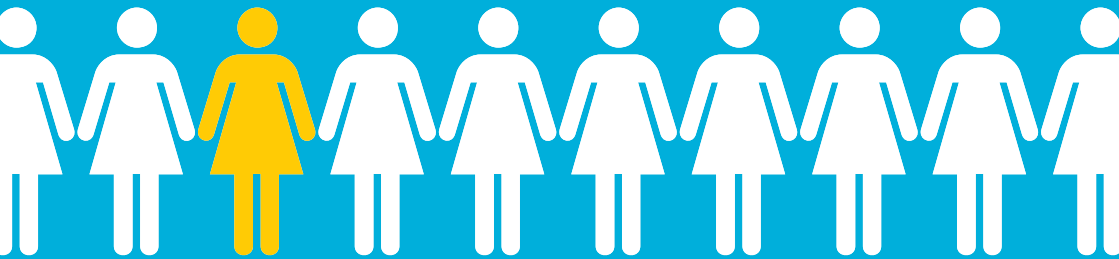


Endometriosis fact sheet



What is endometriosis?

Do you see female patients? Do they have painful periods? Pain pre or post their periods? Painful sex? Painful passing of urine or with bowel movements? Is it painful to place a speculum for a smear test?

Have you considered endometriosis?

One in 10 women have endometriosis and it takes an average of seven years for most women to get diagnosed. Endometriosis can often be confused with or misdiagnosed as IBS (irritable bowel syndrome).

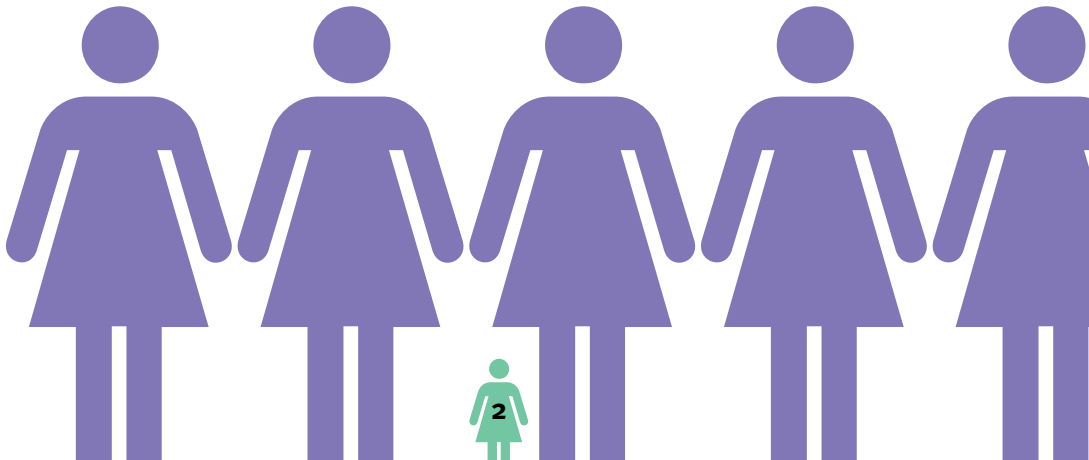
What is endometriosis?

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction.

While some women with endometriosis experience painful symptoms and/or infertility, others have no symptoms at all.

The exact prevalence of endometriosis is unknown but estimates range from between two and 10 per cent of the general female population but up to 50 percent in infertile women.

You can find out more about the condition by taking a look at the informative website www.endometriosis-uk.org. Endometriosis UK is a charity that works to improve the lives of people affected by endometriosis and to decrease the impact it has on those with the condition and their families and friends.

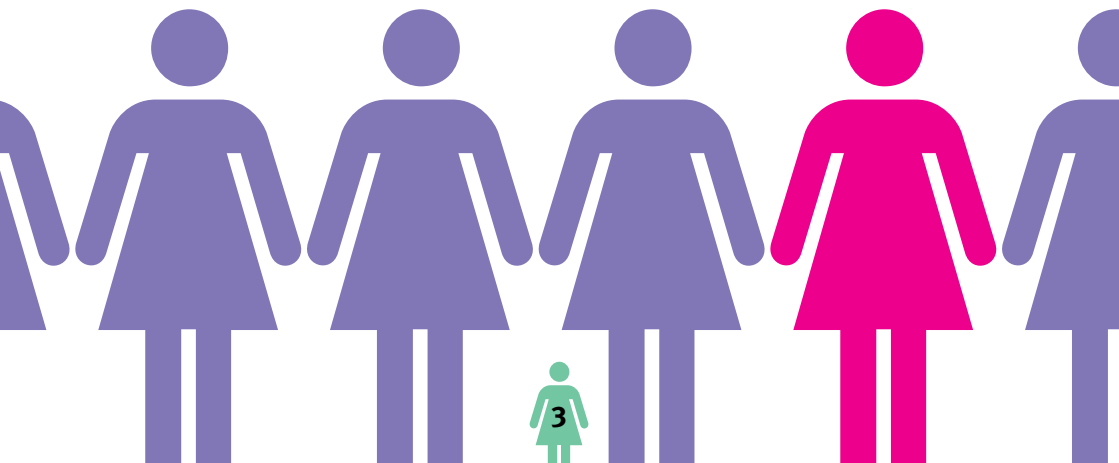


Some quick facts and figures about endometriosis

Facts and figures – from Endometriosis UK www.endometriosis-uk.org

- **One in 10** women of reproductive age in the UK suffer from endometriosis.
- **Ten per cent** of women worldwide have endometriosis – that's **176 million worldwide**.
- The prevalence of endometriosis in women with infertility is as high as 50 per cent.
- Endometriosis is the second most common gynaecological condition (after fibroids) in the UK.
- Endometriosis affects **1.5 million women**, a similar number of women are affected by diabetes.
- On average it takes **7.5 years** from onset of symptoms to get a diagnosis.
- Endometriosis costs the UK economy **£8.2bn** a year in treatment, loss of work and health care costs.
- The cause of endometriosis is unknown, but there are many different treatment options.

Information provided by Endometriosis UK



Who may be affected?

Women of any age can be affected by endometriosis but it is rare for the condition to manifest before a girl has her first period.

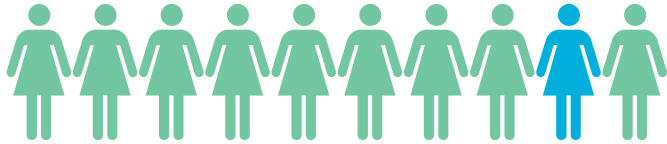
Teenagers who suffer with painful periods, experience fainting or collapse when having a period, or who miss school because of their period problems should be considered as possibly suffering from the condition.

What are the symptoms?

Symptoms may vary from woman to woman and some women may experience no symptoms at all.

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
- chronic fatigue
- depression
- 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 onset of symptoms to receiving a definitive diagnosis.

Care management in primary care

Suspected endometriosis can 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. Referrals should take place in all severe cases of pain or if women are presenting with fertility issues.

Treatments that can be tried in primary care include:

- **analgesics** – either simple or non-steroidal anti-inflammatory drugs (NSAID); these can be used in combination and especially around the time of the period
- **oral hormonal treatments** – combined oral contraceptive pills can be 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 amenorrhea so pain may persist; other alternatives include a course of medroxyprogesterone acetate (MPA) or norethisterone
- **intra-uterine hormones** – an intra-uterine system such as Mirena IUS can provide relief from pain and is also a long-term treatment.

When to refer?

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:

- 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
- if complex/severe endometriosis is suspected – for example, endometriomas
- for women with treatment failures in primary care.



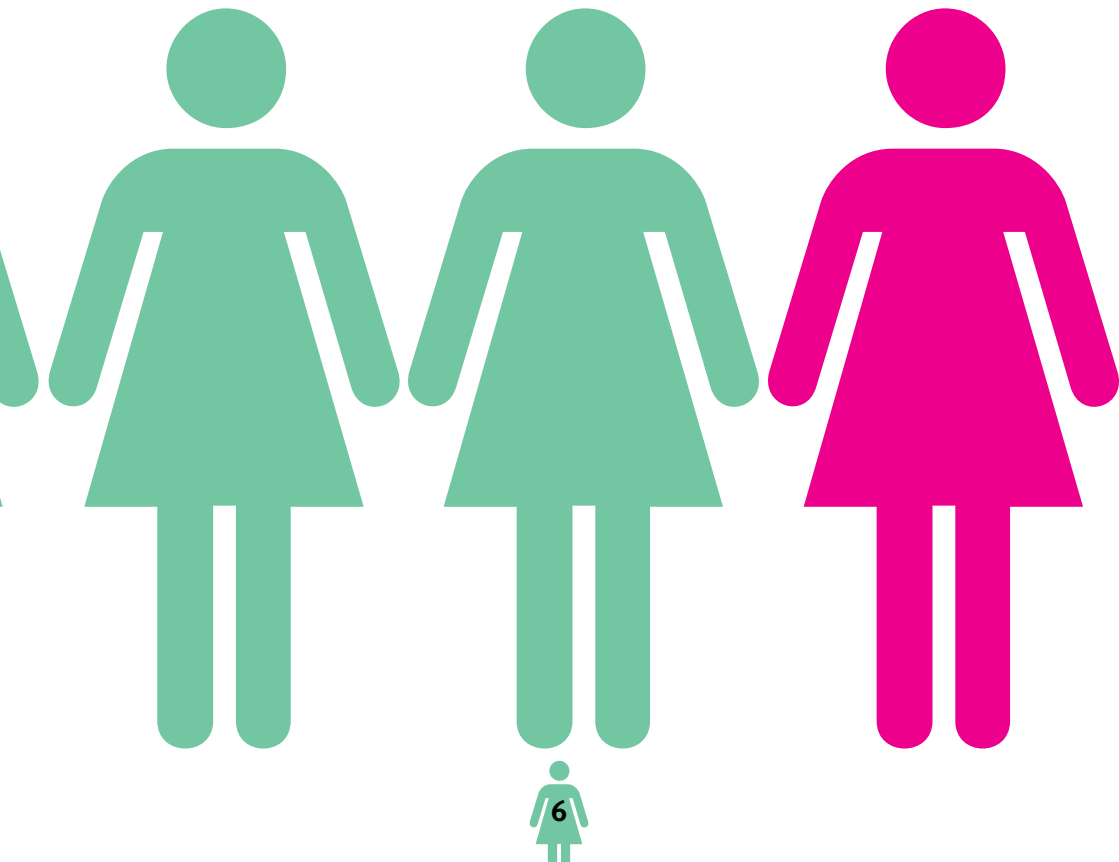
Care in secondary care and endometriosis centers

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

The investigations offered include ultrasound scan, MRI and the gold standard for diagnosis – laparoscopy. Laparoscopy can be diagnostic but more often this is combined with operative surgical procedures to remove the endometriosis.

Cases of 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 also have links with a local fertility team.

A full list of accredited specialist endometriosis centres in the UK can be found online at the BSGE website at www.bsge.org.uk



Further information and resources

To discover more about the condition or access additional information resources, here are some websites together with some topical research studies you might find helpful.

Endometriosis UK

www.endometriosis-uk.org

The British Society for Gynaecological Endoscopy

www.bsge.org.uk

Royal College of Obstetricians and Gynaecologists

www.rcog.org.uk

European Society of Human Reproduction and Embryology

www.eshre.eu

The World Endometriosis Society

www.endometriosis.ca

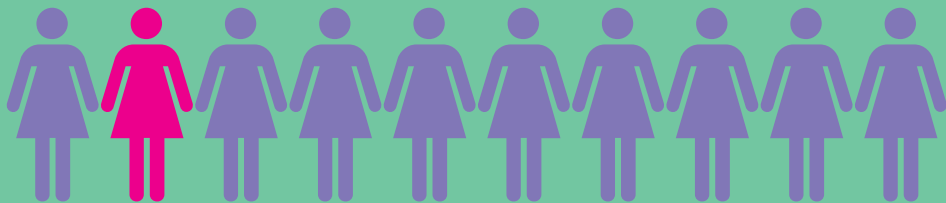
The ENDOPART study findings, published in 2013, provide a powerful insight into the emotional, sexual and relational impacts of the disease. See *Endometriosis: improving the wellbeing of couples – summary report and recommendations*. Available at: www.dmu.ac.uk/research

A 2010 study provides valuable indicators for providing care and services to women from minority ethnic groups. See *Endometriosis and cultural diversity: improving services for minority ethnic women* at www.endocul.co.uk



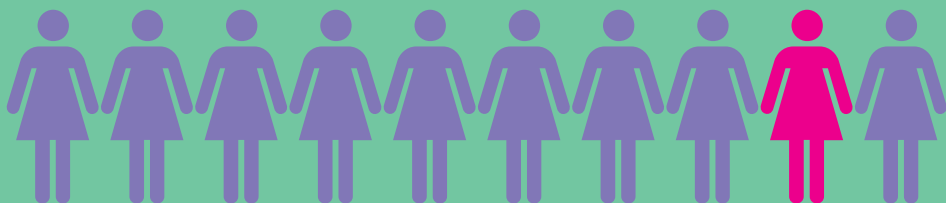
It has been suggested that I may have endometriosis.

Symptoms	Yes/no	Notes
Painful periods		
Heavy periods		
Deep pain during sex		
Chronic pelvic pain		
Pain during bowel movements		
Painful urination and blood in urine		
Cyclical or premenstrual symptoms with or without abnormal bleeding and pain		
Chronic fatigue		
Depression		
Family history of endometriosis		
Infertility		
Painful caesarean section scar or cyclical lump in the scar		
Pain in back, legs and chest		



Endometriosis

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



The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

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