Endometriosis

An information guide
Endometriosis

The Royal Oldham Hospital is a specialist centre for the management of endometriosis. Our endometriosis centre is accredited by the British Society of Gynaecology (BSGE). This means that women in the area covered by The Pennine Acute Hospitals NHS Trust are able to access a local highly specialised, nationally accredited service for endometriosis and pelvic pain. The hospital provides a multidisciplinary team approach to treatment.

Patients with evidence of severe endometriosis including rectovaginal disease or deep infiltrating endometriosis (involving organs in or outside the pelvis) which are suspected on history, examination, radiological imaging (MRI) or confirmed on laparoscopy, will be discussed at our bi-weekly MDT meeting. Any patient with endometriomas of more than equal to 5 cm will have an MRI and discussion.

Members of the MDT include consultant gynaecologists with an interest in endometriosis and minimal access surgery, consultant gynaecologist with interest in subfertility, consultant radiologist, consultant colorectal surgeon, consultant urologist and a specialist nurse.

The purpose of the MDT is to discuss the evidence based treatment option, however patients may chose a treatment option which is different. If so this would be fed back to the MDT. At your follow-up appointment the results of the MDT will be discussed with you. You will also be asked to complete the BSGE 'quality of life' questionnaire and consent for details to be put in the BSGE database. Patients who fulfil MDT criterion will be treated by consultants experienced in performing complex laparoscopic surgery.

It is estimated that between 2 and 10% of women within the general population have endometriosis and also that up to 50% of
infertile women have endometriosis. Women with endometriosis often have severe complaints and significantly reduced quality of life, including restraint of normal activities, pain/discomfort and anxiety/depression.

What is endometriosis?

Endometriosis is a common condition in which small pieces of the lining of the womb (the endometrium) are found outside the womb. This could be in the fallopian tubes, ovaries, bladder, bowel, vagina or rectum. Endometriosis triggers a chronic inflammatory reaction resulting in pain and adhesions. Adhesions develop when scar tissue attaches separate structures or organs together. The activity and the complaints due to endometriosis may vary during the woman’s menstrual cycle as hormone levels fluctuate. Consequently, symptoms may be worse at certain times in the cycle, particularly just prior to and during the woman’s menstrual period. While some women with endometriosis experience severe pelvic pain, others have no symptoms at all or regard their symptoms as simply being ‘ordinary menstrual pain’.

What happens?

The endometriosis cells behave in the same way as those that line the womb, so every month they grow during the menstrual cycle and are shed as a bleed. Normally before a period, the endometrium thickens to receive a fertilised egg in response to a release of the hormone oestrogen. When pregnancy does not happen, the lining breaks down and leaves the body as menstrual blood (a period). Endometriosis tissue anywhere in the body will go through the same process of thickening and shedding, but it has no way of leaving the body and is trapped. This leads to pain, swelling and sometimes damage to the fallopian tubes or ovaries, causing fertility problems.
Who is affected?

Endometriosis affects around two million women in the UK. Most of them are diagnosed between the ages of 25 and 40.

Outlook

There is no known cure for endometriosis. It is a chronic (long-term) condition that can cause pain, lack of energy, depression and fertility problems. However, symptoms can be managed and fertility improved with pain medication, hormone treatment or surgery, so that the condition does not interfere with your daily life.

What are the symptoms of endometriosis?

The classical symptoms of endometriosis are:

- Dysmenorrhea (painful menstruation)
- Non-menstrual pelvic pain or pain occurring when a woman is not menstruating
- Dyspareunia (painful intercourse)
- Infertility
- Fatigue
- Cyclical intestinal complaints (periodic bloating, diarrhoea or constipation)
- Cyclical dyschezia (painful or difficulty opening bowels)
- Cyclical dysuria (painful urination)
- Cyclical haematuria (presence of blood in the urine)
- Cyclical rectal bleeding
- Cyclical shoulder pain
- Any other cyclical symptom.

Cyclical symptoms are symptoms that develop a few days before a woman’s menstruation (period) and disappear a few days after her menstruation has stopped, or symptoms that occur only during the menstruation. The symptoms reappear the next month, following the woman’s menstrual cycle.
If you experience one or more of these symptoms and they cause you (severe) pain, you should go to your family doctor and ask him/her to consider endometriosis. Severe pain can be measured by not doing your normal daily activities (without taking pain medication).

**What causes endometriosis?**

The cause of endometriosis remains unknown. There are several theories, but none of them has been entirely proven. The most accepted theory is centred on the so-called retrograde (moving backwards) menstruation. During menstruation, pieces of endometrium arrive in the abdominal cavity through the Fallopian tubes, stick to the peritoneal lining (lining of the abdominal cavity) and develop into endometriotic lesions. The hormone oestrogen is crucial in this process. Subsequently, most of the current treatments for endometriosis attempt to lower oestrogen production in a woman’s body in order to relieve her of symptoms.

It has been argued that endometriosis is a genetic disease, since some families show more patients with endometriosis compared to other families. Other suggestions are an immune response triggering inflammation.

**Stages of Endometriosis**

While a higher stage is generally regarded as denoting a more severe form of disease, the staging system neither predicts severity of pain nor complexity of surgery.

**Stages 1 & 2 (minimal to mild disease):** Superficial peritoneal endometriosis

**Stages 3 and 4 (moderate to severe disease):** The presence of superficial peritoneal endometriosis, deeply invasive endometriosis with moderate to extensive adhesions between the uterus and bowels and/or endometriom (fluid filled cyst) with moderate to extensive adhesions involving the ovaries and tubes.
How can you reduce the chances of getting endometriosis?

Doctors sometimes get questions from relatives of women with endometriosis on how they can prevent the disease.

Studies investigating whether taking the oral contraceptive pill or regular exercise could prevent endometriosis did not show a clear causal relation and have limitations. Therefore, it is uncertain whether taking the combined oral contraceptive pill or having regular physical exercise will prevent the development of endometriosis. Other interventions have not been studied.

Up to now, there are no known ways to reduce the chance of getting endometriosis.

Diagnosing endometriosis

In addition to your symptoms, clinical examination can provide additional information to the doctor.

During clinical vaginal examination the doctor looks for tenderness, nodules or swelling of the vaginal wall especially in the deepest point of the vagina between the back of the uterus and the rectum by inspection using the speculum and by palpation using his/her fingers. In women with deep endometriosis or endometriosis of the ovaries, clinical examination may give considerable information regarding the appropriate diagnosis, while in peritoneal disease the clinical examination most of the time is completely normal.

If your GP suspects that you have endometriosis, they will refer you to a gynaecologist (specialist) for a proper diagnosis. Endometriosis can only be diagnosed with an examination called a laparoscopy.

What is laparoscopy?

Laparoscopy is done under general anaesthesia (you are asleep). Instead of making a large incision in your abdomen (tummy), the surgeon uses a laparoscope (a thin telescope with light) through a
keyhole incision. For a laparoscopy, the abdomen is inflated with gas (carbon dioxide). If needed, the surgeon makes one or two more small incisions for inserting other surgical instruments. If endometriosis or scar tissue needs to be removed, the surgeon will use one of various techniques, including cutting and removing tissue (excision) or destroying it with electric current (electrocautery) or vaporization with laser. After the procedure, the surgeon closes the abdominal incisions with a few stitches. Usually there is very little scarring. At the end of the procedure some fluid may be left in your tummy to try to prevent the formation of scar tissue and organs sticking together.

For a definite diagnosis, laparoscopy is needed. However, if your doctor suspects endometriosis based on your symptoms, clinical examinations and transvaginal ultrasound, he or she may also propose to try medical treatment without establishing a definitive diagnosis first to reduce your symptoms. Options for medical treatment are analgesics (pain medication), hormonal contraceptives or progestogens (synthetic hormones). If these treatments help relieve your symptoms, you may decide not to undergo laparoscopy. If these treatments are not helping you, you can still decide to undergo a laparoscopy.

**Treatment**

Endometriosis is a chronic disease. In that sense, there is no cure for endometriosis, but the symptoms can be reduced with the right treatment. Communication is the key to finding a treatment that fits you. Please discuss your options with your doctor and ask any questions you may have. Your doctor will be happy to explain the different options and answer your questions.

Women with endometriosis have either pain, fertility problems or they have both. Treatment of endometriosis focuses on resolving or reducing pain due to endometriosis or on improving fertility, so a patient can get pregnant naturally or through fertility treatments.
For treating endometriosis, the doctor can prescribe medical treatment or advise surgical treatment.

Depending on the patient, the treatment will be different. Your doctor will take several factors into consideration when prescribing medical treatment or advising surgical treatment.

These factors include:

- The preferences of the woman
- The type of disease (peritoneal disease, ovarian cyst or deep endometriosis)
- The severity and type of pain symptoms
- The wish to become pregnant immediately or at a later stage
- The costs and side-effects of some treatments
- The age of the woman
- The treatments she has already received.

This means that two women with endometriosis could receive different treatments and even that one woman could receive different treatments over time depending on her preferences, her age, her wish to become pregnant.

Endometriosis can be difficult to treat. The aim of treatment is to ease the symptoms so that the condition does not interfere with your daily life. Therefore, treatment will be given to relieve pain, slow the growth of endometriosis, improve fertility or prevent the disease from coming back. The options are pain medication, hormone treatment and surgery.

Deciding which treatment

Your gynaecologist will discuss the treatment options with you and outline the risks and benefits of each.
In deciding which treatment is right for you, you may wish to consider:

- Your age
- Whether your main symptom is pain or difficulty getting pregnant
- Whether you want to become pregnant (some treatments may prevent you from becoming pregnant whilst you are taking them)
- How you feel about surgery
- Whether you have tried any of the treatments before.

Treatment may not be necessary if your symptoms are mild and you have no fertility problems. In about one third of cases, endometriosis gets better by itself without treatment.

It is possible to keep an eye on symptoms and decide to have treatment if they get worse. Support from self-help groups can be very useful if you are learning to manage endometriosis.

**Pain medication**

Non-steroidal anti-inflammatories (NSAIDs), such as ibuprofen and naproxen, are usually the preferred treatment as they act against the inflammation (swelling) caused by endometriosis, as well as helping to ease pain and discomfort. It is best to take NSAIDs the day before (or several days before) you expect the period pain.

Paracetamol can be used to treat mild pain. It is not usually as effective as NSAIDs, but may be used if NSAIDs cause any side effects, such as nausea, vomiting and diarrhoea.

Codeine is a stronger painkiller that is sometimes combined with paracetamol or used alone if other painkillers are not suitable. However, constipation is a common side effect, which may aggravate the symptoms of endometriosis.

Pregabalin belongs to a group of medicines called anti-convulsants which are used to treat epilepsy. Pregabalin can be used to treat
some kinds of persistent pain, it is particularly good for nerve pain such as burning stabbing and shooting pain.

Duloxetine and venlafaxine are anti-depressants that have lots of potential to help people with pelvic pain. These drugs are special because they have 2 different effects in that they can treat pain and anxiety.

**Hormone treatments**

Hormone treatments aim to limit or stop the production of oestrogen in your body. This is because oestrogen encourages endometriosis to grow and shed. Without exposure to oestrogen, the endometriosis tissue can be reduced, which helps to ease your symptoms. However, hormone treatment has no effect on adhesions ('sticky' areas of endometriosis, which can cause organs to fuse together), and cannot improve fertility. Hormone treatments stop the production of oestrogen by putting you in either an artificial state of pregnancy or an artificial state of menopause, which stops your periods. Once your periods have stopped, the endometriosis is no longer aggravated. However, it is important to note that most of these treatments are not contraceptives.

**There are four broad types of hormone-based treatment:**

- Progestogens
- Antiprogestogens
- Hormonal contraceptives
- Gonadotrophin-releasing hormone (GnRH) analogues.
Progestogens

Progestogens are synthetic hormones that behave like the natural hormone progesterone. They stop eggs from being released (ovulation), which can help to shrink endometriosis tissue. However, they can have side effects such as bloating, mood changes, irregular bleeding and weight gain. Drug names include medroxyprogesterone acetate, dydrogesterone and norethisterone.

The Mirena intrauterine system, a T-shaped contraceptive device that fits into the womb and releases progestogen, has been successfully used for the treatment of endometriosis.

Antiprogestogens

Also known as testosterone derivatives, antiprogestogens are synthetic hormones that bring on an artificial menopause by decreasing the production of oestrogen and progesterone. 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 unpleasant side effects.

Hormonal contraceptives

Hormonal contraceptives are widely used for contraception and generally accepted. They contain low doses of hormones (oestrogen and progesterone) and can reduce pain associated with endometriosis by stopping follicular growth and hence reducing the production and concentration of oestrogens. Low oestrogens stop the activity of the growth of the endometrium in and outside the uterus, and thus pause endometriosis. The progesterone in the pill decreases the activity of the endometrium directly.

The side effects are limited and hormonal contraceptives are not expensive. Your doctor can prescribe different types of hormonal contraceptives.
GnRH agonists

GnRH agonists induce a very low oestrogen level by stopping the follicular growth in the ovary completely. GnRH agonists can be taken intranasal, or through subcutaneous injection as a depot working either one or three months. GnRH agonists have more side effects than oral contraceptives and progestagens and are more expensive.

The side effects of GnRH agonists are related to the low level of oestrogens and are similar to the consequences of the menopausal status. These symptoms are hot flushes and night sweats, vaginal dryness and related pain during intercourse, and influences on the mental health up to depressive feelings. In the long term GnRH agonists are associated with osteoporosis. To reduce these symptoms, clinicians are recommended to prescribe hormonal add-back therapy. Hormonal add back means adding a combination of oestrogens and progesterone. This add-back therapy takes away the side effects while the therapeutic effect is maintained.

Surgery

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

- Laparoscopic surgery (the most commonly used and least invasive technique)
- Laparotomy
- Hysterectomy.

Any surgical procedure carries risks. Discuss them with your surgeon.
Laparoscopic surgery
During a laparoscopy (a surgical procedure to gain access to the inside of your pelvis), endometriosis tissue can be destroyed or cut out using delicate instruments that are inserted into the body. This is also known as keyhole surgery. Although this kind of surgery can relieve your symptoms, they can sometimes recur, especially if some endometriosis tissue is left behind at the time of surgery.

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 cut around your bikini line and opens up the area to access the affected organs and remove the endometriosis tissue.

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) can be an option however, this is rarely required. A hysterectomy is a major operation that will have a significant impact on your body. Deciding to have a hysterectomy is a big decision, which you should discuss with your GP or gynaecologist. Hysterectomies cannot be reversed and there is no guarantee that the endometriosis will not return after the operation. If the ovaries are left in place, the endometriosis is more likely to return.

Beyond usual treatment
Medical and surgical treatment of endometriosis has been studied widely and is used in clinical practice. Since these treatments have limitations, some women prefer to explore other options. You may have heard about complementary and alternative therapies. These therapies are very popular, but are not often given by doctors. Examples are acupuncture, behavioural therapy,
nutrition (including dietary supplements, vitamins, and minerals), expert patient programmes, recreational drugs, reflexology, homeopathy, psychological therapy, Traditional Chinese Medicine, herbal medicine, sports and exercise. Several of these complementary and alternative therapies are used by women with endometriosis to reduce pelvic pain, dysmenorrhea, improve the chances of pregnancy and improve quality of life.

Endometriosis and infertility

Infertility is defined as not reaching pregnancy after 1 year of regular intercourse. It is estimated that 60-70% of women with endometriosis are fertile and can get pregnant spontaneously and have children. Studies have shown that surgery (with removal of endometriotic lesions) can enhance the chance of spontaneous pregnancy in women with peritoneal endometriosis.

Menopause in endometriosis

Menopause is the point in time when women stop having menstrual periods. It is a natural process in women of around 50 years old. Some women have hardly any problems during menopause, while others suffer from typical menopausal symptoms like hot flushes, night sweats, vaginal and urinary problems, mood changes, osteoporosis (decreased bone density). These symptoms are caused by low levels of oestrogen. For women with menopausal symptoms, medical treatments exist to reduce the symptoms and discomfort from menopause.

Women with endometriosis may have similar symptoms of menopause as women without endometriosis. The problem in women with endometriosis is that the medical treatments given to women to reduce the symptoms and discomfort of menopause could have a negative effect on their endometriosis. Until now, there is no strong evidence of pain or disease recurrence in women with endometriosis taking medication for menopausal symptoms, but it is a possibility.
Contact details

Centre: Pennine Endometriosis Centre

Address: Royal Oldham Hospital, Rochdale Road, Oldham, Manchester, OL1 2JH, 0161 627 8161. Endometriosis Specialist Nurse 07817022694

Recommended NHS link sites:


Endometriosis SHE Trust - www.shetrust.org.uk

Endometriosis UK - www.endometriosis-uk.org

Royal College of Obstetricians and Gynaecologists - www.rcog.org.uk

Women’s Health: endometriosis - www.womens-health.co.uk/endo.asp
If English is not your first language and you need help, please contact the Ethnic Health Team on 0161 627 8770.