Endometriosis:

what you need to know

Royal College of Obstetricians and Gynaecologists

Setting standards to improve women's health

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What is endometriosis?

Endometriosis is a very common condition where cells of the lining of the womb (the endometrium) are found elsewhere, usually in the pelvis and around the womb, ovaries and fallopian tubes. It mainly affects women during their reproductive years. It can affect women from every social group and ethnicity. Endometriosis is not an infection and it is not contagious. Endometriosis is not cancer.

What could endometriosis mean for me?

The main symptoms of endometriosis are pelvic pain, pain during or after sex, painful, sometimes heavy periods and, for some women, problems with getting pregnant.

Endometriosis can affect many aspects of a woman's life including her general physical health, emotional wellbeing and daily routine.

Endometriosis is common and many women may have no symptoms. An estimated two million women in the UK have this condition.

Endometriosis is a long-term condition which affects women of all ages during their reproductive years (from the onset of menstrual periods to the menopause). It affects women from all social and ethnic groups.

Women who do experience symptoms may have one or more conditions:

- painful periods (dysmenorrhoea) which do not respond to over-the-counter pain relief. Some women have heavy periods.
- pain during or after sexual intercourse (dyspareunia)
- lower abdominal pain

- pelvic pain which can be long-term
- difficulty in getting pregnant or infertility
- pain related to the bowels and bladder (with or without abnormal bleeding)
- long-term fatigue.

Some women do not have any symptoms at all.

Pain is a common symptom of endometriosis. The pain can be a dull ache in the lower abdomen, pelvis or lower back. Pain affects each woman differently: where it hurts, when it hurts and how much it hurts. The pain, and the effects of endometriosis, can make you feel depressed.

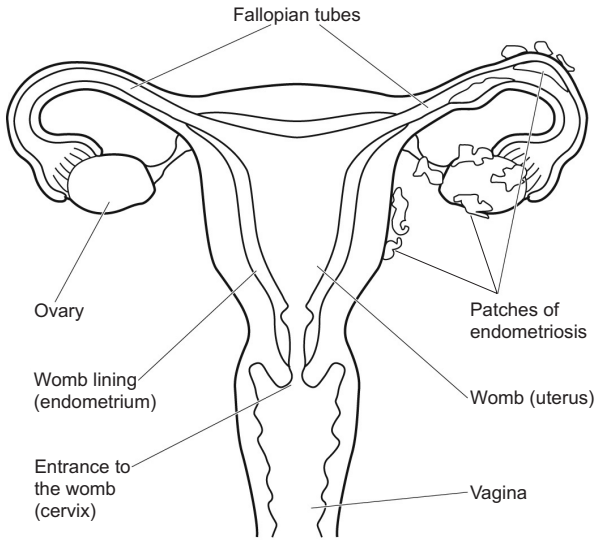
Most women with endometriosis get pain in the area between their hips (known as the pelvis) and the tops of their legs. For further information see **Long-term pelvic pain: information for you**. Some women get pain only at certain times, such as during their periods, when they have sex or when they open their bowels. Other women have pain all the time.

Some women with endometriosis become pregnant easily while others have difficulty getting pregnant. The pain may get better during pregnancy and then recur after the birth of the baby. Some women find that their pain resolves without any treatment.

What causes endometriosis?

During the menstrual cycle, under the influence of the female hormones estrogen and progesterone, the lining (endometrium) of the womb thickens in readiness for a fertilised egg. If pregnancy does not occur, the lining is shed as a period.

Endometriosis occurs when the cells of the lining of the womb are found in other parts of the body, usually the pelvis. Each month this tissue outside the womb thickens and breaks down and bleeds in the same way as the lining of the womb. This internal bleeding into the pelvis, unlike a period, has no way of leaving the body. This causes inflammation, pain and damage to the reproductive organs.



Reproductive areas where endometriosis can be found

Endometriosis commonly occurs in the pelvis. It can be found:

- on the ovaries where it can form cysts (often referred to as 'chocolate cysts')
- in or on the fallopian tubes
- almost anywhere on, behind or around the womb
- in the peritoneum (the tissue that lines the abdominal wall and covers most of the organs in the abdomen).

Less commonly, endometriosis may occur on the bowel and bladder, or deep within the muscle wall of the uterus (adenomyosis). It can also rarely be found in other parts of the body.

Why does endometriosis occur?

It is not yet known why endometriosis occurs. A number of theories have been suggested but none has been proved. The most commonly accepted theory is that, during a period, light 'backward' bleeding carries tissue from the womb to the pelvic area via the fallopian tubes. This is called 'retrograde menstruation'.

How soon can I expect to get a diagnosis?

For many women, it can take years to get a diagnosis. Doctors say that this is because:

- no one symptom or set of symptoms can definitely confirm a diagnosis of endometriosis
- the symptoms of endometriosis are common and could be caused by a number of other conditions such as irritable bowel syndrome (IBS) and pelvic inflammatory disease (PID) (for further information see **Acute pelvic inflammatory disease: what the RCOG guideline means for you**)
- different women have different symptoms
- some women have no symptoms at all.

There is no simple test for endometriosis. The only way to make a definite diagnosis is by a small surgical operation known as laparoscopy (see **What treatment can I get?**). This is not performed on every woman.

If you have painful periods and no other symptoms, your GP may suggest that you try pain relief before having further surgical investigation or treatments.

Living without a diagnosis can be distressing. Many women may fear the worst about why they are in pain or why they are having problems becoming pregnant. They may think that they have cancer (see **Other organisations**).

What happens when I see a specialist?

At your appointment, you may be asked specific questions about your periods and your sex life. It is important that you provide as much information as possible, as this will help your doctor find the correct diagnosis. You may find it helpful to write down your symptoms beforehand and take your notes along to the appointment with you. In this way, you will be sure to provide all the information required. Some women find it helpful to take a friend or partner along with them as well.

You should also have an opportunity to ask questions (for further information see BestTreatment NHS Direct in **Useful organisations**).

Your gynaecologist may examine your pelvic area, this will include an internal examination. Your doctor will discuss the best time to do this. This may be when you are having your period. If you have concerns about this, you should have an opportunity to discuss them.

What types of tests might I be offered?

You should be given full information about the tests that are available. These may include:

Ultrasound

You may be offered a scan. This can identify whether there is an endometriosis cyst in the ovaries. A normal scan does not rule out endometriosis.

Laparoscopy

For most women, having a laparoscopy is the only way to get a definite diagnosis; because of this, it is often referred to as the 'gold standard' test. A laparoscopy is a small operation which is carried out under general anaesthesia. A small cut is made in your abdomen near your tummy button (navel), then a telescope (known as a laparoscope), which is about the width of a pen, is inserted. This allows the gynaecologist to see the pelvic organs clearly and look for any endometriosis. This is usually carried out as day surgery.

As with any surgical procedure, there are risks and benefits. These should be fully explained to you when you are offered the test (see **Are there any risks?**).

If you have a laparoscopy, you should be given full information about your results.

Making a decision about treatment

You should be given full information about your options for treatment. This should also include information about the risks and benefits of each option.

Several factors may influence your decision about treatment. These include:

- how you feel about your situation
- your age
- whether your main symptom is pain or problems getting pregnant
- whether you want to become pregnant – some hormonal treatments which help to reduce the pain will stop you from becoming pregnant
- how you feel about surgery
- what treatment you have had before
- how effective certain treatments are.

You may decide that no treatment is the best way forward. This could be because your symptoms are mild, you have not had problems getting pregnant or you are nearing the menopause, when symptoms may get better.

What treatment can I get?

The options for treatment may be:

Pain relief

Pain-relieving drugs reduce inflammation and help to ease the pain.

Hormone treatments

There is a range of hormone treatments to stop or reduce ovulation (the release of an egg) to allow the endometriosis to shrink or disappear.

The hormonal methods below are contraceptives and will prevent you from becoming pregnant:

- The combined oral contraceptive (COC) pill or patch

  These contain the hormones estrogen and progestogen and work by preventing ovulation and can make your periods lighter, shorter and less painful.

- The intrauterine system (IUS): this is a small T-shaped device which releases the hormone progestogen. This helps to reduce the pain and makes periods lighter. Some women get no periods at all.

  The hormonal methods below are non-contraceptive, so contraception will be needed if you do not want to become pregnant:

- Use of hormonal progestogens or testosterone derivatives
- GnRH agonists – these drugs prevent estrogen being produced by the ovaries and cause a temporary and reversible menopause.

Surgery

Surgery can be used to remove areas of endometriosis. Surgery including hysterectomy does not always successfully remove the endometriosis. There are different types of surgery, depending on where the endometriosis is and how extensive it is. How successful the surgery is can vary and you may need further surgery. Your gynaecologist will discuss this with you before any surgery.

- Laparoscopic surgery

  The gynaecologist removes patches of endometriosis by destroying them or cutting them out.

- Laparotomy

  If the endometriosis is severe and extensive, you may be offered a laparotomy. This is major surgery which involves a cut in the abdomen, usually in the bikini line.

- Hysterectomy

  Some women have surgery to remove their ovaries or womb (a hysterectomy). Having this surgery means that you will no longer be able to have children after the operation. Depending upon your own situation, your doctor should discuss hormone replacement therapy (HRT) with you if you have your ovaries removed.

What if I am having difficulty getting pregnant?

Getting pregnant can be a problem for some women with endometriosis. Your doctor should provide you with full information about your options such as assisted conception. Infertility Network provides information about this (see **Other organisations**).