

Endometriosis Awareness

Information and resources



All links here

Watch the ALLIANCE and Scottish Government webinar on endometriosis here:

<https://www.youtube.com/watch?v=y2mSYM8V8>

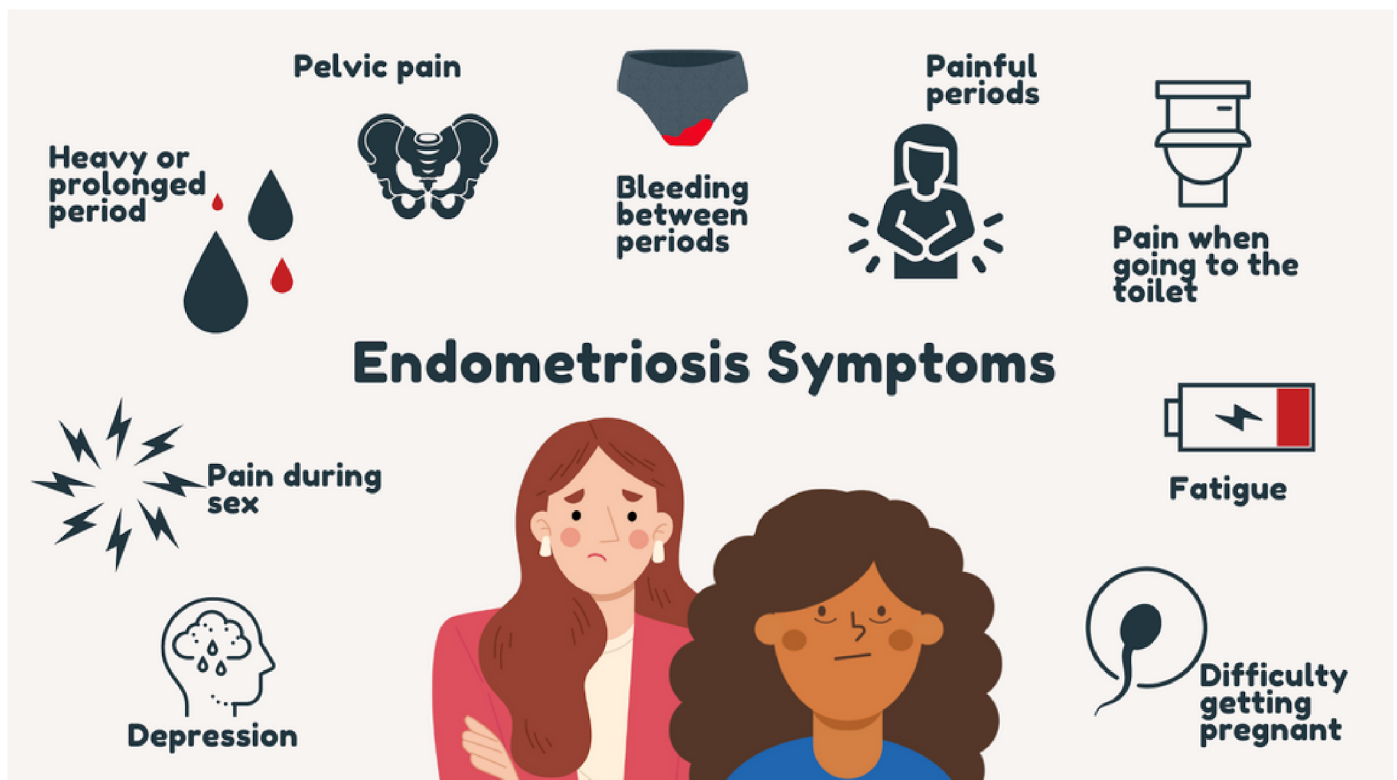


What is endometriosis?

Endometriosis is a common condition, estimated to affect 1 in 10 women* worldwide. Endometriosis occurs when **tissue similar to the lining of the womb ('lesions') is found elsewhere in the body**. These lesions can be found anywhere in the body, but are most commonly found within the pelvic area.

Endometriosis is affected by the hormones oestrogen and progesterone so endometriosis symptoms can often be influenced by the menstrual cycle.

The cause of endometriosis is not currently fully understood.



**This leaflet uses the term woman/women throughout but it is important to highlight that it is not only those who identify as women that can have endometriosis.*

- More information on endometriosis can be found on NHS Inform: <https://www.nhsinform.scot/healthy-living/womens-health/girls-and-young-women-puberty-to-around-25/periods-and-menstrual-health/endometriosis>
- The University of Edinburgh's EXPPECT centre conducts research on the condition, and has a number of resources: <https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/about-endometriosis>
- For young people under 26, Young Scot has several pages on the condition: <https://young.scot/campaigns/lets-talk-endometriosis/>
- A patient information leaflet can be accessed via the RCOG: <https://www.rcog.org.uk/for-the-public/browse-our-patient-information/endometriosis-patient-information-leaflet/>
- Watch a short animation from the University of Edinburgh's EXPPECT team about the condition here: <https://www.youtube.com/watch?v=34syY5N5ZQA>



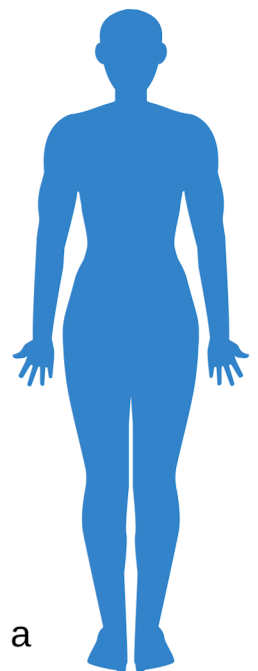
Symptoms of endometriosis

There are multiple symptoms associated with endometriosis, and these can vary from person to person and from month to month.

Endometriosis can affect the whole body. Symptoms can relate to different types of severe pain, heavy bleeding during menstruation, fertility difficulties, depression, fatigue and gastrointestinal and urinary issues.

Not everyone with endometriosis will experience all endometriosis symptoms.

Severe pain during your period is not normal. Periods should not stop you from living your life. If you are concerned about symptoms you are experiencing then visit your GP. You may find it helpful to have a note of your symptoms on hand.



- For more information on endometriosis symptoms see NHS Inform.
- To understand what a normal period is, and what symptoms could indicate a concern watch this short video with Dr Jackie Maybin: <https://www.youtube.com/watch?v=WyX5fAkOvJo&t=15s>



Diagnosis of endometriosis

Endometriosis can be difficult to diagnose due to the variation of symptoms and similarity of symptoms to other conditions.

The main way to confirm endometriosis is through a laparoscopy. This is keyhole surgery carried out under a general anaesthetic.

There are however symptoms that can flag the possibility of endometriosis to a clinician, such as chronic pelvic pain, severe period pain and cyclical pain. It is therefore important to **understand and note your own symptoms** so you can present your experience to a doctor.

- Information on the diagnosis process for endometriosis can be downloaded from Endometriosis UK: <https://www.endometriosis-uk.org/getting-diagnosed-0>
- The Royal College of Obstetricians and Gynaecologists provides information on what to expect, and how to recover well, from a laparoscopy: <https://www.rcog.org.uk/for-the-public/browse-our-patient-information/laparoscopy-recovering-well-patient-information-leaflet/>

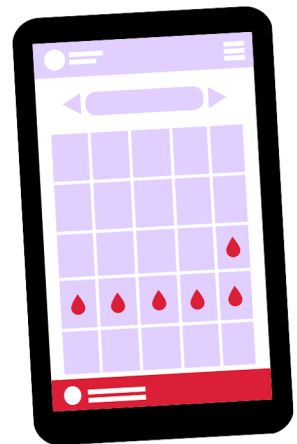


Tracking symptoms

Understanding your own symptoms and patterns is useful within the diagnosis journey for endometriosis and helps you to manage the condition.

Sharing your symptoms and their regularity with a doctor can give them a better understanding of what you are experiencing.

It can be helpful to keep a note of your period dates and symptoms using a calendar, a diary or an app.



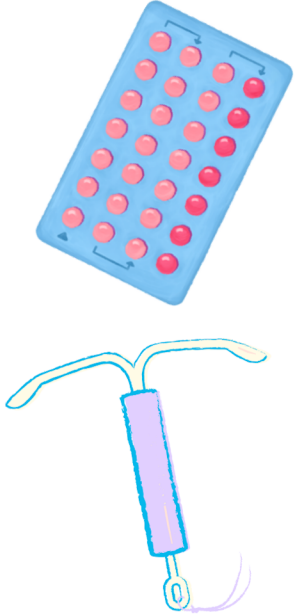
You can download a pain and symptoms diary from a number of sources for free:

- https://www.endometriosis-uk.org/sites/default/files/2022-08/pain-symptoms-diary_0.pdf
- https://www.endosos.org/_files/ugd/0259f2_e4dbfe20715242c5ab28a5d80045be24.pdf
- https://www.bupa.co.uk/womens-health/~/_media/Files/MMS/bins-05609.pdf



Managing endometriosis

Endometriosis is a complex condition, and so managing and treating it can involve different medical disciplines and you may be referred to other specialist consultants, outwith gynaecology, such as pain management specialists, colorectal surgeons or urologists.



Hormonal treatments are commonly used to help people manage endometriosis, as research has shown that endometriosis responds to oestrogen. Hormonal treatment options are either hormonal contraceptives, such as the pill, injection, implant or hormone producing coil, or medication that puts the body into temporary menopause. Hormonal options only have an affect while the person continues to take them.

Various pain management strategies are also offered to people with endometriosis. These should be discussed with your doctor.

Another treatment option is surgery, usually carried out via a laparoscopy, to remove the endometriosis tissue. However, not everyone with endometriosis has to have a laparoscopy if the symptoms can be managed. Even after surgery, the endometriosis may grow back so some people may need further surgery. Therefore, it's important to discuss the best treatment option for you with your doctor so you can decide what's best for you.

Many people with endometriosis can get pregnant naturally. However, some women with endometriosis can find it more difficult to get pregnant. There are fertility treatments available that are effective in women with endometriosis, such as IVF, which can be explored with your doctor.

- The EXPPECT centre has produced a number of leaflets detailing both surgical and medical treatment options for endometriosis: <https://www.ed.ac.uk/centre-reproductive-health/exppect-endometriosis/information-for-patients/patient-information-sheets>
- EXPPECT also have information on pelvic pain management options: <https://www.ed.ac.uk/centre-reproductive-health/exppect-pelvic-pain/information-for-patients/patient-information-sheets>
- Endometriosis UK also has an extensive break down of treatment for the condition: <https://www.endometriosis-uk.org/treatment-and-management>

- The “It’s Ok to Ask” campaign from NHS Inform can help you prepare for appointments with doctors, and support you in making informed decisions: <https://www.nhsinform.scot/campaigns/its-ok-to-ask/>
- For more information on fertility and planning pregnancy see Tommy’s: <https://www.tommys.org/pregnancy-information/planning-a-pregnancy/fertility-and-causes-of-infertility>
- You can access a self-help guide on NHS Inform which is focused on managing chronic pain: <https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/chronic-pain-self-help-guide>



Living with endometriosis

Endometriosis can have a big impact on a person’s life and can be challenging to live with. As symptoms vary from person to person, everyone has their own story and things that work best for them.

The challenges of endometriosis can impact a person’s mental wellbeing, but being able to **talk openly with others about what you’re going through can be supportive to your own journey**. There are lots of peer support networks operating on a national and local level throughout Scotland which provide a space for listening and learning



- A short video from NHS 24 explores three different experiences of living with endometriosis: <https://www.youtube.com/watch?v=0gPMjFjl5A>
- At the ALLIANCE webinar on endometriosis, we heard from two women about their lived experience journey with the condition (watch from 29.24): <https://www.youtube.com/watch?v=y2mSYMi-8V8>
- The Scottish Government has published a report which details the findings from a series of endometriosis lived experience interviews: <https://www.gov.scot/publications/endometriosis-lived-experience-insight-report-2023/>
- Resources are available from NHS Inform to support better mental health during your period: <https://www.nhsinform.scot/self-help-guides/self-help-tool-periods-and-mental-wellbeing/>
- Young Scot provides information to help young people to support someone they know who is living with endometriosis: <https://young.scot/get-informed/supporting-someone-with-endometriosis/>



Find your local endometriosis peer support group:

- Endometriosis UK - <https://www.endometriosis-uk.org/support-groups>
- North Highland Women's Wellbeing Hub - <https://www.northhighlandwwh.com/>
- Endo South of Scotland - <https://www.endosos.org/>
- Endo Warriors West Lothian - <https://www.facebook.com/groups/318047295326256/>



Endometriosis and Work

Endometriosis can impact on a person's work. Dealing with recurring symptoms, trying treatment options and recovering from surgery can affect people's experience in the workplace.

Speak to your employer about available policies that could support you to work well with endometriosis.

- There is guidance for employers on how to support employees with endometriosis and menstrual health conditions. This can be found through the Endometriosis Friendly Employer Scheme. Details here: <https://www.endometriosis-uk.org/endometriosis-friendly-employer-scheme>
- Further guidance can also be found here: <https://www.bupa.co.uk/~media/Files/MMS/bins-11373.pdf>
- NHS Scotland's menopause and menstrual health workplace policy and resources also provides insight into getting/providing support at work: <https://wellbeinghub.scot/resource/mmhp/>

