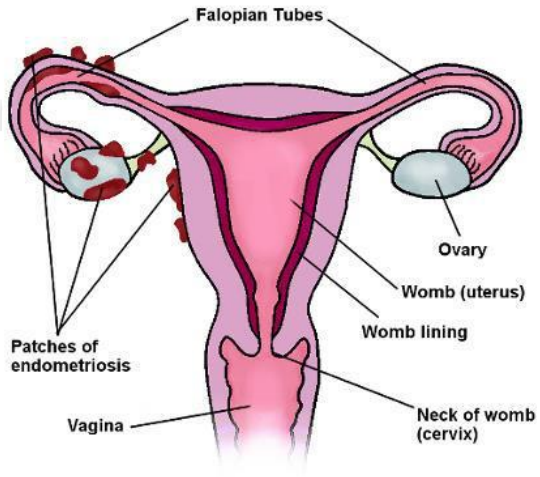
Understanding Endometriosis - Information Pack

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 (uterus) are found elsewhere in the body.



Every month a woman's body goes through hormonal changes. Hormones are naturally released which cause the lining of the womb to increase in preparation for a fertilized egg. If pregnancy does not occur, this lining will break down and bleed – this is then released from the body as a period.

Endometriosis cells react in the same way – except that they are located outside the womb. During the monthly cycle hormones stimulate the endometriosis, causing it to grow, then break down and bleed. This internal bleeding, unlike a period, has no way of leaving the body. This leads to inflammation, pain, and the formation of scar tissue (adhesions).

- Endometriosis is not an infection.
- Endometriosis is not contagious.
- Endometriosis is not cancer.

Endometrial tissue can also be found in the ovary, where it can form cysts, called 'chocolate cysts' because of their appearance.

Endometriosis is most commonly found inside the pelvis, around the ovaries, the fallopian tubes, on the outside of the womb or the ligaments (which hold the womb in place), or the area between your rectum and your womb, called the Pouch of Douglas. It can also be found on the bowel, the bladder, the intestines, the vagina and the rectum. You can also have endometrial tissue that grows in the muscle layer of the wall of the womb (this is another condition called adenomyosis). Endometriosis can grow in existing scars from previous operations. In rare cases, it has been found in other parts of the body such as the skin, the eyes, the spine, the lungs and the brain. The only site that endometriosis has not been found is the spleen.

Why does it occur?

There is no proven cause for endometriosis. There are several theories as to what can cause the condition. However, each theory does not fully explain how endometriosis appears and the actual cause remains unknown**.** These theories are:

- **Retrograde menstruation:** This theory suggests that 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.

- **Lymphatic or circulatory spread:** This theory is that endometriosis tissue particles 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.

- **Genetic predisposition to the condition:** This theory suggests that endometriosis is passed down to new generations through the genes of family members. Some families may be more susceptible to endometriosis.

- **Immune dysfunction:** This theory is 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 – such as dioxin exposure:** The theory is 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:** This 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.

  Others believe that some adult cells retain the ability they had as an embryo, to transform into endometriosis cells.

What are the symptoms of endometriosis?

The classic symptoms of endometriosis are:

- Painful periods
- Painful sex
- Infertility

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Women with the condition also report many other symptoms:

Pain

- Painful periods
- Pain starting before periods
- Pain during or after sexual intercourse
- Ovulation pain
- Pain on internal examination
- Leg pain
- Back pain

Bleeding

- Heavy periods with/without clots
- Prolonged bleeding
- Pre-menstrual spotting
- Irregular periods
- Loss of dark or old blood before a period or at the end of a period

Bowel and Bladder Symptoms

- Painful bowel movements
- Pain before or after opening bowels
- Bleeding from the bowel
- Pain when passing urine
- Pain before or after passing urine
- Blood in the urine (haematuria)
- Symptoms of an irritable bowel – diarrhoea, constipation, colic

Other symptoms can include:

- Lethargy
- Nausea
- Extreme tiredness
- Depression
- Frequent infections such as thrush (candida)
- Feeling faint/ fainting during periods

The majority of women with the condition will experience some of these symptoms. Some women with endometriosis will have no symptoms at all.

The amount of endometriosis does not always correspond to the amount of pain. Chocolate cysts on the ovary can be pain-free and only found as part of fertility investigations. A small amount of endometriosis can be more painful than severe disease. It depends largely on the site of the endometrial deposits.

All of the symptoms above may have other causes. It is important to seek medical advice to clarify the cause of any symptoms. If symptoms change after diagnosis it is important to discuss these changes with a medical practitioner. It is easier to put all problems down to endometriosis and it may not always be the reason.

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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.

Because endometriosis manifests itself in a variety of ways, diagnosis can be difficult and often delayed. Recent research shows that there is now an average of 7.5 years between women first seeing a doctor about their symptoms and receiving a firm diagnosis.

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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 or fertility
- Side effects of drugs
- Risks
- Intended duration of treatment

Types of treatment include:

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

Some myths still exist about treatment – pregnancy or hysterectomy is not a 'cure' for endometriosis.

You should be as informed as you can about possible treatments for endometriosis, so you can choose a route that is right for you. This may include several types of treatment, such as hormone treatment (e.g. GnRh analogues such as Zoladex) followed by surgery. Many women also use complementary therapies for relief. Endometriosis affects women differently and therefore treatment options that work for others may not necessarily be right for you; it can take time to work out the right treatment. Working with your consultant, GP and hospital team and being honest about what you want to achieve (e.g. is pain relief or fertility the main priority, for example) will be very helpful.

For more information on treatments, please request the 'Recently diagnosed' information pack from Endometriosis UK.

Helpline: 0808 808 2227

This document was originally created in March 2012. It's currently being reviewed and updated to reflect recent changes in endometriosis care, with input from medical practitioners and patients. Please keep an eye on our website for an updated version soon.

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