

# Endometriosis

## What is endometriosis?

Endometriosis occurs when the cells that normally line the womb (the endometrium) are found elsewhere in the body; usually in the pelvis, around the womb (uterus), ovaries and fallopian tubes. It may also affect the bladder and bowel. Endometriosis is a common condition affecting between 5 and 10 women out of 100. Endometriosis is not cancer and is not infectious. You are more likely to develop endometriosis if your mother or sister has had it. It usually affects women during their reproductive years, from the onset of menstrual periods to the menopause.

## What are the symptoms?

Many women with endometriosis have no symptoms. If symptoms develop, they can vary and include one or many of those listed below

- Painful periods (dysmenorrhoea) which do not respond to over-the-counter pain relief.
- Persistent pain in the pelvic area/ lower abdominal pain sometimes constant, but usually worse on the days just before and during a period
- Pain in the middle of your cycle due to ovulation
- Pain during or after sexual intercourse (dyspareunia)
- Difficulty becoming pregnant (subfertility)
- Pain on passing urine (dysuria)
- Pain with opening your bowels, with or without bleeding (dyschezia)
- Long term fatigue and chronic tiredness.

However, these symptoms can be caused by other conditions so even if you experience some of these problems it may not be due to endometriosis. This means it is important to discuss your symptoms with your doctor or nurse specialist.

## What causes endometriosis?

Unfortunately, we do not fully understand what causes endometriosis or why some patients have more symptoms than others. It is possible that there are several factors that can lead to endometriosis. Combinations of these factors may increase the chance of developing the disease. A number of theories have been suggested but none have been proven.

- Retrograde menstruation: the most commonly accepted theory is that during a period, light 'backward' bleeding carries tissue (or endometrial cells) from the womb to the pelvic area, via the fallopian tubes.
- Each month these endometrial cells which are now situated in the pelvic area, then respond to the female hormone oestrogen. These cells thicken and break down in the same way as the lining of our womb does during a period, causing a small amount of bleeding inside your abdomen which causes pain, and forms sticky patches of tissue called endometriosis.

- Metaplasia: this is where cells within the body change into other cells, in this case skin cells (peritoneal cells) inside your abdomen can develop into endometriosis.
- Disorders of the immune system: studies have shown that women with endometriosis have different immune function to women without the condition. It is not known whether this contributes to endometriosis or whether it is a result of endometriosis.

### **Where is endometriosis found?**

Endometriosis may be found on the ovaries, fallopian tubes, on or behind the womb, in the area behind between the vagina and the rectum or in the peritoneum (the lining of the pelvis and abdomen). Endometriosis may then cause inflammation and irritation, causing pain and scarring to the surrounding reproductive organs and sometimes the bowel and bladder.

Endometriosis can also occur within the muscle wall of the womb (adenomyosis) and occasionally on the bowel and /or bladder.

### **What is adenomyosis?**

Adenomyosis is a similar condition to endometriosis when the lining of the womb is more deeply invaded into the muscle layer of the womb. This makes the junction between the two layers thicker and promotes an inflammatory response at the time of a period. This inflammation increases blood supply to the lining of the womb and can make periods heavy and painful. These symptoms can occur alongside endometriosis or may occur alone.

### **How is the diagnosis of endometriosis confirmed?**

The doctor or nurse will take a careful and thorough history which may highlight symptoms which could be due to endometriosis.

It can often be helpful to keep a diary of your symptoms over 2-3 months prior to your appointment. We will also ask about your periods, when they occur, whether they are painful and how heavy they are. We may also ask about the symptoms you experience during sex, pain that you may experience when emptying your bladder and pain and bleeding that may occur when you open your bowels. Please do not be embarrassed about these questions as they give us really useful information about your condition.

The doctor may carry out an internal examination with your consent. This helps to localise the pelvic pain, the doctor may be able to feel an ovarian cyst, nodules of endometriosis between the bowel and vagina or scarring on the ligaments which support the womb. You will be offered a chaperone during this examination.

It is virtually impossible for a firm diagnosis to be reached from taking a history and examination alone.

A pelvic ultrasound scan may be requested, this may be a transvaginal scan to check the uterus and ovaries. It may show whether there is an endometriotic (chocolate) cyst in the ovaries or may identify endometriosis between the vagina and bowel.

If more information is needed about the extent of your endometriosis, you may need a MRI (magnetic resonance imaging) scan. This uses a very strong magnet to influence water molecules in your body and create an image. It does not use radiation and so is considered safe. However, it is important that you tell us if you have any metal anywhere in your body, e.g., from previous surgery or following injuries.

The most reliable way to make a definite diagnosis of endometriosis is to carry out an operation called a laparoscopy; this is carried out under general anaesthetic. It involves inserting a thin telescope like instrument (a laparoscope) through a small cut in your belly button, to allow a direct view inside the abdomen and pelvis. You may also have a biopsy to confirm diagnosis and images may be taken for your medical records.

The doctor may suggest treating the endometriosis at the time of your first laparoscopy, either by removing cysts on the ovaries or treating areas on the lining of your pelvis. This may avoid a second operation, however sometimes the extent of the endometriosis found means that you may need further tests or treatment.

### **What are the treatment options?**

The aims of treatment are to reduce the severity of your symptoms, improve your quality of life and increase fertility, if this has been affected. Broadly speaking treatments can be broken down into medical (drugs) and surgical treatments.

- Medical treatment aims to improve symptoms by suppressing the endometriosis.
- Surgery aims to treat the endometriosis by excising (removing) the endometriosis, dividing adhesions or removing cysts.

### **Not treating as an option**

If symptoms are mild and fertility is not an issue for you then you may not want any treatment. You can always change your mind and opt for treatment if symptoms do not get better or become worse.

### **Options for medical treatment**

- Pain relieving medication– paracetamol taken during periods may be all that is needed if the symptoms are mild. Non-steroidal anti-inflammatory painkillers (NSAIDS) such as ibuprofen, diclofenac, and naproxen may be more effective; however, these are not suitable for everyone. If pain is severe these can be supplemented with opiate medications such as codeine, although constipation can be a common side effect. In more severe situations you may be referred to a specialist pain management team.
- Hormone treatments – the aim of hormone treatments is to suppress or stop the growth of endometriosis deposits. Hormonal suppression is effective in relief of symptoms and probably preventing progression, but it does not clear or remove the endometriosis.

### **Types of hormone treatments**

- The combined oral contraceptive pill or patch works by making your periods lighter, shorter and less painful. In endometriosis it is best taken in a continuous way for three months at a time as this stops ovulation and temporarily either stops your periods or makes them lighter and less painful.
- The progesterone only contraceptive pill, which you take every day. It can be effective for treating endometriosis but can also cause spotting bleeding.
- Progestogens in the form of 3 monthly injections or contraceptive implant Nexplanon which last for 3 years. They are both good at providing both contraception and long-term suppression of endometriosis. Unfortunately, they can also cause spotting bleeding, skin changes, mood changes and bloating symptoms.

- The Mirena system (coil) sits inside the uterus and releases a very small amount of progesterone to suppress the lining of the womb. It is effective in some patients with endometriosis, particularly if they have problems with heavy periods or adenomyosis is suspected. It can be used as a contraceptive.
- GnRH (gonadotrophin releasing hormone) agonists. These drugs are given as a monthly implant under the skin. These drugs prevent oestrogen being produced by the ovaries and cause a temporary and reversible menopause. The reduction in oestrogen reduces the hormonal drive to the endometriosis. If you take these drugs for a long time (more than 6 months) they can make your bones weaker, a condition called osteoporosis. We therefore usually recommend taking a small amount of hormone replacement therapy to prevent the menopausal side effects, and to protect your bones from becoming weak. It is important to note that some of these hormone treatments are not contraceptive therefore if you do not wish to become pregnant, you will need to use a contraceptive as well.

## **Surgery for endometriosis**

Surgery can treat or remove areas of endometriosis; the surgery recommended will depend on where the endometriosis is and how extensive it is.

- Laparoscopy (keyhole surgery) is performed under general anaesthetic and is now most commonly used to diagnose and treat all grades of endometriosis. Some more complex surgery is performed by two specialists (two gynaecologists or a gynaecologist and a bowel or urology surgeon).
- Laparotomy is occasionally required for more severe cases. This is a major operation that involves a cut in the abdomen, usually along the bikini line. If you have severe endometriosis a specialist team that may include a gynaecologist, a bowel surgeon or urologist, a radiologist and specialist in pain management may discuss your treatment options. Any surgical procedure carries risks; therefore, all options will be discussed with you before making decisions about your treatment.

As a BSGE (British Society of Gynaecological Endoscopy) accredited Endometriosis Centre, we are required to collect questionnaire data about our patients. This data is anonymised and relates to the symptoms you experience, the surgery you may have and any changes in your quality of life as a result. We will ask your permission before any information is shared and you have the right to say no if you don't want your information shared. If you say no to these questionnaires, it will have no effect on the care you receive. More detailed information leaflets regarding the surgical options are available.

## **Other options**

Some women have found the following measures helpful:

- Exercise, this may improve your wellbeing and also some symptoms of endometriosis
- Cutting out certain foods such as dairy or wheat products from the diet
- Psychological therapies and counselling.

## Complementary Therapies

Although there is only limited evidence for their effectiveness, some women find the following therapies helpful to reduce pain and improve their quality of life

- Reflexology
- Transcutaneous electrical nerve stimulation (TENS)
- Acupuncture
- Vitamin B1 and magnesium supplements
- Traditional Chinese medicine
- Herbal treatments

## References

RCOG Royal College of Obstetricians and Gynaecologists

BSGE British Society Gynaecological Endoscopy

Endometriosis UK

[patient.co.uk/health/endometriosis](http://patient.co.uk/health/endometriosis)

