

# Endometriosis

## Patient Information

Gynaecology Department



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<https://www.wwl.nhs.uk/patient-information-leaflets> or scan the QR code.

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## Introduction

Endometriosis is a common condition where tissue similar to inner lining of the womb (endometrium) is found elsewhere. These pieces of tissue can be found in many different areas of the body, including:

- on the ovaries, where it can form cysts (often referred to as endometriomas or 'chocolate cysts')
- in the peritoneum (the lining of the pelvis and abdomen)
- in or on the fallopian tubes
- on, behind or around the womb
- in the area between the vagina and the rectum

Endometriosis can also occur within the muscle wall of the womb, called adenomyosis. It is a very common condition affecting around 1 in 10 women. Most of them are diagnosed between the ages of 25 and 40. Endometriosis is rare in women who have been through the menopause.

## Symptoms of endometriosis

Endometriosis is a long-term (chronic) condition. Symptoms can vary significantly from person to person, and some women have no symptoms at all.

### **The most common symptoms include:**

- painful periods or heavy periods
- pain in the lower abdomen (tummy), pelvis or lower back
- pain during and after sex
- bleeding between periods
- difficulty getting pregnant

### **Other symptoms may include:**

- persistent exhaustion and tiredness
- discomfort when going to the toilet
- bleeding from your back passage (rectum) or blood in your poo
- coughing up blood – in rare cases when the endometriosis tissue is in the lung

How severe the symptoms are, depends on where in your body the abnormal tissue is, rather than the amount of tissue you have. A small amount could be more painful than a large amount.

## What causes endometriosis?

The causes of endometriosis are not fully known, but there are several theories.

The most widely accepted theory is that the womb lining doesn't leave the body properly during a period and embeds itself on the organs of the pelvis. This is known as "retrograde menstruation".

However, this doesn't explain why the condition can occur in women who have had a hysterectomy.

## Diagnosing endometriosis

It can be difficult to diagnose endometriosis, because the symptoms can vary considerably, and many other conditions can cause similar symptoms, including Irritable Bowel Syndrome (IBS) or Pelvic Inflammatory Disease (PID).

Your gynaecologist will ask about your symptoms, your periods and possibly your sexual activity. They may also carry out an internal pelvic exam or recommend an ultrasound scan to look for cysts in your ovaries that may have been caused by endometriosis.

## Laparoscopy

Endometriosis can only be confirmed with a surgical examination called a laparoscopy. This is carried out under general anaesthetic (where you're put to sleep) and you can usually go home the same day.

A thin tube with a light on the end (laparoscope) is passed into your body through a small cut in the skin at your belly button. It has a tiny camera that transmits images to a video monitor, so the specialist can see any endometriosis tissue.

During the procedure, a small sample of tissue (biopsy) can be taken for laboratory testing, or other surgical instruments can be used to treat the endometriosis.

## How endometriosis is treated

The symptoms of endometriosis can often be managed with painkillers and hormone medication, which help prevent the condition interfering with your daily life. However, there is no known cure for endometriosis.

### Pain-relieving medication

There are several different medications to help relieve your pain. These can range from over-the-counter remedies to prescribed medications. In more severe situations, you may be referred to a specialist pain management team.

## Hormone treatments

These treatments reduce or stop ovulation (the release of an egg from the ovary), and therefore allow the endometriosis to shrink, by decreasing hormonal stimulation. Some hormone treatments that may be offered are contraceptive and will also stop you becoming pregnant. They include:

- the combined oral contraceptive (COC) pill or patch, given continuously without the normal pill-free break; this usually stops ovulation and temporarily either stops your periods or makes your periods lighter and less painful
- an intrauterine system (IUS/Mirena®), which helps to reduce the pain and makes periods lighter; some women using an IUS get no periods at all
- progestogens in the form of injection, the mini pill or the contraceptive implant
- GnRH analogues (gonadotrophin-releasing hormone agonists), which are given as an injection or tablet. They are very effective, but can cause menopausal symptoms, such as hot flushes; they are also known to reduce bone density. To help reduce these side-effects and bone loss, you may be offered 'add-back' therapy in the form of hormone replacement therapy (HRT). Tablet form of GnRH analogue called Ryego has add-back HRT in it. It is taken as one tablet a day.

## Surgery

Surgery can treat or remove areas of endometriosis. The surgery recommended will depend on where the endometriosis is and how extensive it is. This may be done when the diagnosis is made or may be offered later. Success rates vary and you may need further surgery. Your gynaecologist will discuss the options with you fully. Sometimes other surgeons, such as bowel specialists, will be involved in your surgery. If you have severe endometriosis, you will be referred to an endometriosis specialist centre, where a specialist team that could include a gynaecologist, a bowel surgeon, a radiologist and specialists in pain management will discuss your treatment options with you.

## Other options

Some women have found the following measures helpful:

- exercise, which may improve your wellbeing, and may help to improve some symptoms of endometriosis
- cutting out certain foods, such as dairy or wheat products from the diet
- psychological therapies and counselling

## Complementary therapies

Although there is only limited evidence for their effectiveness, some women may find the following therapies help to reduce pain and improve their quality of life:

- reflexology

- transcutaneous electrical nerve stimulation (TENS)
- acupuncture
- vitamin B1 and magnesium supplements
- traditional Chinese medicine
- herbal treatments
- homeopathy

Endometriosis can be a difficult condition to deal with, both physically and emotionally. Charities such as Endometriosis SHE Trust UK and Endometriosis UK can offer advice and support to help you cope.

## Endometriosis and pregnancy

One of the main complications of endometriosis is difficulty getting pregnant or not being able to get pregnant at all (infertility) in severe cases.

Although surgery cannot guarantee that you will be able to get pregnant there is good evidence that removal of endometriosis tissue with a laser or an electric current during keyhole (laparoscopic) surgery can improve your chances of having a successful pregnancy.

If you have endometriosis and you do become pregnant the condition is unlikely to put your pregnancy at risk. Pregnancy sometimes reduces the symptoms of endometriosis, although they often return once you've given birth and finished breastfeeding, and your menstrual cycle returns to normal.

If you have any questions or worries, please feel free to speak to a member of staff by calling:

### **Hanover Women's Healthcare Unit Nurses**

Tel: 01942 264962 or 01942 264963  
(Monday to Friday 9am to 4:30pm)

Or

### **Swinley Ward**

Tel: 01942 822568 (24 hours)

Or visit: <https://www.endometriosis-uk.org/>

Endometriosis UK is the leading charity with many links and support articles available online.

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## Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends, and carers.

## Contact Us

Tel: 01942 822376 (Monday to Friday 9am until 4pm)

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## Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the positives and negatives of each option for me?
3. How do I get support to help me make a decision that is right for me?



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## How We Use Your Information

For details on how we collect, use, and store the information we hold about you, please see patient information leaflet, Ref. **Corp 006** How we use your information, this can be found on the Patient Information Leaflets page on the Trust website, see details on the front cover.

This leaflet is also available in audio, large print, Braille, and other languages upon request. For more information, please ask in the department/ward.

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