

# What is Endometriosis?



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# Information for patients

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## What is endometriosis?

Endometriosis (pronounced en- doh – mee – tree – oh – sis) is the name given to the condition where cells like the ones in the lining of the womb are found elsewhere in the body.

Around 1.5 million women in the UK are currently living with the condition and it can affect all women and girls of a childbearing age, regardless of race or ethnicity.

It is a chronic and debilitating condition that causes painful or heavy periods. It may also lead to infertility, tiredness, bowel and bladder problems.

## What are the symptoms of endometriosis?

Endometriosis can have a significant impact on a woman's life in a number of ways, and may present with a number of different symptoms, though some women may not have any symptoms at all. Endometriosis can cause pain that occurs in a regular pattern, becoming worse before and during your period. The pain may be there all the time, but for some women may come and go. The following symptoms can be caused by endometriosis:

- Chronic pain
- Fatigue / lack of energy
- Depression / isolation
- Painful periods
- Painful intercourse
- Fertility problems

Some women also experience non-specific symptoms such as bloating, nausea and vomiting.

## How does Endometriosis produce symptoms?

Womb-like cells appear and grow outside the uterus and respond to hormones produced during a woman's normal menstrual cycle. Just as the endometrial tissue inside the uterus bleeds monthly, so do the abnormal deposits outside the womb.

This bleeding irritates the surrounding tissue causing pain, inflammation and scarring, which can lead to possible damage of the pelvic organs.

Endometriosis can be found:

- In the ovaries - cysts called endometriomas or "chocolate cysts" can form
- In the fallopian tubes
- In the lining of the pelvis and abdomen (the peritoneum)
- On, behind or around the womb
- In the space between the vagina and rectum

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Endometriosis can also occur within the muscle wall of the womb (adenomyosis) and occasionally on the bowel and / or bladder. It may sometimes be found in other parts of the body, but this is rare.

## How is the diagnosis made?

Making the diagnosis of endometriosis can be difficult. This is because the symptoms can be very varied. Different women have different symptoms, and some may have none at all.

You will be asked questions about your symptoms, including information about your periods, pain or discomfort during sex, and any difficulty becoming pregnant.

Your doctor may perform an internal examination with your consent and you will be offered a chaperone during the examination. The doctor will be checking for the location of your pain, and any lumps or tender areas.

Extra tests may be arranged. These might include:

- An Ultrasound scan to check the womb and ovaries. Endometriomas (cysts on the ovaries caused by endometriosis) may be seen
- Laparoscopy (camera surgery) - this is the best way to make a diagnosis of endometriosis. This is performed asleep under general anaesthetic, and a telescope is inserted into your tummy to look at your pelvis. Biopsies may be taken to confirm the diagnosis, and pictures may be taken and filed in your medical records. Some cysts and areas of endometriosis can be treated at the same time, but more severe conditions may require further tests or treatment. Before the operation the risks and benefits will be discussed with you, and afterwards you will be informed of the results. Most patients can return home the same day after a laparoscopy
- If the condition appears very severe or advanced, an MRI scan may be necessary

## How is endometriosis treated?

If you have been diagnosed with endometriosis, your doctor or specialist should discuss possible treatment options with you.

The different treatments aim to reduce the severity of symptoms and improve the quality of life of women living with endometriosis. The treatment options are listed below.

This may include pain-relieving medications, hormone therapy and surgery.

### Pain relieving-medications

This can range from over-the-counter medications such as paracetamol and ibuprofen, to stronger pain relief prescribed by your doctor. In cases of severe pain, you may be referred to a specialist pain management team.

### Hormonal treatments

Hormonal treatments reduce or stop ovulation, which can allow the endometriosis tissue to shrink and become inactive.

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Some hormonal treatments used are also contraceptives, which stop you becoming pregnant. These include:

- Combined Oral contraceptive pill or patch - this is taken continuously without the normal pill-free break. This may mean you do not have a monthly bleed - this is not abnormal and can help to reduce new endometriosis tissue growth
- Mirena IUS (coil) - reduces pain and lightens periods. Some women will have no periods at all
- Progestogens in the form of injection, contraceptive implant or the mini pill
- Other hormonal treatments do not act as contraceptives, meaning if you do not want to become pregnant, you will need to use another form of contraceptive
- Gonadotrophin-Releasing Hormone Agonists (GnRHa). These prevent oestrogen production from the ovaries. They are given as a monthly injection for 6 months. They are very effective but can cause menopausal symptoms such as hot flushes and if used for a long time can cause bone thinning. To help reduce these side-effects and bone loss, you may be offered Hormone Replacement Therapy (HRT)

## Surgical Therapy

The aim of surgery is to remove or destroy as much or all of the noticeable endometriosis to improve pain or help fertility. Surgery offers more long lasting and effective treatment without the side effects of medical therapy.

The precise surgery recommended for you by your doctor will depend on the extent and location of your endometriosis. Options include:

- Laparoscopic (keyhole) surgery - areas of endometriosis can be seen and destroyed - either by burning or removing
- Laparotomy (open surgery) - this is a major operation, requiring a cut in the tummy, and the removal of large amounts of tissue to improve symptoms. This may involve removal of large cysts, ovaries and/or womb (a hysterectomy). You will not be able to have children after removal of the womb

Surgery may also help women who have infertility by releasing scarring around the fallopian tubes or the ovaries.

The procedure, risks and recovery from laparoscopic surgery are as outlined in the leaflet on laparoscopic surgery.

## Summary

Endometriosis affects many women and usually presents with pain or difficulty becoming pregnant.

Fertility problems can be further discussed with your doctor, who may arrange a referral to specialist fertility services.

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Your doctor will discuss the best management option with you depending on your individual circumstances. These may include hormonal and surgical treatments.

Professionals from other specialties may be involved in your care, especially if your endometriosis is advanced and complex.

Even though medical or surgical treatment may initially cure your symptoms, it is not unusual for symptoms to return after a while. If this happens to you, you will probably need further treatment and should make an appointment to see your General Practitioner for another referral to your Gynaecologist.

Maintaining a healthy lifestyle will aid to improve your wellbeing.

### Useful Information and Support

Endometriosis UK: [www.endometriosis-uk.org](http://www.endometriosis-uk.org)

NHS Choices: [www.nhs.uk/conditions/Endometriosis/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Endometriosis/Pages/Introduction.aspx)

National Institute for Health and Care Excellence (NICE) – Endometriosis: Diagnosis and Management: [www.nice.org.uk/guidance/ng73](http://www.nice.org.uk/guidance/ng73)

Fertility Network UK: <http://fertilitynetworkuk.org>

**This leaflet is up to date in accordance with Royal College of Obstetricians and Gynaecologists and NICE guidelines.**

### Any Comments, Compliments, Concerns or Complaints

If you have any other concerns please talk to your nurse, therapist or doctor. Our Patient Advice and Liaison Service (PALS) are available on 03033 306518 (Grimsby, Scunthorpe and Goole). You can also contact [nlg-tr.PALS@nhs.net](mailto:nlg-tr.PALS@nhs.net)

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