Endometriosis and Adenomyosis

Gynaecology

Introduction

This information leaflet is intended for ladies who have been diagnosed with endometriosis or adenomyosis. It gives them a better understanding of what endometriosis and adenomyosis is and how it may be treated. Please feel free to ask a member of the team if this leaflet does not answer all your questions.

What is endometriosis?

Endometriosis is a condition in which cells that normally line the womb (the endometrium) are found elsewhere, usually in the pelvis around the womb, ovaries and fallopian tubes. Endometriosis usually affects women during their reproductive years. It is a very common condition estimated to affect 10-15% of women of reproductive age. Endometriosis is not an infection, it is not contagious and it is not cancer. Sometimes, it runs in families and you are more likely to develop endometriosis if your mother or sister has had it.

What is adenomyosis?

Adenomyosis is a condition where the endometrium-like tissue of endometriosis is found in the muscle layer of the womb, the myometrium.

What are the symptoms of endometriosis and adenomyosis?

Endometriosis and adenomyosis can vary in severity. Some women do not have any symptoms at all, whereas other women suffer with many effects of the condition. Endometriosis can affect many aspects of a woman's life including her physical health, emotional wellbeing, daily activities and relationships.

Symptoms may include:

- Pelvic pain and period-related pain (dysmenorrhoea): Pelvic pain is one of the most common symptoms of endometriosis and affects each woman differently. Endometriosis can cause pain that occurs in a regular pattern, becoming worse before and during your period. Some women experience pain all the time, but for others it may come and go. The severity of the pain can vary greatly; some women with extensive endometriosis have no symptoms, whereas others with minimal disease have incapacitating pain
- Deep pain during or after sexual intercourse (dyspareunia)

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- **Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available**
- **If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111**
- **Keep the environment clean and tidy**
- **Let's work together to keep infections out of our hospitals and care homes.**

- Period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements or rectal bleeding during menstruation
- Period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- Long-term fatigue or anxiety
- Difficulty getting pregnant.

Keeping a pain and symptom diary can aid discussions and help you and your doctor to manage your symptoms.

What causes endometriosis and adenomyosis?

The exact cause remains unclear. There are several theories, but none of them has been entirely proven. One theory is that the endometrial cells (from the lining of the womb) are carried to the pelvis via the fallopian tubes during your period (retrograde menstruation).

An alternative theory is that endometrial cells are laid down in the incorrect place whilst you were developing as a foetus in the womb. Another theory is that normal cells turn into endometriosis as a result of an inflammatory process.

How does it produce symptoms?

The endometrial-like tissue in the pelvis, muscle layer of the uterus and elsewhere in the body acts as endometrial tissue would — it thickens, breaks down and bleeds with each menstrual cycle. As this tissue cannot exit your body, it becomes trapped. Surrounding tissue can become irritated by the trapped blood, eventually developing scar tissue and adhesions. These are abnormal bands of fibrous tissue that can cause pelvic tissues and organs to stick to each other. These adhesions can interfere with the normal function of those organs, including the bowel and fallopian tubes. When endometriosis involves the ovaries, cysts called endometriomas may form. If the endometriosis is on the bowel or in the bladder, it can cause bleeding when the bowels are opened or when passing urine at the time of a period.

When the endometriosis is trapped in the muscle layer of the womb, the blood is trapped in pockets causing pain just above the pubic bone and during intercourse.

Where can endometriosis occur?

Endometriosis may be found:

- On the ovaries, where it can form cysts (often referred to as ‘endometrioma or chocolate cysts’)
- In or on the fallopian tubes
- On, behind or around the womb
- In the area between the vagina and the rectum
- In the peritoneum (the lining of the pelvis and abdomen).

Endometriosis can also occur within the muscle wall of the womb (adenomyosis) and occasionally on the bowel and/or bladder. It can also rarely be found in other parts of the body, such as in surgical scars, in the lining of the chest cavity or even in the lungs themselves.

How are endometriosis and adenomyosis diagnosed?

Endometriosis can be a difficult condition to diagnose. This is because:

- The symptoms of endometriosis vary so much
- The symptoms are common and can be similar to pain caused by other conditions, such as irritable bowel syndrome (IBS) or pelvic inflammatory disease (PID).

In addition to your symptoms, clinical examination can provide additional information to the doctor. Abdominal and pelvic examination would usually be recommended by the doctor to identify abdominal masses and pelvic signs, such as tenderness, nodules or reduced organ movement and enlargement, and visible vaginal endometriotic lesions. If a pelvic examination is not appropriate, abdominal examination may be offered.

What other types of tests might I be offered?

- Ultrasound: You may be offered a pelvic ultrasound scan to check the uterus and ovaries. This may be a transvaginal scan whereby a slim probe is gently placed into the vagina. This gives clearer views of the ovaries which may contain cysts and the area between the vagina and the back passage (rectum) which may contain endometriosis. Endometriosis in this position often cannot be seen on an abdominal scan alone. Adenomyosis is often visible on a transvaginal scan within the muscle layer of the womb. A normal scan does not rule out endometriosis
- An MRI scan (a scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body) may be suggested if the condition appears to be advanced
- You may be offered a laparoscopy. This is a keyhole procedure carried out when you are asleep under a general anaesthetic. A small cut is made through your belly button (navel) or near it and then a telescope (known as a laparoscope), which is about the width of a pen is inserted. This allows the gynaecologist to see the pelvic organs clearly and to look for any endometriosis. Usually, the laparoscopy will be a day case procedure. However, if extensive treatment for endometriosis is being done at the same time occasionally you may have to stay overnight. If you have a laparoscopy, you should be given full information about your operation.

If your doctor suspects endometriosis based on your symptoms, clinical examinations and transvaginal ultrasound, they may also propose to try medical treatment without establishing a definitive diagnosis first to reduce your symptoms. Options for medical treatment are analgesics 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.

What is the treatment for endometriosis and adenomyosis?

The different treatments available for endometriosis and adenomyosis aim to reduce the severity of symptoms and improve the quality of your life. The type of treatment you receive for your endometriosis should be decided in partnership between you and your healthcare professional. The choice of treatment will depend on your age, preferences, symptoms and pregnancy plans, as well as the extent of the disease. Endometriosis can be quite a difficult condition to treat. Even though medical or surgical treatment may initially cure your symptoms, it is not unusual for similar presenting symptoms to return after sometime.

Treatment options available to women with endometriosis and adenomyosis are:

1. **Pain-relieving medication**: Paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination can be used for management of endometriosis-related pain. NSAIDs (such as ibuprofen and naproxen) 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 you expect the period pain. If a trial of paracetamol or an NSAID (alone or in combination) does not provide adequate pain relief, other forms of pain management may be considered. In more severe situations, you may be referred to a specialist pain management team

2. **Hormone treatments**: Many hormonal methods are contraceptives and will prevent you from becoming pregnant. These treatments reduce or stop ovulation (the release of an egg from an ovary) and often also lighten, delay or stop your periods. This allows the endometriosis to shrink or disappear by decreasing hormonal stimulation. Some hormonal preparations commonly used include:

    - The **combined oral contraceptive (COC) pill** or patch contain the hormones oestrogen and progestogen; your periods are likely to become lighter, shorter and less painful. We often suggest taking 3 packets of the tablets back to back with no breaks so that you have a period less often. This slows further buildup of endometriosis tissues and blood
    - The **Mirena coil** (the intrauterine system (IUS) is a small T-shaped device which is inserted inside the womb and releases the hormone progestogen; this helps to reduce the pain and makes periods lighter or indeed disappear. It lasts up to 5 years
    - **Progestogens in the form of mini-pill/progestogen-only pill** or **injections** or **implants**. The aim of these treatments is usually to stop your periods altogether to try to limit further buildup of the endometriosis.

    Other hormonal treatments are available, but these are not contraceptives. Therefore, if you do not want to become pregnant, you will need to use a contraceptive as well. Non-contraceptive hormone treatments include:

    - **Progestogens** in the form of tablets
    - **GnRHa (gonadotrophin-releasing hormone agonists)**, which prevent oestrogen from being produced by the ovaries and cause a temporary and reversible menopause. These are given as injections, implants or a nasal spray. They are very effective, but can cause menopausal symptoms such as hot flushes. To help reduce these side-effects and bone loss, you may be offered 'add-back' therapy in the form of hormone replacement therapy (HRT).

3. **Surgery**: Surgery can be used to remove or destroy areas of endometriosis, which can help improve symptoms. The kind of surgery you have will depend on where the endometriosis is and how extensive it is. Any surgical procedure carries risks and your gynaecologist will discuss these with you. The options are:

    - Laparoscopic surgery (the most commonly used and least invasive technique) – when patches of endometriosis are destroyed or removed. Although this kind of surgery can relieve your symptoms, they can recur if the endometriosis regrows and repeated surgeries may be necessary. Most endometriosis surgery can be done laparoscopically. Sometimes, if the surgery is expected to be complex it may be done using the Robot system
    - Laparotomy – This can sometimes be necessary if laparoscopic surgery is not possible or if other surgeons, such as bowel or bladder specialists need to be involved. This is a major operation that involves a cut in the abdomen, usually along the bikini line. Recovery time is longer than that for keyhole surgery.
    - If keyhole surgery to remove just the endometriosis has not given you relief from your symptoms, if you have adenomyosis or if you have decided that you do not want any (more) children a hysterectomy (removal of your womb) can be an option. This can be done with or without removing your ovaries. Deciding to have a hysterectomy is a big decision that can have consequences for your physical and mental health and does not guarantee that endometriosis will not return. If the ovaries are left in place, endometriosis is more likely to return. However, if your ovaries are removed you will experience menopause and this is irreversible. Your doctor will discuss these options with you and the possible need for hormone replacement therapy (HRT) which can alleviate the symptoms of menopause.

If you have severe endometriosis, you usually need to have surgery in a specialist endometriosis centre.

We must seek your consent for any procedure or treatment beforehand. Your doctor will explain the risks, benefits and alternatives before they ask for your consent.

All treatment options that are appropriate for your individual circumstances will be discussed with you by your doctor and you can decide which treatment is right for you.

If you are unsure about any aspect of the procedure or treatment proposed, please do not hesitate to ask for more information.

What other options may help?

Some women have found the following measures helpful:

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

How does endometriosis affect fertility?

Getting pregnant can be a problem for some women with endometriosis but most women will be able to conceive. Medical treatment does not enhance fertility although surgical treatment sometimes can improve the chances of pregnancy. Pregnancy itself is a good treatment for endometriosis. Your gynaecologist can provide you with information about your options.

Where can I get further help and support?

Gynaecology Outpatients at New Cross Hospital is available for queries Monday - Friday 08.30 - 17.00 on 01902 307999 ext 88363

Endometriosis SHE Trust

www.shetrust.org.uk [Also provides specific information for teenagers with endometriosis]

Endometriosis UK

www.endometriosis-uk.org

Pelvic Pain Support Network Website

www.pelvicpain.org.uk

References

NICE. Endometriosis: diagnosis and management. NICE Guideline 73. NICE, 2017. Available at: nice.org.uk/ng73

RCOG Endometriosis patient information leaflet (published July 2016)

Endometriosis UK website - www.endometriosis-uk.org

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

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Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

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ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

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Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。

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