Information Leaflet

Liverpool Women's NHS Foundation Trust

Endometriosis

What is Endometriosis?

Endometriosis is a condition where tissue similar to the lining of the womb (endometrium) is found outside the womb. About 1 out of 10 women of childbearing age may have endometriosis and symptoms typically present between the ages of 25 and 40.

Any woman in the reproductive period of her life (teenage years until the menopause) can be affected.

Endometriosis tissue can be found anywhere in the pelvis, but most commonly it is found on the ligaments that support the uterus (the uterosacral ligaments) or on the ovaries; occasionally it can be found in the bladder or bowel, affecting their function.

Endometriosis tissue are responsive to hormones produced by the ovary. When the lining of the womb thickens and grows each month and breaks down as a period in response to the ovarian hormones, endometriosis tissue does the same. However, this cause accumulation of blood and inflammatory material near the endometriosis tissue. For instance, altered blood can be collected in an ovary as a cyst called endometrioma or a chocolate cyst. Endometriosis is not a malignant disease (not cancerous), and disappears after menopause.

Endometriosis doesn't always cause symptoms. In those who have symptoms, we believe the inflammation and scarring in the surrounding tissue have a role in causing the symptoms such as pelvic pain. The scarring may appear as filmy webs that are called "adhesions". These adhesions can cause the pelvic organs to stick together. There are varying degrees of endometriosis; Some women may only have few spots of endometriosis (mild endometriosis) while in others the disease may be widespread throughout the pelvis. In very severe cases the pelvic organs such as womb, bowels and ovaries can become fixed and attached to each other and made immobile by the scar tissue. This we believe can lead to severe pain. However, severity of symptoms do not mean severe disease. So you may have severe pelvic pain, but either no endometriosis or mild disease, where as some women have severe endometriosis with very little symptoms.

What Causes Endometriosis?

The exact cause of endometriosis is not known. There are many theories that includes, backflow of tissue shed with menses in to the pelvis through the fallopian tubes (retrograde menstruation); or a genetic cause because in some women it is found in other close relatives (mother, aunts, daughters etc.).

What are the symptoms?

Some women who have endometriosis have no symptoms; however common symptoms include:

- Pain before the period starts
- Pain during periods (dysmenorrhoea)
- Pain during intercourse (dyspareunia)
- Heavy periods (menorrhagia)
- Infertility – difficulty getting pregnant
- Uncommon symptoms include pain when bowels have opened, pain in the lower abdomen when passing urine and blood in the urine or faeces. Very rarely, patches of endometriosis can occur in other sites of the body. This can cause unusual pains in various parts of the body that occur at the same time as period pains.

How is Endometriosis Diagnosed?

There are no blood tests used in the clinic to diagnose endometriosis.

Ultrasound scans and MRI scans can suggest a diagnosis of particular types of endometriosis, such as endometriosis cysts in the ovaries or severe endometriosis involving bowels, but may not always diagnose the common form of mild endometriosis.

Definite diagnosis of endometriosis can be made by examining the pelvis during surgery (usually laparoscopy or key hole surgery: see separate patient information leaflet: Laparoscopy), when the spots/patches/ ovarian cysts made by endometriosis tissues are seen and can be biopsied and tested in the lab.

Active areas of endometriosis can be seen as red vesicles (blisters), or blue spots where altered blood collected in these and white or brown patches represent older or inactive endometriosis. Extensive adhesions, lumps of endometriosis tissue (nodules) and endometrioma (endometriosis cysts on the ovaries) can also be seen during a laparoscopy surgery carried out to diagnose the disease.

How does Endometriosis Progress?

The natural cause of endometriosis is currently unknown. The available limited evidence from research studies suggest that untreated endometriosis may get better in 3 out of 10 women; becomes worse in 3 out of 10 women; whilst remain unchanged in the remaining women without treatment.

At present there are no curative treatment for endometriosis or associated symptoms, and when offering treatments to women with endometriosis, doctors cannot predict who are likely to have their endometriosis worsened if untreated. Even with treatment,

endometriosis can recur, but some women with severe untreated endometriosis may be at risk of complications such as obstruction or blockage of the ureter (the tube between the kidney and bladder). These issues need to be considered when choosing the treatment options.

Why & How is Endometriosis Staged?

The amount of the endometriosis tissue present in the pelvis is usually described by doctors in a certain way to standardise their assessment for doctors and patients to consider surgical treatment and other treatment options. Many doctors use the classification provided by the American Society for Reproductive Medicine to assess the severity and extent of the disease. This system gives points based on where the endometriosis tissue is and how deep beneath the surface they extends to, so it can assist in staging the extent of endometriosis.

How is Endometriosis Treated?

There is no known cure for endometriosis; the aim of the treatment is to manage and improve the symptoms associated with the condition. This can be done medically and / or surgically. There are some lifestyle changes that may also help to alleviate symptoms.

Medical Treatment

Medical treatment is simulating the hormonal background of either pregnancy or menopause, because symptoms associated with endometriosis, settle during those times. The available treatments are;

- The combined oral contraceptive pill (OCP) or progestogen only pill (POP) (to mimic pregnancy). These treatments will reduce the number of menses so will reduce the pain and symptoms associated with endometriosis.
- Gonadotrophin releasing hormones (GNRH)(to mimic menopause) this treatment is usually given for 6 months, during which you won't have periods. Endometriosis tissue is expected to dry out when you are on treatment. The menopause symptoms that some women experience can be reduced by using a low dose hormone replacement therapy – or add-back as necessary (although this is a hormone based treatment is does not reduce the efficiency of the medication). This treatment offers temporary relief but some women experience benefit for many months/years even after treatment. Since using this treatment for long periods can make bones thin (osteoporosis) it is not used for longer periods.

Surgical Treatment

Endometriosis can be surgically removed and this is favourably done using key-hole surgery called a laparoscopy (see separate Laparoscopy patient information leaflet). Laparoscopy may provide symptom control and may improve fertility in some women. For mild endometriosis in particular, surgical excision does not provide any additional benefit over medical therapy in symptom relief or return of symptoms after treatment.

Occasionally bigger operations are offered to separate adhesions and remove endometriosis cysts from ovaries. The women who need extensive and complex surgeries for endometriosis should be done in specialist centres, where they are discussed at

regular multidisciplinary team meetings involving other specialist than gynaecologists (bowel surgeons, urologists, radiologists and pain specialists) and these specialists will decide that final surgery may need to be done by the appropriate team of surgeons with specific skills. As a last resort removal of the uterus, cervix, fallopian tubes and ovaries (hysterectomy and bilateral salpingo-oophorectomy – please see separate leaflet) may be offered, this is usually reserved for women who have completed their family and is often a technically difficult procedure. The important points to consider with surgical treatments are that there is no guarantee of symptom relief even with these extensive operations; the complications associated with surgery; permanent loss of fertility with some surgeries (e.g. hysterectomy or removal of both ovaries); and the fact that current research suggests that approximately 35% of women will develop recurrence of their endometriosis after surgery and may consider further and repeated surgery. Repeated surgery for endometriosis excision is potentially more risky with increase possibility of serious complications.

Endometriosis and Fertility

The relationship between endometriosis and fertility is not yet fully established or understood. There are many women with endometriosis who become pregnant without difficulty, but endometriosis is found in 1 in 4 women who are undergoing investigations such as a laparoscopy for subfertility investigation (Cochrane 2002).

There are no preventative surgical treatments that have shown to be effective to improve future fertility, yet for those women who are having difficulties in getting pregnant; consultation with an infertility expert is initially needed for particular advice for treatment for endometriosis.

Frequently Asked Questions

How do I get a referral to an Endometriosis Centre?

Most commonly through your GP or Consultant.

Once your referral has been received this will be triaged and an appointment will be sent to you.
It is important to note that as an Endometriosis Centre we only see confirmed or suspected deep and severe cases diagnosed on Laparoscopy or Scan. Mild or moderate cases are seen in the general gynaecology setting, however depending on the clinical findings you may have further follow up in the endometriosis service.

When will I have my surgery?

This depends upon the severity of the disease; you may need further investigations which require the expertise of other specialists, i.e Colorectal or Urology (bowel and bladder). In these cases you will be referred to a local hospital who work alongside us, they will send you an appointment for consultation in the first instance. If you require further investigation such as Sigmoidoscopy (camera into the lower part of the bowel) this will discussed with you at consultation.

Once a date for surgery has been allocated you will be contacted by the Admissions team. Any queries relating to your admission the team can be contacted on 0151 702 4475.

Please leave a message with your name, hospital number and your contact details. Please do not leave a message for the Clinical Nurse Specialist as they are unable to organise operation dates.

How do I contact the Specialist Nurse?

If you attended the Endometriosis Centre, you may have been given the contact number of the Specialist Nurse.

The telephone number is 0151 702 4259, please leave a message and your contact details.

You should only contact the Specialist Nurse if:

1. You wish to ask further questions about your diagnosis or your treatment plan.
2. You have been advised by the doctor to let them know of completed investigations.
3. You have had your operation and have been seen or admitted back in a hospital due to problems or complications.

Please do not contact the Specialist Nurse to routinely change your appointments as they are unable to do this (see Q1)

Useful Addresses and Websites

http://www.endometriosis.org
http://www.endometriosis.co.uk
http://www.womens-health.co.uk/endo.asp

This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at pals@lwh.nhs.uk

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