Central Manchester University Hospitals NHS
NHS Foundation Trust

Saint Mary's Hospital
Gynaecology Unit

Saint Mary's Hospital

Endometriosis

Information For Patients

INVESTOR IN PEOPLE

POSITIVE ABOUT DISABLED PEOPLE

Contents

What is endometriosis?

Endometriosis is a common condition in which small pieces of the womb lining (the endometrium) are found outside the womb. This could be in the fallopian tubes, ovaries, bladder, bowel, vagina or rectum.

Endometriosis commonly causes pain in the lower abdomen (tummy), pelvis or lower back. It may also lead to fertility problems. However, some women have few or no symptoms.

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?

Symptoms of endometriosis vary from person to person. Some women have no symptoms. The most common symptoms include:

- Painful or heavy periods.
- Pain in the lower abdomen (tummy), pelvis or lower back.
- Pain during sexual intercourse.
- Bleeding between periods.
- Fertility problems.

The experience of pain varies between women. Most women with endometriosis get pain in the area between their hips and the tops of their legs. Some women have this all the time, while others only have pain during their periods, when they have sex or when they go to the toilet.

Other symptoms may include:

- Discomfort when urinating.
- Bleeding from your back passage (rectum).
- Bowel blockage (if the endometriosis tissue is in the intestines).
- Coughing blood (if the endometriosis tissue is in the lung).

How severe the symptoms are depends largely on where in your body the endometriosis is, rather than the amount of endometriosis you have. A small amount of tissue can be as painful as, or more painful than, a large amount.

When does it occur?

Patches of endometrial tissue may be found:

- Around the ovaries.
- Around the fallopian tubes.
- On the outside of the womb.
- In the area between the rectum (back passage) and womb.
- In the bowel.
- On the bladder.
- In the vagina.
- In the rectum.
- In the muscle layer of the wall of the womb.
- In scars from previous operations.
- In rare cases, in the skin, eyes, spine, lungs or brain.

Causes of endometriosis

The exact cause of endometriosis is unknown, but there are a number of theories:

- Retrograde menstruation.
- Genetic predisposition.
- Spreading through the bloodstream or lymphatic system.
- Immune dysfunction.
- Environmental causes.
- Metaplasia.

It is likely that endometriosis is caused by a combination of genetic, immune system and hormonal factors.

- **Retrograde menstruation**

Retrograde menstruation occurs when the womb lining (endometrium) flows backwards through the fallopian tubes and into the abdomen, instead of leaving the body as a period. This tissue then embeds itself onto the organs of the pelvis and grows.

It is thought that retrograde menstruation happens in most women, but that they are able to clear the tissue naturally without it becoming a problem. It is possible that this is how endometriosis occurs in some women.

Retrograde menstruation is the most commonly accepted theory for endometriosis. However, it does not explain why the condition can occur in women who have had a hysterectomy.

- **Genetic disposition**

Endometriosis is sometimes believed to be hereditary, being passed down through the genes of family members. It is rare in women of African-Caribbean origin, and is more common in Asian women than in white (Caucasian) women. This suggests that genes may be involved.

- **Spreading through the bloodstream or lymphatic system**

Although it is not known how, endometriosis cells are believed to get into the bloodstream or lymphatic system (a network of tubes, glands and organs that is part of the body's defence against infection). This theory could explain how, in very rare cases, the cells are found in remote places such as the eyes or brain.

- **Immune dysfunction**

It is believed that some women's immune systems are not able to effectively fight off endometriosis. Many women with endometriosis are said to have lower immunity to other conditions. However, this may be a result of the endometriosis, rather than something that is caused by the disease.

- **Environmental causes**

It is thought that endometriosis may be caused by certain toxins in the environment, such as dioxins (chemical byproducts) affecting the body and its immune system.

- **Metaplasia**

Metaplasia is the process of one type of cell changing into another to adapt to its environment. It is this development that allows the human body to grow in the womb before birth.

It has been suggested that some adult cells retain the ability they had as an embryo to transform into endometrial cells.

Diagnosing endometriosis

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.

- **Laparoscopy**

For this procedure, you will be given a general anaesthetic (put to sleep) and a special viewing tube with a light on the end (a laparoscope) will be passed into your body. The laparoscope has a tiny camera that transmits images to a video monitor so that the specialist can view the endometriosis tissue.

The specialist will then either take a small sample (a biopsy) for laboratory testing or insert other surgical instruments to treat the endometriosis.

The area of your body where the laparoscope will be inserted depends on where the specialist thinks the endometriosis tissue is. Because many women have symptoms around their pelvis and lower abdomen (tummy), the laparoscope is usually inserted into the pelvis through the navel (belly button).

You can usually go home the same day as a laparoscopy.

Treating endometriosis

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 stop you getting pregnant).
- 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.

- **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.
- The combined oral contraceptive pill.
- 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.

- **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.

Laparoscopy is now commonly used to diagnose and treat endometriosis. All grades of endometriosis can be successfully treated with this minimally invasive technique (where only small cuts are needed to insert the instruments). Heat, a laser or an electric current may be applied to destroy the patches of tissue.

Endometriomas (ovarian cysts formed as a result of endometriosis) can also be easily treated using this technique, which can be used alongside medication such as GnRH analogues.

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.

Complications of endometriosis

- **Fertility problems**

The main complication of endometriosis is difficulty getting pregnant (subfertility) or not being able to get pregnant at all (infertility).

Surgery can improve fertility by removing endometriosis tissue, but there is no guarantee that this will allow you to get pregnant.

- **Adhesions and ovarian cysts**

Other problems include the formation of adhesions, which are 'sticky' areas of endometriosis tissue that can fuse organs together, and endometriomas (fluid-filled cysts in the ovaries), which can occur when the endometriosis tissue is in or near the ovaries. In some cases, endometriomas can become very large and painful. Both of these complications can be removed through surgery, but may recur if the endometriosis returns.

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

Suggestions, Concerns and Complaints

If you wish to make a comment, have a concern or want to complain, it is best in the first instance to speak to the manager of the ward or department involved.

The Trust has a Patient Advice and Liaison Service (PALS) who can be contacted on (0161) 276 8686 and via e-mail: pals@cmft.nhs.uk. They will help you if you have a concern, want advice, or wish to make a comment or complaint.

Information leaflets about the service are readily available throughout the Trust. Please ask any member of staff for a copy.

Notes

No Smoking Policy

The NHS has a responsibility for the nation's health.

Protect yourself, patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted within any of our hospital buildings or grounds.

The Manchester Stop Smoking Service can be contacted on Tel: (0161) 205 5998 (www.stopsmokingmanchester.co.uk).

Translation and Interpretation Service

Do you have difficulty speaking or understanding English?

আপনি কি ইংরেজীতে বুঝতে কিংবা বুঝাতে পেরেছেন ? (BENGALI)

क्या आपको अंग्रेजी बोलने या समझने में कठिनाई है ? (HINDI)

તમે ભાષા કારણે વાતચીત કરવામાં મુશ્કેલી આવે છે ? (GUJARATI)

ਕਿ ਤੁਹਾਨੂੰ ਅੰਗ੍ਰੇਜ਼ੀ ਬੋਲਣ ਜਾਂ ਸਮਝਣ ਵਿਚ ਦਿੱਕਤ ਹੈ ? (PUNJABI)

Miyey ku adagtahay inaad ku hadasho Ingriisida aad sahamto (SOMALI)

هل لديك مشاكل في فهم اوالتكلم باللغة الأنجليزية ؟ (ARABIC)

你有困難講英語或明白英語嗎？ (CANTONESE)

کیا آپکو انگریزی سمجھنے اور سمجھانے میں دقت پیش آتی ہے ؟ (URDU)

☎ **0161 276 6202/6342**

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