



## 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 similar to the ones in the lining of the womb (uterus) are found elsewhere in the body. These cells can grow and change in response to hormones in the menstrual cycle, this can cause inflammation, pain and scar tissue.

Endometriosis is most commonly found on the lining of the pelvis (peritoneum) and may occur in the ovaries and involve other pelvic organs, like the bowel or bladder. Less commonly, endometriosis can also be found outside the pelvis, such as in the chest.

Endometriosis affects 10% of women and those assigned female at birth from puberty to menopause, although the impact may be felt for life. In the UK, that's over 1.5 million from all races and ethnicities living with the condition.

### Types of endometriosis

There are four different types of endometriosis and it's possible to have more than one type. The different types refer to the location, amount and depth of endometrial lesions.

You may be diagnosed with:

**Peritoneal (superficial) endometriosis** - is found mainly on the pelvic peritoneum – a thin film that lines the inner surface of the pelvis and surrounds the pelvic organs.

**Ovarian endometriosis (endometrioma)** – is when endometriosis cysts are found in the ovaries.

**Deep endometriosis** - is found in locations such as the bladder, bowel and recto-vaginal septum (tissue separating the vagina and the rectum). The lesions of endometriosis are at a deeper level invading the pelvic peritoneum.

**Extra-pelvic endometriosis** - is when endometriosis is found outside of the pelvis, such as the thorax (chest) and caesarean scars.

### Signs and symptoms

Symptoms vary from person to person, some may have severe and debilitating symptoms, others may have no symptoms at all. Symptoms are not always related to the location, amount or the type of endometriosis. It's also important to know that endometriosis symptoms can also be symptoms of other health conditions.

We recommend that you speak to a doctor if your symptoms are interfering with day-to-day life.

### **Common symptoms include:**

- Pelvic pain
- Painful periods that interfere with everyday life
- Heavy menstrual bleeding
- Pain during or after sex
- Painful bowel movements/when having a poo
- Pain when urinating/peeing
- Difficulty getting pregnant – up to 70% of those with endometriosis will be able to get pregnant naturally
- Fatigue, with one or more of the above symptoms

Many with endometriosis also experience significant bloating around the time of a period. However, bloating can also be common for those without endometriosis and bloating that does not go away can be a symptom of other health conditions.

Having endometriosis can significantly impact mental health and wellbeing.

### **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
- Frequent urinary tract infections
- 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)
- Prolonged bleeding
- Bleeding after sex
- 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](http://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](mailto: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.*

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