

# Endometriosis

Department of Gynaecology

Information for Patients

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## Introduction

This leaflet will describe the main symptoms of endometriosis and how it affects your quality of life and fertility. This leaflet also looks at possible ways of diagnosis and treatment of endometriosis.

## Who is the leaflet for and what it covers?

This booklet is for women who have endometriosis and for their relatives and friends who care for them. It has been written to help you understand more about endometriosis. It will not answer all your questions but will help you to learn.

- what endometriosis is,
- how it is recognised,
- diagnosed,
- treated and
- where to get more information and advice.

If you have any questions about endometriosis, please ask your doctor or specialist nurse.

## What is endometriosis?

Endometriosis is a condition where cells of the lining of the womb (the endometrium) are found in other parts of the body. This is usually in the tummy around the womb, ovaries and fallopian tubes. Endometriosis can lead to pain and can cause scar tissue to form called “**adhesions**”. This scar tissue (adhesions) can cause your organs to attach together. During your menstrual cycle, as hormone levels change, the swelling (inflammation) caused

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or call 111 for non-emergency medical advice**

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by endometriosis may vary. This means symptoms may be worse at certain times in your cycle, mainly just before and during your period. Some women with endometriosis may have very painful low tummy pain, others have no symptoms at all. Endometriosis is not an infection so you cannot catch or pass it on and it is not cancer.

## What could endometriosis mean for me?

Some women do not have any symptoms at all. For women that have symptoms, the most common symptoms are

- pelvic pain,
- pain during or after sex,
- painful heavy periods.
- Some women may have problems getting pregnant.
- Pain is the most common symptom of endometriosis. Pain affects each woman in different ways:
  - where it hurts,
  - when it hurts and
  - how much it hurts.
- The pain can be a dull ache in the lower tummy, pelvis or lower back.
- Some women get pain only at certain times, such as before or during their periods, when they have sex or when they have a poo or pee. Other women have pain all the time.
- Severe pain and endometriosis can affect many aspects of your life such as general physical health, daily routine, ability to go to work, your emotional wellbeing and can lead to depression.
- Some women with endometriosis become pregnant easily while others have difficulty getting pregnant. The pain may get better during pregnancy and then return after the birth of the baby. Some women find that their pain gets better without any treatment.

## How common is endometriosis?

Endometriosis is common and affects women during the years when they are having periods and before the menopause. About 2 million women in the UK have endometriosis. Up to 1 in 10 women have endometriosis overall and up to half of women who are finding it difficult to get pregnant have endometriosis. It can affect women from any social group and ethnicity. It seems to run in some families. Other suggestions are that it's an immune response triggering inflammation.

## What causes endometriosis?

Endometriosis occurs when the cells of the lining of the womb are found in other parts of the body,

usually in the lower part of the tummy where the womb is found. Each month these cells grow, thicken and then break down and bleed in the same way as the lining of the womb bleeds with your periods.

This internal bleeding inside the tummy has no way of leaving the body. It causes inflammation, pain, scarring and damage to the other organs in the tummy.

Endometriosis most often occurs in the lower tummy. It can be found:

- on the ovaries where it can form cysts (often called chocolate cysts)
- in or on the fallopian tubes
- almost anywhere on, behind or around the womb
- on the lining inside the tummy that covers most of the organs (peritoneum).
- sometimes endometriosis is found on the bowel and bladder, or deep within the muscle wall of the womb (adenomyosis). It can also rarely be found in other parts of the body.

## Why does endometriosis occur?

We are not exactly sure why endometriosis occurs. A number of ideas have been put forward but none have been proven.

## What happens when I see a specialist?

As a new patient you may be sent a pelvic pain questionnaire to complete. Please bring the completed form with you to your first hospital consultation. At your appointment, you may be asked questions about your periods and your sex life. It is important that you give us as much information as possible, as this will help your doctor find the correct diagnosis. You may find it helpful to write down your symptoms beforehand and bring your notes with you to the appointment. Some women find it helpful to take a friend or partner with them as well.

Your specialist may examine your lower tummy; this will include an internal examination of the vagina and/or ultrasound scan of the pelvis. If you are worried about this, please tell the doctor or nurse looking after you. There will be a healthcare assistant present to support you during the examination

## What tests might I be offered?

- **Ultrasound** - you may be offered a scan, which is likely to be an internal scan in the vagina. This can show whether there is an endometriosis cyst in the ovaries. Normal scan findings do not rule out endometriosis as small spots are too small to see on scans.
- **MRI scan** - magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body. MRI can help find smaller sites of endometriosis, mostly along the bowel and pelvic ligaments. It can help with planning complex endometriosis surgery. A normal MRI does not rule out endometriosis.

- **Diagnostic laparoscopy** is a surgical procedure where small cuts (incisions) are made in your tummy. A small camera is inserted to see inside. For most women, having a laparoscopy is the only way to get a definite diagnosis; because of this, it is often referred to as the 'gold standard' test.

This is not always necessary before starting treatment and it comes with risks of surgery.

- A laparoscopy is carried out under general anaesthesia.
- A few small cuts are made in your tummy (abdomen) and one at your tummy button (navel).
- A telescope camera (known as a laparoscope), which is about the width of a pen, is inserted.
- This allows the gynaecologist to see outer surface of the womb tubes and ovaries and surrounding bowel and bladder clearly and look for any endometriosis. This is usually carried out as a day case surgery.

If endometriosis is found, the surgeon may be able to treat less severe endometriosis at the same time. If the bowel or other organs are involved this will be avoided until the risks have been properly explained to you. It may be safer to do the operation with other specialists such as a bowel surgeon.

You may be offered some treatment first to see if your symptoms get better before being offered surgery, especially if there is a strong suspicion that you probably do have endometriosis. Or, if your symptoms are more likely to be due to irritable bowel syndrome or another condition, treatment for this may be offered first or alongside treatment for endometriosis.

## Making a choice about treatment

You will be given full information about your options for treatment with information about the risks and benefits of each option. Several things may affect your decision about treatment including:

- how you feel about your situation.
- your age.
- whether your main symptom is pain or difficulty in getting pregnant (some hormonal treatments might not be suitable since they stop you from becoming pregnant).
- how you feel about surgery.
- what treatment you have had before.
- how effective certain treatments are.

You may decide that no treatment is the best way forward. This could be because your symptoms are mild, you have not had problems getting pregnant or you are nearing the menopause, when symptoms may get better anyway.

## What treatment can I get?

The options for treatment may be:

## Pain relief:

Pain-relieving drugs reduce inflammation and help to ease the pain when needed.

## Hormone treatments:

There are a range of hormone treatments to stop or reduce the release of an egg (ovulation). This can help the endometriosis shrink or disappear. Contraceptives are often used. These will prevent you from becoming pregnant. They include:

- The combined oral contraceptive (COC) pill or patches. They contain the hormones oestrogen and progesterone and work by stopping ovulation. This can make your periods lighter, shorter and less painful. Taken without a break often for 3 packets back to back, they reduce the number of periods that you have.
- The progesterone only contraceptive pill Desogestrel also stops ovulation. It can be taken by women who are unable to take the COC.
- The intrauterine system (IUS) is a small T-shaped device which releases a progesterone hormone. This helps to reduce the pain and makes periods lighter. Some women get no periods at all. Side effects include irregular bleeding or spotting, bloating, breast discomfort, low mood but these usually settle after 3 to 6 months.

Other non-contraceptive hormonal methods are available (contraception will usually be needed if you do not want to become pregnant) these include:

- Progesterones or testosterone preparations. Side effects include breakthrough bleeding (bleeding outside of your normal period cycle), feeling sick (nausea), breast discomfort.
- GnRH agonists – these drugs stop oestrogen being produced by the ovaries. It causes a temporary and reversible menopause. This may be given as a monthly injection or as a combined tablet combined with hormone replacement therapy in one tablet. Side effects include hot flushes, night sweats, dry vagina, low sex drive, headaches and bone thinning. To reduce these side effects, your doctor can prescribe low dose hormone replacement therapy. You may be given a course of treatment for 6 months or sometimes longer.

## Surgery:

Surgery can be used to remove areas of endometriosis. There are different types of surgery, depending on where the endometriosis is and how much there is. How successful the surgery is can vary and you may need further surgery. Surgery including removal of the womb (hysterectomy) does not always successfully remove all of the endometriosis. Your gynaecologist will discuss this with you and the procedures include:

- **Laparoscopic surgery** - using keyhole surgery, the gynaecologist removes patches of endometriosis by destroying them or cutting them out.
- **Laparotomy** – if the endometriosis is severe and extensive, you may be offered a laparotomy. This is major surgery which involves a cut in lower tummy.
- **Hysterectomy** - some women have surgery to remove their tubes and ovaries and/or womb (a hysterectomy). Having a hysterectomy means that you will no longer be able to have

children after the operation. Depending upon your own situation, your doctor should discuss hormone replacement therapy (HRT) with you if you have your ovaries removed. The procedure may be done by keyhole or open surgery, depending upon the extent of endometriosis.

- **Bowel surgery** - at times the bowel can be involved in endometriosis and need freeing up or a portion of the bowel might need removing. If this is a possibility in your case we will discuss the risks of bowel injury/ surgery with its risks and complications separately.
- **Extensive surgery** may occasionally be recommended involving consultants from other specialities such as the bowel and urology surgeons. Rarely endometriosis may involve other parts of the body such as the lungs, where a chest surgeon may be involved in your care.

## Are there any side effects?

You will be given full detailed information about the risks and benefits of any investigation, surgical procedure and treatment suggested. The side effects will vary from woman to woman and depend upon the treatment options being considered.

## How soon can I expect to get a diagnosis?

For many women, it can take years to get a diagnosis because:

- no one symptom or set of symptoms can definitely confirm a diagnosis of endometriosis.
- the symptoms of endometriosis are common and overlap with a number of other conditions such as irritable bowel syndrome (IBS) and pelvic inflammatory disease (PID).
- different women have different symptoms and some women have no symptoms at all.

Living without a diagnosis can be distressing. Many women may fear the worst about why they are in pain or why they are having problems becoming pregnant.

## Complementary therapies

Complementary therapies include

- reflexology,
- traditional Chinese medicine,
- herbal treatments
- treatments for Irritable Bowel Syndrome (IBS) and
- homeopathy.

These may be good at relieving pain. Many women have found that making changes to their diet such as no longer eating certain food types, such as dairy or wheat products may help with symptoms. Most women with endometriosis also suffer from irritable bowel syndrome at the same

time so managing this can help. Therapies such as Transcutaneous electrical nerve stimulation (TENS), acupuncture, vitamin B1 and magnesium help some women with painful periods. There is currently not enough evidence to show whether such therapies are effective at relieving the pain linked to endometriosis.

## Is there anything else I should know?

- Taking the combined oral contraceptive (COC) pill or patch treats the symptoms of endometriosis.
- If you become pregnant, endometriosis is unlikely to put your pregnancy at risk.
- Some women find that exercise improves their wellbeing, which may help to improve some symptoms of endometriosis.
- No treatment is guaranteed to work all the time for everyone.
- Internet forums may be the first place many women turn to for support. The quality of information can vary.

## What if I am having difficulty getting pregnant?

Getting pregnant can be a problem for some women with endometriosis. Your doctor will give you full information and possible investigations that you may need. Surgery rather than hormone treatment may be more suitable for you if you are trying to get pregnant. The type of surgery may depend on whether you hope to fall pregnant naturally or use assisted conception methods such as IVF.

## Living with endometriosis

Not all cases of endometriosis can be cured and for some women there is no long-term treatment that helps. With support many women find ways to live with and manage this condition. Pain specialists and psychologists may be involved in helping you cope with the pain. Sex therapists may be able to help if you are struggling to have sex because of the pain.

## Endometriosis in teenagers

Although not common, in recent years, endometriosis in teenagers has been recognised more as a problem. The symptoms and way we diagnose endometriosis is similar in teenagers as with adults, except some examinations and/or tests may not be appropriate. Your doctor will discuss all options with you. Please tell them if you have any concerns. You would usually be started on painkillers and hormone treatments.

## Further information / Useful contacts

Useful organisations	Address	Telephone / Website
NHS UK		<a href="http://www.nhs.uk">Endometriosis - NHS (www.nhs.uk)</a>
Endometriosis UK	50 Westminster Palace Gardens Artillery Row London SW1 1RR	02072 222781 0808 8082227 <a href="http://www.endometriosis-uk.org">www.endometriosis-uk.org</a>
Endometriosis SHE Trust (UK)	Endometriosis SHE Trust (UK) Waldron Silveroaks Farms, Heathfield, TN21 0RS <a href="mailto:shetrust@shetrust.org.uk">shetrust@shetrust.org.uk</a>	08707 743665 <a href="https://www.facebook.com/EndoSheTrust/">www.facebook.com/EndoSheTrust/</a>
Fertility Network UK	2nd Floor The Forum in Greenwich, Trafalgar Rd, London SE10 9EQ <a href="mailto:info@fertilitynetworkuk.org">info@fertilitynetworkuk.org</a>	01424 732361
Pelvic Pain Support Network	<a href="mailto:info@pelvicpain.org.uk">info@pelvicpain.org.uk</a>	01202 604749 <a href="#">Pelvic Pain Support Network   Support, Information and Advocacy for those with Pelvic Pain</a>

## Contact details

Until you have been seen in the gynaecology clinic, you should see your GP if you have any questions or concerns. Once you have seen a specialist you will be able to contact their secretary if you need to.

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