



Understanding endometriosis

This factsheet is for those who have a diagnosis of endometriosis. It explains what endometriosis is and includes information on diagnosis, treatment and where you can get support.

What is endometriosis?

Endometriosis occurs when cells like the ones in the lining of the womb or uterus are found elsewhere in the body. It is commonly found in the pelvic area but can be found anywhere in the body. Each month these cells react in the same way to those in the womb, building up and then breaking down and bleeding. Unlike the cells in the womb that leave the body as a period, this blood has no way to escape. This can cause inflammation, pain and scar tissue.

Your endometriosis may be on your ovaries, fallopian tubes and other pelvic organs like the bowel or bladder. It can also be found in your vagina or rectum (back passage). In rare cases, endometriosis can also be found outside the pelvis, such as in the chest. It typically affects from puberty to menopause but symptoms, but the impact can be felt for life.

You may be diagnosed with:

Superficial endometriosis – meaning your endometriosis is on the surface of the organ

Deep endometriosis – meaning the endometriosis is invading into the muscle of the organ

Endometriosis can grow anywhere in the body but more commonly it affects the reproductive organs and tissues in the lower abdomen such as the ovaries, fallopian tubes, bladder, bowel, vagina or rectum (back passage). In some cases endometriosis can be found outside of the pelvis, such as the thorax (chest) and cesarean scars.

Signs and symptoms

Symptoms can be varied from person to person, but they can affect all aspects of life. Some people may have symptoms that have a significant impact on their day-to-day life, others may have no symptoms at all. Each individual experience is different.

Common signs and symptoms include:

- Painful periods that interfere with everyday life
- Pelvic pain
- Pain during or after sex

- Pain when going to the toilet
- Blood in poo or pee
- Difficulty getting pregnant
- Fatigue

Symptoms of bladder endometriosis

- Needing to pee more often
- Pain when peeing
- Having an urgent need to pee
- Having trouble emptying your bladder when peeing
- Blood in your pee
- In rare cases you may have kidney pain

Symptoms of bowel endometriosis

- Bloating or gas in your tummy
- Pain in your lower back.
- Pain during sex.
- Rectal bleeding while menstruating.
- Extreme pain when having a poo
- Digestive pain or symptoms similar to IBS - nausea, diarrhoea, constipation

Symptoms of thoracic (chest) endometriosis

It is rare to have endometriosis in your chest. If you do have thoracic endometriosis you may experience:

- Shortness of breath
- chest pain specifically during a period.
- Shoulder-tip pain
- Shortness of breath
- Chest pain during a period
- Shoulder-tip pain

Other symptoms may also be experienced, including:

- Pain starting before periods
- Ovulation pain
- Pain on internal examination (i.e smears)
- Heavy periods
- Prolonged bleeding
- Bleeding after sex
- Frequent urinary tract infections
- Feeling faint or fainting during a period

How common is endometriosis?

Endometriosis is the second most common gynecological condition. It is estimated that around 1.5 - 2 million women in the UK have endometriosis. 1 in 10 women and those assigned female at birth have endometriosis. In the UK means 1.5 million have the condition.

Who gets endometriosis?

Endometriosis affects all women and those assigned female at birth, regardless of their age, race or ethnicity or lifestyle.

Is there a cure for endometriosis?

There has not been enough research into endometriosis and currently no known cause or cure. The treatment options tend to focus on symptom management.

What should I do if I think I have endometriosis?

The first step to getting a diagnosis is to visit your GP. A GP cannot diagnose endometriosis for certain, but they can offer you treatment to help with your symptoms. Your GP can also give you a referral to a gynaecologist to investigate your symptoms further.

Our [consultation questionnaire](#) <link> gives examples of the types of questions your GP might ask. You can fill this in beforehand to help you answer questions in your appointment. Our [pain and symptoms diary](#) allows you to record how your symptoms are affecting your everyday life. It is important that you share as much information as possible about your symptoms with your doctor.

Your GP can check you for infections and arrange for you to have a scans and tests to investigate your symptoms. They may look for or try to rule out other conditions such as polycystic ovary syndrome (PCOS), Heavy menstrual bleeding (HMB), irritable bowel syndrome (IBS) or fibroids. Your GP can help with symptom management including prescribing painkillers. They may also start treatment with the pill or other hormone treatments.

If your symptoms do not improve with treatment, you can ask for a referral to a gynaecologist or an endometriosis specialist.

How is endometriosis treated?

Your treatment plan should be decided in partnership between you and your doctor. The type of treatment you have will depend on your individual case and your own needs and priorities. These could include:

- Surgery

- Pain Management
- Hormone treatment

The decision should depend on several factors:

- Your age
- The severity of your symptoms
- The severity of your endometriosis
- If you've had any previous treatment
- Risks or side effects of treatments
- Your medical history or health risks
- How long you intend to stay on treatment
- Whether or not you want children, and when

Your doctor will explain the treatment options available to you and can advise you any benefits, risks or side effects of treatment.

See our information on <surgery for endometriosis> [hyperlink](#)

See our information on <hormone treatment and pain management> [hyperlink](#)

How we can help

Living with endometriosis can be a daunting experience. If you're finding things difficult, we're here to help. Our trained volunteers, all with personal experience of endometriosis, can offer you the help you need to understand your condition and take control. We offer:

Quality information and advice on endometriosis, including a series of webinars

Emotional and practical support through our network of support groups, helpline, webchat and online forum

Visit www.endometriosis-uk.org/get-support or Helpline: 0808 808 2227

Tell us what you think

You can give us feedback on all our publications by contacting us on information@endometriosis-uk.org

Many thanks to the health practitioners and volunteers who gave their time and shared their expertise and experience to help us produce this factsheet.

