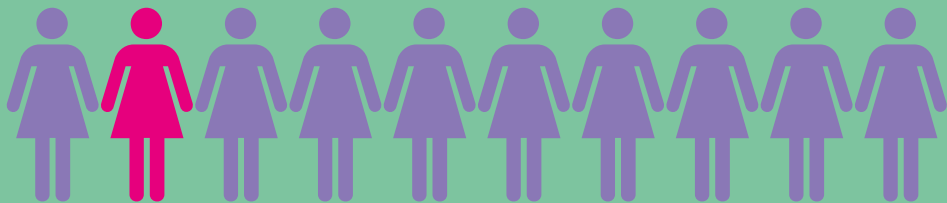
Norton W, Holloway D, Mitchell H and Law C (2020) The role of Endometriosis Clinical Nurse Specialists in British Society for Gynaecological Endoscopy  
Available at: [ncbi.nlm.nih.gov](https://www.ncbi.nlm.nih.gov) *Nursing open*

All Party Parliamentary Group on Endometriosis (2020) **Endometriosis in the UK:**









Please tear off this section and  
give it to women who you feel  
should seek a referral.



