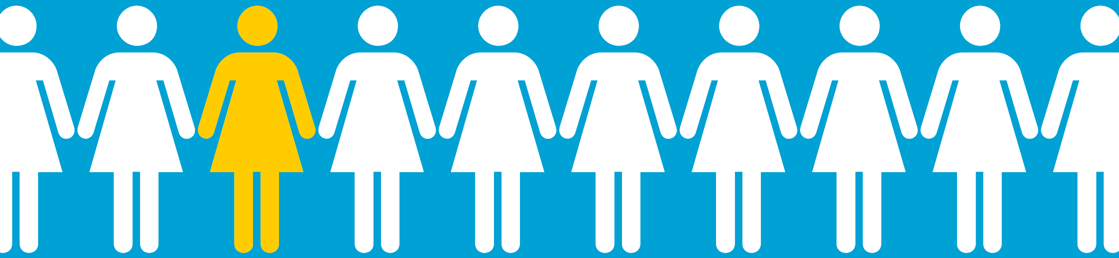
Royal College
of Nursing

Endometriosis factsheet



Endorsed by

endometriosis uk

What is endometriosis?

Do you see female patients? Do they have painful periods? Pain pre or post their periods? Painful sex? Do they suffer chronic pain, which may be intermittent or constant? Do they have pain when passing 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). It is important that women receive a early diagnosis, or working diagnosis, of endometriosis even if hormonal treatments appear to be working, as women need to understand that they have a long term, chronic condition and the impact this might have on their future and their fertility.

What is endometriosis?

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction, and may lead to scar tissue formation.

While some women with endometriosis experience painful symptoms and/or infertility, others have no symptoms at all (or may consider their symptoms to be normal).

The exact prevalence of endometriosis is unknown but estimates range from between 2-10% of the general female population but up to 50% in infertile women.

NICE published new guidance in 2017, which details diagnosing and managing endometriosis, and should be consulted for further information.

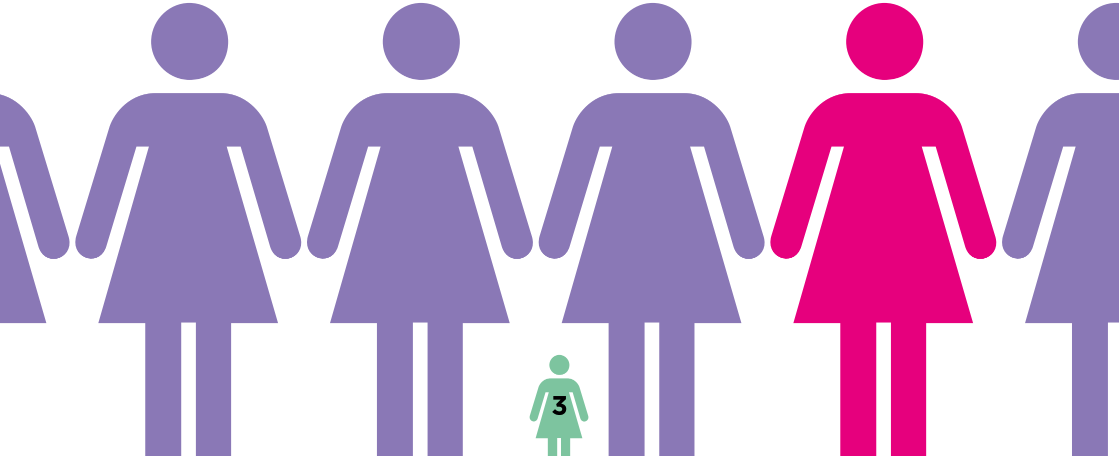
You can find out more about the condition by taking a look at the informative website **www.endometriosis-uk.org**. Endometriosis UK is a charity that works to improve the lives of people affected by endometriosis and to decrease the impact it has on those with the condition and their families and friends.

Some quick facts and figures about endometriosis

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

- **One in 10** women of reproductive age (between puberty and menopause) in the UK suffer from endometriosis.
- **10%** of women worldwide have endometriosis – that's **176 million worldwide**.
- The prevalence of endometriosis in women with infertility is as high as 50%.
- 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 or asthma.
- 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 education, 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?

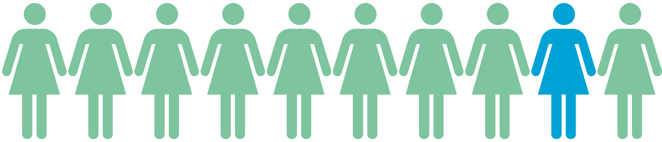
Women of any age can be affected by endometriosis but it is rare for the condition to manifest before a girl has her first period.

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 (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
- 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 may be managed in primary care but consider referral to gynaecolgocy or a specialist endometriosis centre if their 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 (quality standard 2018), and should be informed that endometriosis is being considered.

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 amenorrhoea so pain may persist; other alternatives include a course of medroxyprogesterone acetate (MPA) or norethisterone. If the initial course of hormonal treatment does not manage symptoms, the woman should be referred to a gynaecologist (quality standard 2018).
- **intra-uterine hormones** – an intra-uterine system such as Mirena IUS may 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 women 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 or where endometriosis is affecting the bowel (Quality Standard 2018)
- 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.

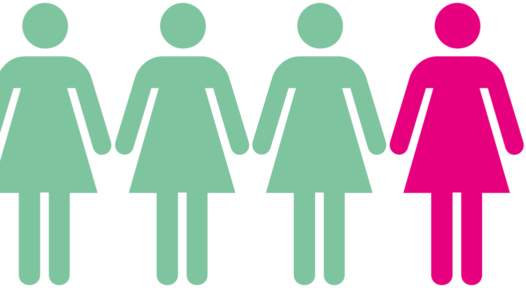
Care in secondary care and endometriosis centres

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. Laparoscopy can be diagnostic but more often this is combined with operative surgical procedures to remove the endometriosis.

Cases of severe endometriosis (or severe suspected 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 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

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

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

Norton W et al., (due to be published shortly) *The Role of the Endometriosis Clinical Nurse Specialist in British Society for Gynaecological Endoscopy Registered Centres*.

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

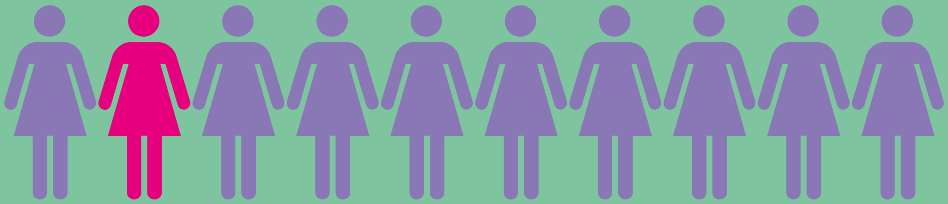
The World Endometriosis Society
www.endometriosis.ca

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 **http://cultureandcompassion.com/wp-content/uploads/2015/04/Endometriosis-and-cultural-diversity.pdf**

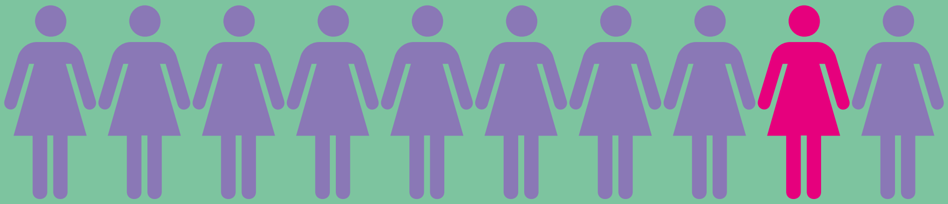
It has been suggested that I may have endometriosis.

Symptoms	**Yes/ no**	**Notes**
Painful periods		
Heavy periods		
Deep pain during sex		
Chronic pelvic pain (periodic or constant)		
Pain during bowel movements		
Painful urination and/or 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/or chest		



Endometriosis

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



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