Royal College of Nursing

What is Endometriosis?

CLINICAL PROFESSIONAL RESOURCE

Acknowledgements

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Endorsed by

ENDOMETRIOSIS UK

Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

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Introduction

Do you see female patients and those assigned female at birth? Do they have painful periods? Pain pre or post their periods? Painful sex? Do they suffer chronic pelvic 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?

The RCN recognises that we all live in a gender diverse society and that this standard may be used by and/or applied to people who identify as nonbinary or transgender.

Have you considered endometriosis?

One in 10 women and those assigned female at birth have endometriosis and it takes an average of over 8 years from the onset of symptoms to get a diagnosis. 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. There are different types of endometriosis including superficial, deep infiltrating disease (>5mm deep into the tissue) and extra-pelvic endometriosis, where endometriosis is found outside of the pelvic cavity.

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 the World Health Organization estimates that 10% (WHO, 2023) of the general female population and up to 50% of infertile women have endometriosis.

NICE updated its guidance on diagnosing and managing endometriosis in 2024, and should be consulted for further information.

You can find out more about the condition by taking a look at the informative website 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
endometriosis-uk.org

- 1 in 10 women and those assigned female at birth of reproductive age (between puberty and menopause) in the UK suffer from endometriosis.
- 10% of women worldwide have endometriosis – that's 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 fibroids) in the UK.
- Endometriosis health care costs are comparable to other common diseases such as type 2 diabetes, rheumatoid arthritis, and Crohn's disease.
- On average it takes over 8 years from the 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 and there is no definite cure, but many different treatment options.

Information provided by Endometriosis UK **endometriosis-uk.org** and European Society of Human Reproduction and Embryology **eshre.eu**

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. The effects of endometriosis can also be experienced during menopause and later in life.

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 that interfere with everyday life. The amount of bleeding varies in women with endometriosis – ranging from heavy to normal (Endo UK, 2024)
- deep pain during sex
- chronic pelvic pain
- painful bowel movements and blood in stool, painful urination and blood in urine
- 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)
- infertility
- painful caesarean section scar or cyclical lump
- back, legs and shoulder tip pain
- chest pain and/or a cyclical cough.

A family history of endometriosis is a risk factor. Endometriosis should be considered early in young women with pelvic pain as there is often a delay of between 8-12 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 there is any suspicion or uncertainty over the cause of pain or if women are presenting with fertility issues. Women with suspected deep endometriosis and extra-pelvic 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 a pelvic ultrasound scan (NICE guidelines) to investigate suspected endometriosis. Even if the pelvic and/or abdominal examination is normal consider referral if symptoms persist.

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** – a combined hormonal contraceptive can be taken conventionally, continuously without a break, or in a tricycling regimen (three packs together); if women cannot have estrogen then a progesterone-only contraceptive 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. Women can have initial treatment while undergoing investigations and awaiting referral (NICE, 2024)
- **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 (this may not be not available in all areas, alternatively refer to local gynaecology department):

- if there is uncertainty over the diagnosis
- if treatment fails
- if a women requests referral
- if the woman has fertility problems
- if surgical and medical management of endometriosis is required
- if endometriosis is suspected or confirmed outside of the pelvic cavity – for example, 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)
- if a woman has symptoms of endometriosis which have a detrimental impact on activities of daily living, or
- if a woman has persistent or recurrent symptoms of endometriosis
- if a woman has pelvic signs of endometriosis, but deep endometriosis is not suspected (NICE, 2024).

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 imaging, (ultrasound scan, specialist ultrasound scan to identify deep infiltrating endometriosis in the pelvis, or MRI) and ovarian endometriosis, endometrioma, although a negative finding does not exclude endometriosis.

Laparoscopy is no longer the diagnostic gold standard; it is now only recommended in patients with negative imaging results and/or where empirical treatment was unsuccessful or inappropriate. Laparoscopic identification of endometriotic lesions is confirmed by histology although negative histology does not entirely rule out the disease (ESHRE, 2022).

Cases of complex 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. Those with deep endometriosis involving the bowel, bladder or ureter, or endometriosis outside the pelvic cavity should be referred to a specialist and those aged 17 and under with suspected or confirmed endometriosis should be referred to either a paediatric and adolescent gynaecology service or a specialist BSGE accredited endometriosis service – depending on local service provisions. These specialist centres also liaise with pain management teams and have links with local fertility teams.

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

Refer women to a specialist endometriosis service (see the recommendation on specialist endometriosis services (endometriosis centre) if they have suspected or confirmed:

- endometrioma
- deep endometriosis, including that involving the bowel, bladder or ureter
- endometriosis outside the pelvic cavity. (NICE, 2024).

Refer young women (aged 17 and under) with suspected or confirmed endometriosis to a paediatric and adolescent gynaecology service or specialist endometriosis service (endometriosis centre) for further investigation and management (NICE, 2024).

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.

The British Society for Gynaecological Endoscopy **bsge.org.uk**

Endometriosis UK **endometriosis-uk.org**

European Society of Human Reproduction and Embryology **eshre.eu**

Royal College of Obstetricians and Gynaecologists **rcog.org.uk**

The World Endometriosis Society **endometriosis.ca**

Dixon S, McNiven A, Talbot A and Hinton L (2021) Navigating possible endometriosis in primary care: a qualitative study of GP perspectives. *British Journal of General Practice*, 71(710), pp.e668-e676.

Law C, Hudson N, Mitchell H, Culley L and Norton W (2024) You feel like you're drifting apart: a qualitative study of impacts of endometriosis on sex and intimacy amongst heterosexual couples. *Sexual and Relationship Therapy*, pp.1-24.

National Institute for Health and Care Excellence (2024) *Endometriosis: diagnosis and management NICE guideline [NG73]*. Available at: **nice.org.uk/guidance/ng73**

National Institute for Health and Care Excellence (2018) *Endometriosis Quality standard [QS172]*. Available at: **nice.org.uk/guidance/qs172**

National Institute for Health and Care Excellence (2017) *Hormone treatment for endometriosis symptoms – what are my options? Patient decision aid*. Available at: **nice.org.uk/guidance/ng73**

Norton W, Holloway D, Mitchell H and Law C (2020) The role of Endometriosis Clinical Nurse Specialists in British Society for Gynaecological Endoscopy registered centres: A UK survey of practice. *Nursing Open*, 7(6), pp.1852-1860. Available at: **ncbi.nlm.nih.gov**

All Party Parliamentary Group on Endometriosis (2020) Endometriosis in the UK: Time for Change – APPG on Endometriosis Inquiry Report 2020. Available at: **endometriosis-uk**

Royal College of General Practitioners (2021) *Menstrual Wellbeing Toolkit*. Available at: **rcgp.org.uk**

Royal College of Nursing (2022) *Promoting Menstrual Wellbeing*. Available at: **rcn.org.uk**

WHO (2023) *Endometriosis*. Available at: **who.int**

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

Symptoms	Yes/no	Notes
Painful 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 shoulder tip pain		
Cyclical cough		

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

This publication provides nurses with guidance on how to recognise symptoms, sets out pathways of care and signposts to useful online resources. Please read in conjunction with *Clinical Nurse Specialist in Endometriosis* (publication code: 011 850).

Publication date: November 2024 Review date: November 2027

The Nine Quality Standards

This publication has met the nine quality standards of the quality framework for RCN professional publications. For more information, or to request further details on how the nine quality standards have been met in relation to this particular professional publication, please contact **publications.feedback@rcn.org.uk**

Evaluation

The authors would value any feedback you have about this publication. Please contact **publications.feedback@rcn.org.uk** clearly stating which publication you are commenting on.

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0345 772 6100

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 3333
www.rcn.org.uk

November 2024
Review date: November 2027
Publication code: 011 851

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