



# Endometriosis

## Patient information Leaflet

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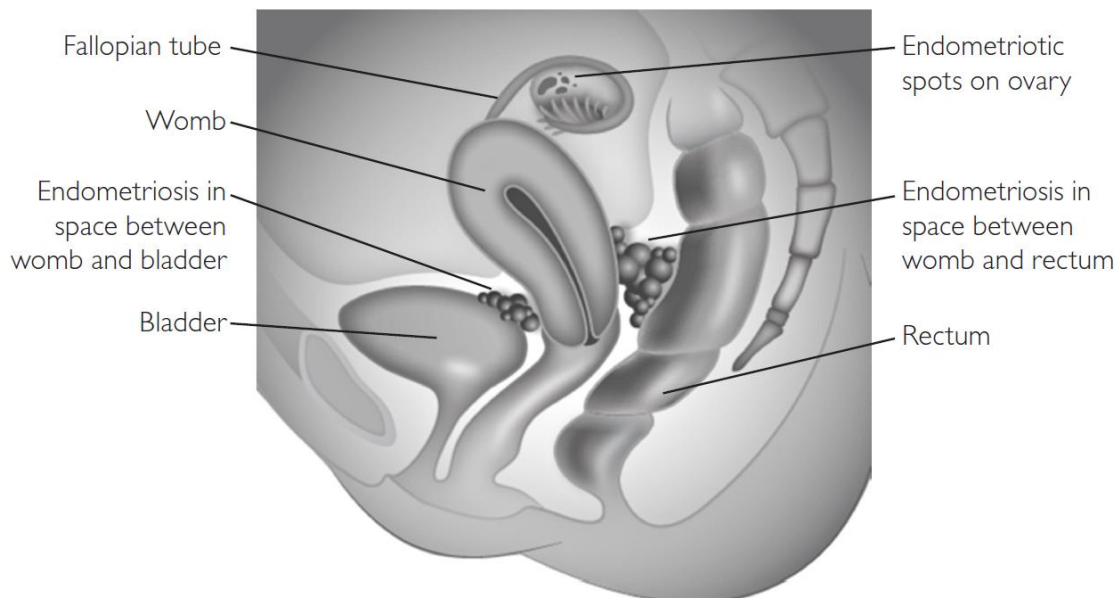
Up to 1 in 10 of women have endometriosis. Some women have no symptoms but in many women it can have a significant impact on quality of life. It often causes pain. Some women with endometriosis find it difficult to get pregnant.

### **What is endometriosis?**

Endometriosis is a condition where tissue similar to the inside lining of the womb (the endometrium) is found outside the womb. Usually it is found inside in the abdominal cavity on the peritoneum, which is a smooth thin layer of tissue that covers the internal organs. Usually endometriosis is found close to the womb, Fallopian tubes, ovaries, bladder and bowel but can rarely be found in other places such as in caesarean section scars.

Endometriosis creates inflammation which can cause pain. Over time this inflammation can result in adhesions, which are bands of scar tissue that cause the internal organs to become stuck together. In some cases adhesions can result in the Fallopian tubes becoming blocked, which can result in difficulty getting pregnant. Sometimes endometriosis can develop into a blood-filled cyst called an endometrioma.

Endometriosis is a long term condition. There is no cure but there are many medical and surgical treatments that are effective in treating the condition.



### **What are the symptoms of endometriosis?**

The typical symptoms of endometriosis are:

- Painful periods
- Pain the pelvic area, which may occur at any time of the month
- Pain during or after sex
- Difficulty getting pregnant
- Pain when passing a bowel motion when a women is on her period
- Pain when passing urine when a women is on her period
- Blood in the urine when a women is on her period
- Blood in the stool when a women is on her period

### **What causes endometriosis?**

Although the precise cause of endometriosis remains unknown there are a few theories on why it occurs. Some believe menstrual blood can travel through the Fallopian tubes when a woman is on her period and this carries some of the womb lining (endometrium) with it which then sticks to tissues outside of the womb and develops into endometriosis. Most cases of endometriosis seem to be random but in some cases there may be a genetic cause as some families have many women affected by the condition.

### **Diagnosing endometriosis**

Your doctor will ask questions to determine if you might have endometriosis. Endometriosis symptoms are usually worst around the time of a woman's period so it can be helpful to keep a symptom diary. You should keep a record of the dates of your periods and the dates when your symptoms occur.

Your doctor is likely to offer you an internal vaginal examination. In many women with endometriosis the examination findings are normal but in some cases clues can be found that help to make the diagnosis. During examination the doctor can check for pain, nodules in the vaginal wall or swelling in the region of the ovaries.

Pelvic ultrasound scans are often offered to look for causes of pelvic pain. Ultrasound can find endometriomas (blood-filled cysts) or large endometriotic nodules but it is not possible to see small patches of endometriosis with ultrasound scans. Magnetic Resonance Imaging (MRI) is a type of scan that involves the body being placed into a tunnel with a large magnet around it. This type of scan is used to check for endometriosis affecting the bowel or bladder.

The best way to confirm a diagnosis of endometriosis is to perform an operation called a laparoscopy. Laparoscopy is not always necessary though as it is possible to start medical treatments for endometriosis if a diagnosis of endometriosis is suspected based on symptoms, examination findings or scan results.

### **What is laparoscopy?**

Laparoscopy is otherwise known as "keyhole" surgery. This involves having a small camera inserted into the abdomen through the belly-button whilst you are under general anaesthetic (medically-induced sleep). During laparoscopy the abdomen is inflated with gas so the surgeon can see the internal organs and look for endometriosis. The surgeon may make one or two additional small cuts in the abdomen to insert other surgical instruments.

If endometriosis or adhesions (scar tissue) are found then they can often be treated during the same surgery. Endometriosis can be treated surgically by removing the affected tissue (excision) or burning it away with heat produced by an electrical instrument (ablation).

Adhesions (scar tissue) can be cut apart, which helps to release the organs that are stuck together. Sometimes a special fluid (Adept) is left inside the abdomen to prevent the tissues becoming stuck together again as the body heals. This fluid is absorbed by the body and goes away within a couple of weeks.

If severe endometriosis or adhesions are found, or if there is unexpected invasion of endometriosis into the bowel or bladder then the surgeon may not be able to complete the surgery and will offer referral to an Endometriosis Centre.

If you are having difficulty getting pregnant then your surgeon may offer a test to check if your Fallopian tubes are blocked. This involves a blue dye being squirted into the cervix (opening into the womb) during laparoscopy. If the tubes are open then the surgeon should be able to see the blue dye flowing out of the tubes.

At the end of the operation the surgeon closes the cuts with dissolving stitches or glue. The scars left behind are small. There will be pain after the surgery which lasts for 2 to 4 weeks.

### **Medical Treatment**

Treatment of endometriosis usually aims to reduce pain or improve fertility. The appropriate treatment options will depend on your personal priorities. It is helpful for your doctor to know whether you want to focus on relieving pain or getting pregnant.

It can be difficult to achieve both at the same time as many medical treatments for endometriosis temporarily prevent pregnancy. Some surgical treatments (such as hysterectomy) can make it impossible to become pregnant afterwards.

There are a number of medical treatments that can be offered for endometriosis. The right treatment for you will depend on the type and severity of your symptoms, the location and severity of endometriosis disease and whether or not you want to get pregnant. Your doctor will discuss the most suitable treatment options for you and outline the risks and benefits of each.

Treatment may not be necessary if your symptoms are mild and you have no fertility problems. For 1 in 3 women with endometriosis the condition gets better by itself without treatment. It is reasonable to monitor symptoms and decide to have treatment only when you feel you need it.

### **Pain medication**

**Anti-inflammatory tablets:** Non-steroidal anti-inflammatories (NSAIDs) such as ibuprofen and naproxen work well for endometriosis-related pain as they act against inflammation caused by endometriosis. It is best to start taking regular anti-inflammatory tablets the day before you expect your period.

**Paracetamol:** Paracetamol is often effective for mild pain and can be taken with anti-inflammatory tablets to help relieve stronger pain.

### **Opiates**

Codeine, Tramadol and Morphine are known as "opiates". These painkillers are usually effective in treating severe pain.

**Co-codamol:** This is a tablet containing codeine combined with paracetamol. It is available in a few different strengths.

Constipation is a common side effect of opiates and being constipated can make abdominal pain worse. Drink lots of water and eat plenty of fibre. Consider taking a laxative if you aren't opening your bowels regularly.

Opiates are highly addictive. If taken on a daily basis they eventually become less effective and higher doses are needed to have the same effect. Coming off of opiates when you have taken them for a long time can be difficult and you may experience unpleasant withdrawal symptoms. It is best to only take opiates occasionally after you have already tried simple painkillers such as paracetamol and ibuprofen.

### **Neuromodulators**

Pregabalin and gabapentin were traditionally used to treat epilepsy but it was discovered that they also have pain-reducing properties. These medicines are usually taken on a daily basis and can take a couple of weeks to start working. They are particularly good for people with long-term pain conditions.

### **Anti-depressants**

Duloxetine and venlafaxine are anti-depressants that can help with pain and also the emotional effects of having a long-term pain condition.

### **Hormone treatments**

Hormone treatments work well for reducing the pain caused by active endometriosis disease but they have no effect on pain caused by adhesions (scar tissue) and do not improve fertility.

There are four main types of hormone-based treatment:

- Progestogens
- Antiprogestogens
- Combined oral contraceptive pills
- Gonadotrophin-releasing hormone (GnRH) analogue injections

### **Progestogens**

Progestogens are synthetic hormones that behave like the natural hormone progesterone. When taking continuous progestogens many women find that their period bleeding reduces and their pain gets better. They occasionally cause side effects such as bloating, mood changes, irregular bleeding and weight gain.

Progestogens can be given in many different forms such as tablets, injections, skin implants and tiny devices that are fitted into the womb. There are a few different types of progestogen tablets available such as medroxyprogesterone acetate (Provera), norethisterone and many types of progesterone-only contraceptive pills.

The levonorgestrel intrauterine system (such as the Mirena coil or Levosert) is a tiny T-shaped device that fits into the womb and releases progestogen. This is a very effective treatment for endometriosis. It is also a good treatment for heavy periods and a reliable form of contraception.

### **Antiprogestogens**

Antiprogestogens are synthetic hormones that decrease oestrogen and progesterone levels. Side effects can include weight gain, acne, mood changes and the development of masculine features (hair growth and deepening voice). Drug names include danazol and gestrinone. Gestrinone has fewer side effects.

### **Combined oral contraceptive pills**

These are contraceptive pills that contain two types of hormone: oestrogen and a progestogen. There are lots of different brands. These pills often come in packs of 21 tablets and usually women take a 7 day break before starting a new pack. During the 7 day break women normally experience period-like bleeding.

If you are taking these tablets to help with endometriosis then you should take three packs in a row before you have your 7 day break, that way you only have to experience a period-like bleeding episode 4 times a year.

### **GnRH analogue injections**

GnRH analogues induce a false menopause. They are given as an injection and are available in two strengths: monthly doses or three-monthly doses. GnRH agonists have more side effects than other medications but can be more effective than other treatments.

The side effects of GnRH agonists are similar to menopause symptoms. These symptoms include hot flushes, night sweats, mood swings and vaginal dryness. In the long term GnRH agonists can cause osteoporosis (weak bones).

A type of hormonal replacement therapy (HRT) tablet called Tibolone should be given whilst on the injections. This HRT reduces the side effects and risk of bone weakness while the beneficial effect of the injections is maintained.

### **Surgery**

Surgery can be used to remove or destroy areas of endometriosis, which can help improve symptoms and fertility. The kind of surgery you be offered will depend on where the endometriosis is. The options are:

- Laparoscopic (keyhole) surgery
- Laparotomy (open surgery)
- Hysterectomy (removal of the womb)

Any surgical procedure carries risk. Your surgeon should discuss this with you.

### **Laparoscopic surgery**

During a laparoscopy (a keyhole procedure to view and operate inside the abdomen), endometriosis tissue can be identified and destroyed or cut out using instruments that are inserted into the body through small cuts in the abdominal wall.

Although this kind of surgery can relieve symptoms of endometriosis temporarily, the endometriosis may come back in future.

### **Laparotomy**

This is major surgery that is used if your endometriosis is severe and extensive. Recovery time is longer than that for keyhole surgery. The surgeon makes a wide "bikini line" cut and opens up the abdomen to access the affected organs and remove the endometriosis.

### **Hysterectomy**

If keyhole surgery and other treatments have not worked and you have decided not to have any more children, a hysterectomy (removal of the womb) might be an option however, this is usually a last resort.

It is important to note that hysterectomy is not a cure for endometriosis, especially if the ovaries are not removed. A hysterectomy is a major operation that involves more risks than other treatment options.

### **Oophorectomy (Removal of ovaries)**

Whether or not to remove the ovaries can be a difficult decision. It is not recommended to remove ovaries in women before the natural age of menopause (around 50 years old) as this can increase the risk of health problems later in life and can reduce the overall life expectancy, however, as long as the ovaries are still present there is a chance of endometriosis coming back.

Removal of the ovaries is rarely offered for women with severe endometriosis as a last resort. If the ovaries are removed then it is recommended that hormone replacement therapy (HRT) is taken until the age of 50.

### **Alternative therapies**

In some cases endometriosis symptoms can be difficult to treat. Although medical and surgical treatments work most of the time, they may not completely resolve symptoms in all women. Some women choose to explore alternative therapies to help manage their symptoms.

Alternative therapies are widely available but are not often offered by doctors as there isn't much research to help doctors advise whether or not they are safe and effective. Examples of alternative therapies that women with endometriosis have found helpful include acupuncture, cognitive behavioural therapy, dietary changes, reflexology, homeopathy, hypnosis, psychological therapy, traditional Chinese medicine, herbal medicine, meditation and exercise.

### **Endometriosis and fertility**

Infertility is defined as not becoming pregnant after one year of having sex on a regular basis. Around 70% of women with endometriosis are able to get pregnant and have children without medical help. Studies have shown that keyhole surgery to treat endometriosis can improve the chance of getting pregnant naturally in women who have endometriosis.

### **Menopause in endometriosis**

Menopause is medical term for when a women stops having menstrual periods. It usually happens when women are around 50 years old. In most cases endometriosis gets better after the menopause.

Some women have hardly any problems during menopause, while others suffer from menopausal symptoms like hot flushes, night sweats, vaginal and bladder problems, mood changes and osteoporosis (weak bones).

Some women choose to take hormone replacement therapy (HRT) to reduce menopausal symptoms. Combined HRT (containing an oestrogen and a

progesterone) is better than oestrogen-only HRT for women with endometriosis as oestrogen-only HRT might make endometriosis worse.

### **Support groups**

Support from self-help groups can be very useful if you are learning to manage endometriosis. **Endometriosis UK:** [www.endometriosis-uk.org](http://www.endometriosis-uk.org)

If you have any questions you want to ask, you can use this space to remind you:

If you have a visual impairment this leaflet can be made available in bigger print or on audiotape. If you require either of these options please contact the Patient Information Centre on 0161 922 5332

If you require an interpreter, please ask an appropriate person to contact our central booking office between Monday to Friday 8am to 5pm on 0161 922 6991 to arrange this for you.

#### 語言翻譯及病者支持服務 (LIPS):

如果閣下需要翻譯員在您的預約當日幫助您的話 請找一名合適的家庭成員 0161 922 6991 聯絡本中央預約辦事處來您您安排 我們的辦公時間是星期一至星期五 上午 8 時至下午 5 時

#### Językowo Tłumaczeniowa Usługa Pomocy dla Pacjenta (Language, Interpretation and Patient Support Service LIPS):

Jeśli potrzebujesz pomocy tłumacza w trakcie swojej wizyty, proszę poprosić odpowiedniego członka rodziny o skontaktowanie się z Centralnym Biurem Zamówień (Central Booking Office), w celu zorganizowania tłumacza pomiędzy poniedziałkiem a piątkiem w godzinach od 08:00 - 17:00 pod numerem 0161 922 6991.

لینگویج، انٹریپریٹیشن اینڈ پیسٹنٹ سپورٹ سروس (Lips)

اگر آپ کو اپنی اپائنٹمنٹ کے لئے مترجم کی مدد کی ضرورت ہو تو براہ مہربانی اپنے خاندان کے کسی موزوں فرد سے کہیں کہ وہ ہمارے سنٹرل بکنگ آفس سے پیر سے جمعہ 8.00 بجے صبح سے 5.00 بجے شام کے دوران 0161 922 6991 پر فون کر کے اس کا بندوبست کریں۔

**Authors:** Mohamed Osman, Obstetrics & Gynaecology Specialty Trainee & Nathalie Smilovici, Obstetrics & Gynaecology Consultant

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