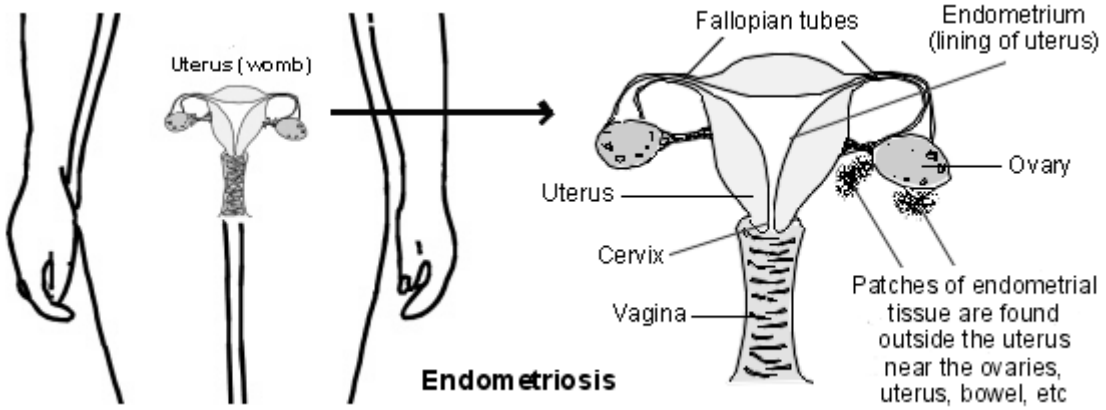
Endometriosis

Endometriosis can cause painful periods, persistent pain in the pelvic area, infertility, and other symptoms. The symptoms can range from mild to severe. Treatment options include painkillers, hormone treatments, and surgery.

What is endometriosis?

The endometrium is the tissue that lines the inside of the uterus (womb). Endometriosis is a condition where endometrial tissue is found outside the uterus. It is 'trapped' in the pelvic area and lower abdomen, and rarely in other areas in the body.



Who gets endometriosis?

The exact number of women who develop endometriosis is not known. This is because many women have endometriosis without symptoms, or with mild symptoms, and are never diagnosed. Investigations to diagnose endometriosis are only done if symptoms become troublesome and are not eased by initial treatments (see below). So, estimates vary from about 1 in 10 to as many as 5 in 10 of all women develop some degree of endometriosis.

If symptoms develop they typically begin between the ages of 25-40. Sometimes symptoms begin in the teenage years. Endometriosis can affect any woman. However:

- Sometimes it runs in families. Therefore, endometriosis is more common in close blood relatives of affected women.
- Endometriosis is rare in women past the menopause as to develop endometriosis you need oestrogen, the female hormone. Oestrogen levels fall after the menopause.
- The oral contraceptive pill ('the pill') reduces the risk of developing endometriosis. This protective effect may persist for up to a year after stopping 'the pill'.

What causes endometriosis?

The exact cause is not known. It is thought that some cells from the lining of the uterus (the endometrium) get outside the uterus into the pelvic area. They get there by spilling backwards along the fallopian tubes when you have a period.

The 'spilt' endometrial cells then continue to survive next to the uterus, ovary, bladder, bowel, or fallopian tube. The cells respond to the female hormone oestrogen, just like the lining of the uterus does each month. Throughout each month the cells multiply and swell, and then break down as if ready to be shed at the time of your period. However, because they are trapped inside the pelvic area, they cannot escape. They form patches of tissue called endometriosis.

Patches of endometriosis tend to be 'sticky' and may join organs to each other. The medical term for this is adhesions. For example, the bladder or bowel may 'stick' to the uterus. Large patches of endometriosis may form into cysts which bleed each month when you have a period. The cysts can fill with dark blood known as 'chocolate cysts'.

What are the symptoms of endometriosis?

Patches of endometriosis can vary in size from the size of a pinhead to large clumps. Many women with endometriosis have no symptoms. If symptoms develop they can vary, and include those listed below.

In general, the bigger the patches of endometriosis, the worse the symptoms. However, this is not always the case. Some women have large patches of endometriosis with no symptoms. Some women have just a few spots of endometriosis, but have bad symptoms.

- **Painful periods.** The pain typically begins a few days before the period and usually lasts the whole of the period. It is different to normal period pain which is usually not as severe, and doesn't last as long.
- **Painful sex.** The pain is typically felt deep inside, and may last a few hours after sex.
- **Pain in the lower abdomen and pelvic area.** Sometimes the pain is constant, but is usually worse on the days just before and during a period.
- **Other menstrual symptoms may occur.** For example, bleeding in between periods.
- **Difficulty becoming pregnant (reduced fertility).** This may be due to clumps of endometriosis blocking the passage of the egg from an ovary to the fallopian tube. Sometimes, the reason for reduced fertility is not clear.
- **Uncommon symptoms** include pain on passing faeces (motions), pain in the lower abdomen when you pass urine, and, very rarely, blood in the urine or faeces. Very rarely, patches of endometriosis occur in other sites of the body. This can cause unusual pains in parts of the body that occur at the same time as period pains.

How is the diagnosis of endometriosis confirmed?

The symptoms caused by endometriosis can be caused by other conditions. Therefore, if any of the above symptoms becomes persistent then tests are usually advised to find the cause of the symptoms. Endometriosis is usually confirmed by a laparoscopy. This is a small operation that involves making a small cut in the abdominal wall below the umbilicus (tummy button) under anaesthetic. A laparoscope (like a thin telescope) is pushed through the skin to look inside. Patches of endometriosis can be seen by the doctor.

A small pilot research study published in 2009 (cited at the end) showed that the diagnosis may be able to be confirmed by a new test. In the study, a small sample (biopsy) was taken from the endometrium (inner lining of the uterus) of women with endometriosis. The sample was looked at in the lab for some specific 'markers' of endometriosis. The results were that in most cases, this new test was able to confirm the presence of endometriosis. So, if these results are confirmed by further studies, it may mean that in the future the diagnosis can be confirmed without the need for a laparoscopy (which involves a small operation).

How does endometriosis progress?

If endometriosis is left untreated, it becomes worse in about 4 in 10 cases. It gets better without treatment in about 3 in 10 cases. For the rest it stays about the same. Endometriosis is **not** a cancerous condition.

Complications sometimes occur in women with severe untreated endometriosis. For example, large patches of endometriosis can sometimes cause an obstruction (blockage) of the bowel or of the ureter (the tube from the kidney to the bladder).

What are the aims of treatment?

The main aims of treatment are to improve symptoms such as pain and heavy periods, and to improve fertility if this is affected. There are various treatment options which are discussed below.

Not treating as an option

If symptoms are mild and fertility is not an issue for you then you may not want any treatment. In about 3 in 10 cases, endometriosis clears and symptoms go without any treatment. You can always change your mind and opt for treatment if symptoms do not go, or become worse.

Painkillers for endometriosis

- **Paracetamol** taken during periods may be all that you need if symptoms are mild.
- **Anti-inflammatory painkillers** such as ibuprofen, diclofenac, naproxen, may be better than paracetamol. However, some people have side-effects with these.
- **Codeine** alone, or combined with paracetamol, is a more powerful painkiller. It may be an option if anti-inflammatories don't suit. Constipation is a common side-effect.

To ease pain during periods, it is best to take painkillers regularly over the time of your period rather than 'now and then'. You can take painkillers in addition to other treatments.

Hormone treatments for endometriosis

Understanding oestrogen and how hormone treatments work
Oestrogen is a hormone that is made in the ovaries. The cells that line the inside of the uterus (endometrial cells) need oestrogen to grow and survive. The endometrial cells outside the uterus that cause endometriosis also need oestrogen. Hormone treatment works by reducing the amount of oestrogen that you make, or by blocking the effect of oestrogen on the endometrial cells. The endometrial cells are then starved of oestrogen which they need to survive. Therefore, patches of endometriosis gradually shrink, and may clear away.

It may help to understand how oestrogen is made. Hormones called gonadotrophins are made in the pituitary gland, which is a gland next to the brain. Gonadotrophin hormones are released into the bloodstream and stimulate the ovaries to make oestrogen which is also released into the bloodstream. The stimulus to release gonadotrophins into the bloodstream comes from a hormone called gonadotrophin releasing hormone (or GnRH for short). This is made in the brain and travels to the pituitary. So, in effect there is a cascade:

GnRH (brain) >> Gonadotrophins (pituitary) >> Oestrogen (ovaries) >>Endometrial cells.

The different hormone treatments work by affecting different parts of this cascade. However, the end result of all of them is to reduce the amount of oestrogen that is made, or to block the action of oestrogen on endometrial cells.

Types of hormone treatments
There are several options. They all have similar success rates at easing pain. However, they do not improve fertility. (Surgical treatments may improve fertility - discussed later.)

The combined oral contraceptive pill ('the pill')
The pill is not licensed for the treatment of endometriosis. However, many women report improved symptoms when they are on 'the pill'. The pill stops ovulation which reduces the amount of oestrogen made by the ovaries. Periods are also lighter and less painful. Other symptoms such as painful sex, and pain in the pelvic area may also improve.

The intrauterine system (IUS)
The IUS is a small device made from plastic and contains a progestogen hormone called levonorgestrel. It is also called the LNG-IUS which is short for levonorgestrel intrauterine system. Mirena® is the trade name for the only IUS available in the UK, although others will probably become available. The progestogen in the IUS makes the lining of the uterus thinner. It probably also has some effect on the ovary, and ovulation may not occur (the release of the egg each month). The IUS is put into a woman's uterus (womb) by a doctor or nurse. It is a popular type of contraceptive. However, it can also reduce endometriosis-associated pain. It also greatly reduces or even abolishes bleeding of periods. Once put in place, it can remain effective (for contraception and to ease pain) for up to five years.

GnRH (gonadotrophin releasing hormone) analogues
These drugs block the pituitary from releasing gonadotrophins. This greatly reduces the amount of oestrogen that you make in the ovaries. There are several GnRH analogue preparations which include buserelin, goserelin, nafarelin, leuprorelin, and triptorelin. Some preparations are taken as a nasal spray, some are given by injection. A six month course is usual. Side-effects may occur due to the very low levels of oestrogen that this treatment causes. For example, hot flushes, dry vagina, reduced sex drive, headaches, and difficulties with sleeping. Periods usually stop too. An option is to take a small dose of oestrogen and progestogen as hormone replacement therapy (HRT) to stop these side-effects. This 'add-back' HRT does not affect the effectiveness of the treatment.

Progestogen hormone tablets
These reduce the effect of oestrogen on the endometrial cells which causes the cells to 'shrink'. Progestogens also prevent ovulation which lowers the oestrogen level. Progestogen hormone tablets include norethisterone, dydrogesterone and medroxyprogesterone. Side-effects that may occur include: irregular menstrual bleeding, weight gain, mood changes, and bloating. Progestogen hormone tablets are less commonly used these days as other treatments tend to be used.

Danazol and gestrinone
These drug works mainly by reducing the amount of gonadotrophins that you make. This has a 'knock-on' effect of reducing the amount of oestrogen that you make. Side-effects commonly occur including: weight gain, hair growth, acne, and mood changes. Rarely, they cause a deepening of the voice which may be irreversible. They usually stop periods too. Danazol and gestrinone are not often used now as it is common for them to cause unacceptable side effects

Note: you should use contraception with condoms if you have sex whilst taking hormone treatments (apart from 'the pill' and the LNG-IUS which are contraceptives). This is because there is a risk that hormone treatments may affect a developing baby.

Surgery for endometriosis

Sometimes an operation is advised to remove some of the larger patches of endometriosis. There are various techniques that can be used. Most commonly, a thin telescope-like instrument (a laparoscope) is pushed through a small cut in the abdomen. The surgeon then uses the laparoscope to see inside the abdomen and to direct heat, or a laser, or a beam of special helium gas to destroy patches of endometrium. Cysts can also be removed via this kind of 'laparoscopic surgery' (key hole surgery). Sometimes a more traditional operation is done with a larger cut to the abdomen to remove larger patches or cysts.

An operation may ease symptoms and increase the chance of pregnancy if infertility is a problem. If you have completed your family, and other treatments have not worked well, a hysterectomy (removal of the uterus) and removal of the ovaries may be an option. This has a high chance of success for curing the symptoms.

Some general points about the treatment of endometriosis

Initial treatment without a conclusive diagnosis may be advised
The way to confirm a diagnosis of endometriosis is to have a laparoscopy (a small operation, described earlier). However, many women develop symptoms that are 'probably' due to endometriosis such as painful periods - but have not yet had a laparoscopy. In such circumstances, your doctor may suggest an initial treatment of painkillers and/or the pill or the LNG-IUS, in particular, if you require contraception as well. These treatments are used to treat period pains anyway, even without endometriosis. If the symptoms improve with this initial treatment (as often they do), then a laparoscopy may not then be needed.

Laparoscopy to diagnose and treat
A laparoscopy is done under general anaesthetic. You may have one to confirm a diagnosis of endometriosis. Your specialist may also ask for your consent at the same time to treat any large patches they may find (as described earlier) 'whilst they are in there'. This saves having two laparoscopies - one to diagnose and one to treat.

Severity and type of symptoms may influence the choice of treatment.
Some women with endometriosis have no symptoms, and need no treatment. If symptoms are mild, painkillers alone may be fine. Hormone treatments usually work well to ease pain, but do not improve fertility. Surgery may be needed if infertility is caused by endometriosis.

Success of treatment and side-effects
Overall, the hormone treatment options all have about the same success rate at easing pain. However, some women find one treatment better than others. Also, the treatments have different possible side-effects. You may try one, and it may be fine. However, it is not unusual to switch from one treatment to another if the first does not suit.

Age and plans for pregnancy
Symptoms often improve during pregnancy. Also, the longer you have endometriosis, the greater the chance of reduced fertility. You may need to take this into account if you have plans for having children. If your family is complete, and symptoms are severe, then hysterectomy (removal of the uterus) may be a good option.

Length of treatment
It may take a few months of hormone treatment to get full benefit. Do persevere for a few menstrual cycles if pain does not ease straight away. Danazol, gestrinone, and GnRH analogues are usually only advised for six months. Symptoms may be much improved after six months treatment, but may recur once treatment is stopped. Progestogens, 'the pill' and the LNG-IUS are suitable for long-term treatment.

Recurrences
Once the endometriosis has gone with treatment it may recur again in the future. Further treatment may need to be considered if symptoms recur.

Further help and information

Endometriosis UK
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Helpline: 0808 808 2227 Web: www.endometriosis-uk.org

References

- Endometriosis, Clinical Knowledge Summaries (June 2009)
- The investigation and management of endometriosis, Royal College of Obstetricians and Gynaecologists (2006)
- Laparoscopic helium plasma coagulation of endometriosis, NICE (2006)
- Davis L, Kennedy SS, Moore J, et al; Modern combined oral contraceptives for pain

associated with endometriosis. Cochrane Database Syst Rev. 2007 Jul 18; (3):CD001019. [abstract]
- Farquhar C; Endometriosis. BMJ. 2007 Feb 3;334(7587):249-53.
- Harada T, Momoeda M, Taketani Y, et al; Low-dose oral contraceptive pill for dysmenorrhea associated with endometriosis: a placebo-controlled, double-blind, randomized trial. Fertil Steril. 2008 Nov;90(5):1583-8. Epub 2007 Dec 27. [abstract]
- Al-Jefout M, Dezarnaulds G, Cooper M, et al; Diagnosis of endometriosis by detection of nerve fibres in an endometrial biopsy: a double blind study. Hum Reprod. 2009 Aug 18. [abstract]
