NHS
Northern Care Alliance
NHS Group

Endometriosis

An information guide

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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 Northern Care Alliance NHS Foundation 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 Multi-disciplinary Team (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 with experience in complex laparoscopic 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 best evidence based treatment options. 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.

It is estimated that between 2 and 10% of women within the general population have endometriosis and that up to 50% of women with suberfertility have endometriosis. Women with endometriosis often have severe symptoms and significantly reduced quality of life, including restriction in 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 symptoms of endometriosis may vary during the woman's menstrual cycle as hormone levels fluctuate. 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 mild symptoms or even no symptoms at all.

The extent of endometriosis found on investigation (such as laparoscopy) does not correlate with extent of symptoms. Even a small spot of endometriosis can cause debilitating symptoms, while some women with minimal symptoms have been known to be diagnosed with extensive endometriosis during an investigation or operation for something unrelated (eg at caesarean section or during laparoscopic sterilisation).

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 builds up/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, inflammation and scarring.

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:

- Painful periods.
- Continuous pain.
- Painful sexual intercourse.
- Infertility.
- Fatigue.
- Cyclical intestinal complaints (periodic bloating, diarrhoea or constipation).
- Cyclical difficulty or pain when opening bowels.
- Cyclical painful urination.
- Cyclical blood in the urine.
- Cyclical rectal bleeding.
- Cyclical shoulder pain.

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 them to consider endometriosis.

What causes endometriosis?

The cause of endometriosis remains unknown. There are several theories, but none of them have been proven. The most accepted theory is centred on the so-called retrograde (moving backwards) menstruation. During menstruation, pieces of endometrium travel backwards into 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 endometrioma (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 proven 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 gently feeling on internal examination. Normal examination findings do not exclude the diagnosis of endometriosis.

If your GP suspects that you have endometriosis, they will refer you to a gynaecologist (specialist). 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. The abdomen is inflated with gas (carbon dioxide). If needed, the surgeon makes between one and three more small incisions for inserting other surgical instruments. If endometriosis or scar tissue needs to be treated, the surgeon will use one of various techniques, including cutting and removing tissue (excision) or destroying it with electric current (electrocautery). After the procedure, the surgeon closes the abdominal incisions with a few stitches. Usually there is very little scarring.

For a definite diagnosis, laparoscopy is needed. However, if your doctor suspects endometriosis based on your symptoms, clinical examinations and ultrasound, you may wish to try medical treatment to reduce your symptoms without undergoing laparoscopy.

Options for medical treatment are analgesics (pain medication) or hormonal treatments. 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 suits 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.

Treatment of endometriosis focuses on resolving or reducing symptoms or on improving fertility.

Treatment will be personalised and several factors need to be taken into consideration.

These factors include:

- The type of disease (peritoneal disease, ovarian cyst or deep endometriosis).
- Severity and type of symptoms.
- Wishes regarding fertility.
- Side-effects of some treatments/personalised risks of surgery.
- Age at diagnosis (symptoms of endometriosis often improve after the menopause).
- Treatments already tried.

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.

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 caused by endometriosis, as well as helping to ease pain and discomfort. It is best to take NSAIDs before you expect the pain.

Paracetamol can be used to treat mild pain. It is not usually as effective as NSAIDs, but may be used as well as, or instead of NSAIDs if you experience side effects.

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 and other 'neuropathic' pain killers 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 have 2 different effects in that they can treat pain and anxiety/depression.

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 (scarred areas of endometriosis, which can cause organs to fuse together) and cannot improve fertility.

Once your periods have stopped, the endometriosis is no longer aggravated. However, it is important to note that some of these treatments are not contraceptives.

There are three broad types of hormone-based treatment:

- Progestogens
- 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 (this is the drug used in the contraceptibe injection, but can be taken as tablets), dydrogesterone and norethisterone.

The Mirena intrauterine system (coil), a T-shaped contraceptive device that fits into the womb and releases progestogen, has been successfully used for the treatment of endometriosis. The dose of progesterone administered by this device is significantly smaller than when progestogens are used by other routes.

Combined hormonal contraceptives

These contain low doses of oestrogen and progesterone in combination, and also stop ovulation/ the menstrual cycle and can therefore help to reduce symptoms of endometriosis. The combination of the two hormones gives a different side effect profile to progesterone only treatments, and there are many different combinations.

GnRH agonists

GnRH agonists (or analogues) induce a very low oestrogen level by temporarily completely stopping the function of the ovaries. GnRH agonists are usually given by injection which work for either one or three months. GnRH agonists have more side effects than oral contraceptives and progestogens.

The side effects of GnRH agonists are related to the low level of oestrogens and are similar to the symptoms of menopause. These

symptoms are hot flushes and night sweats, vaginal dryness and related pain during intercourse, and mood changes. If used long term GnRH agonists can also lead to osteoporosis.

'Addback' hormonal replacement therapy (HRT) can be used to reduce these symptoms. This means adding a combination of oestrogens and progesterone at a low dose so that symptoms are reduced without reducing the effects of the treatment. Please see our separate information leaflet on GnRH analogues.

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:

- Laparoscopy and excision of emdometriosis.
- Hysterectomy (removal of uterus and cervix) +/- salpingo-oophorectomy (removal of tubes and ovaries).

Any surgical procedure carries risks. These will be discussed at your clinic appointment.

Please see separate information leaflets regarding laparoscopy/ hysterectomy.

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.

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 uterus) can be an option. 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 and 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. However, removing ovaries can have significant long term health implications and is not usually appropriate for those under the age of 40.

Beyond usual treatment

Medical and surgical treatment of endometriosis has been studied widely and are used routinely in clinical practice. Since these treatments have limitations, some women prefer to explore other options.

You may have heard about complementary and alternative therapies. Examples are acupuncture, behavioural therapy, nutrition (including dietary supplements, vitamins, and minerals), expert patient programmes, reflexology, homeopathy, psychological therapy, Traditional Chinese Medicine, herbal medicine, sports and exercise.

There is good evidence that exercise can help to improve symptoms of chronic pain but unfortunately there is not enough scientific evidence for alternative therapies to be recommended by doctors. However, 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 to 70% of women with endometriosis can get pregnant spontaneously.

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 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. Medical treatments (Hormone Replacement Therapy (HRT)) exist to reduce the symptoms of menopause. This contains oestrogen.

Women with endometriosis may have similar symptoms of menopause as women without endometriosis. The problem in women with endometriosis is that HRT 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: The Royal Oldham Hospital, Rochdale Road, Oldham, Manchester, OL1 2JH, 0161 627 8161. Endometriosis Specialist Nurse 07817022694

Recommended NHS link sites:

www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline/Patient-version.aspx

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

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For general enquiries please contact the Patient Advice and Liaison Service (PALS) on 0161 604 5897

For enquiries regarding clinic appointments, clinical care and treatment please contact 0161 624 0420 and the Switchboard Operator will put you through to the correct department / service

The Northern Care Alliance NHS Group (NCA) is one of the largest NHS organisations in the country, employing 17,000 staff and providing a range of hospital and community healthcare services to around 1 million people across Salford, Oldham, Bury, Rochdale and surrounding areas. Our Care Organisations are responsible for providing our services, delivering safe, high quality and reliable care to the local communities they serve.

The NCA brings together Salford Royal NHS Foundation Trust and the hospitals and community services of The Royal Oldham Hospital, Fairfield General Hospital in Bury, and Rochdale Infirmary (currently part of The Pennine Acute Hospitals NHS Trust).

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