

Community Gynaecology Service

Endometriosis

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.

The actual cause of endometriosis is unknown. There are several theories about the cause of endometriosis, but none fully explains why endometriosis occurs.

It is possible that a combination of the following factors could be causing endometriosis to develop in some women:

Retrograde menstruation

When you have a period, some of the endometrium (womb lining) flows backwards, out through the fallopian tubes and into the abdomen. This tissue then implants itself on organs in the pelvis and grows. It has been suggested that most women experience some form of retrograde menstruation, but their bodies are able to clear this tissue and it does not deposit on the organs. This theory does not explain why endometriosis has developed in some women after hysterectomy, or why, in rare cases, endometriosis has been discovered in some men when they have been exposed to oestrogen through drug treatments.

Genetic predisposition

Some research suggests that endometriosis can be passed down to new generations through the genes of family members. Some families may be more susceptible to endometriosis but the causes of this are unclear.

Lymphatic or circulatory spread

Endometriosis tissue particles are thought to somehow travel round the body through the lymphatic system or in the bloodstream. This could explain why it has been found in areas such as the eyes and brain.

Immune dysfunction

It is thought that, for some women, their immune system is not able to fight off endometriosis. Many women with endometriosis appear to have reduced immunity to other conditions. It is not known whether this contributes to endometriosis or whether it is as a result of endometriosis.

Environmental causes

This theory suggests that certain toxins in our environment, such as dioxin, can affect the body, the immune system and reproductive system and cause endometriosis. Research studies have shown that when animals were exposed to high levels of dioxin they developed endometriosis. This theory has not yet been proven for humans.

Metaplasia

Metaplasia is the process where one type of cell changes or morphs into a different kind of cell. Metaplasia usually occurs in response to inflammation and enables cells to change to their surrounding circumstances to better adapt to their environment.

In the case of endometriosis, metaplasia would explain how the endometriosis cells appear spontaneously inside the body – and how they appear in areas such as the lung and skin. It would also explain the appearance of endometriosis cells in women with no womb – or in men who have taken hormone treatments.

During development in the womb, metaplasia allows for the development of the human body as a natural process. To explain endometriosis, some researchers believe this change from

one type of cell into an endometriosis cell happens as an embryo (developing baby in the womb), when the baby's womb (uterus) is first forming. Other researchers believe that some adult cells retain the ability they had as an embryo to transform into endometriosis cells.

I think I may have endometriosis, what should I do?

If you think you may have endometriosis, book an appointment with your GP. It is extremely important that you provide as much information as possible to your GP, as the symptoms of endometriosis may also be symptoms of other conditions, making it difficult to diagnose. In order to prepare for your appointment, take the time to read the fact-sheet 'Visiting your GP' included in this pack. Also fill out the pain and symptom diary and questionnaire, and take these with you to the appointment.

How common is endometriosis?

Endometriosis is the second most common gynaecological condition. It is estimated that around 1.5 - 2 million women in the UK have endometriosis.

Who gets endometriosis?

There are many myths surrounding who can get endometriosis, but in fact, it can affect *all* women and girls of a childbearing age, regardless of race or ethnicity.

How is endometriosis diagnosed?

The only definitive way to diagnose endometriosis is by a laparoscopy. This is an operation in which a camera (a laparoscope) is inserted into the pelvis via a small cut near the navel. This allows the surgeon to see the pelvic organs and any endometrial implants and cysts. The fact sheet 'Laparoscopic surgery for endometriosis' that is included in this pack has further information on laparoscopy.

Occasionally diagnosis is made during a laparotomy. A laparotomy is a major operation, which involves opening the abdomen through a larger incision (cut).

Scans, blood tests and internal examinations are not a conclusive way to diagnose endometriosis and a normal scan, blood test and internal examination does not mean that you do not have endometriosis.

However, not all patients will actually require a diagnostic laparoscopy as recent guidelines have recommended a trial of potential treatments can be offered without patients having to go through an invasive procedure. Your consultant will discuss this with you.

Can endometriosis be treated?

Yes, there are ways of managing the symptoms and the disease. The type of treatment you choose should be decided upon in partnership with your healthcare professional. The decision will depend on your individual circumstances including:

- Your age
- The severity of your symptoms
- Your desire to have children
- The severity of the disease
- Previous treatment
- Your priorities pain relief / fertility
- Side effects of drugs
- Risks
- Intended duration of treatment

Types of treatment include:

- Surgery
- Hormone treatment
- Pain management
- Nutrition
- Complementary therapies
- Emotional support