Endometriosis

Exceptional healthcare, personally delivered
Understanding Endometriosis

Our aim is continuity of care, however this is not always possible, and when you are in hospital you will be looked after by a team of Doctors and Nurses.

This information leaflet helps to explain:

- What endometriosis is
- How often it occurs
- What problems it may cause
- Where endometriosis can be found in the body
- What endometriosis may mean for you
- What tests may be needed
- What treatments may be offered
- Further sources of support and information

Understanding endometriosis and the treatments is easier if you can picture what is inside your pelvis and how the menstrual cycle works:

The menstrual cycle

Hormones released from glands in the body control the menstrual cycle. Day one of the menstrual cycle is usually counted as the first day of your period with menstrual bleeding usually ending between days four and seven.

Early in the cycle the pituitary gland (inside your head) releases a hormone into the blood stream. The ovaries respond by stimulating ovarian cells called follicles to prepare an egg. At this stage the ovary starts to produce the hormone oestrogen.

Rising levels of oestrogen in the blood stream cause the uterus to grow a lining (known as the endometrium) in preparation for a fertilised egg. A rise in oestrogen signals that an egg is being developed and another hormone goes into the blood stream, which causes the release of an egg (ovulation). Ovulation occurs around day 14 or usually two weeks before the start of a period as this may vary from woman to woman. The cycle then begins all over again!
What is endometriosis?

Endometriosis is a very common condition where cells of the lining of the womb (the endometrium) are found elsewhere, usually in the pelvis, around the womb, ovaries and fallopian tubes. It can also affect the bowel and the bladder. Each month this tissue outside the womb bleeds in the same way as the lining of the womb does with a period. These patches are ‘sticky’, and can cause inflammation, pain, and can also cause organs to join together after time, forming scar tissue. Some large patches of endometriosis can form into cysts. Endometriosis is not an infection, it is not contagious and it is not cancer.

Is endometriosis common?

Endometriosis affects as many as one in ten women of childbearing age, many of whom will have no symptoms. An estimated two million women in the UK have this condition. As many as one third of women attending gynaecology clinics are found to suffer from endometriosis and two out of five women who are infertile will have endometriosis. Sometimes it runs in families. It mainly affects women during their reproductive years. It can affect women from every social group and ethnicity. The risk of having developed endometriosis is also higher in women who had their first period earlier than normal. The oral contraceptive pill would seem to reduce the risk of a woman developing endometriosis.

What causes endometriosis?

The exact cause remains unclear. One theory is that the endometrial cells (from the lining of the womb/uterus) pass backwards along the fallopian tubes when you have had a period (retrograde menstruation). An alternative theory is that endometrial cells are laid down in the incorrect place whilst you yourself were developing as a foetus in the womb. Another theory is that normal cells turn into endometriosis as a result of an inflammatory process.
What could endometriosis mean for me?

The condition can vary in severity. Some women have mild endometriosis causing few problems; 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 painful periods (dysmenorrhoea), pain during or after sexual intercourse (dyspareunia), lower abdominal pain, difficulty getting pregnant and pain related to the bowels and bladder. Some women do not have any symptoms at all.

Pelvic pain is one of the most common symptoms of endometriosis and affects each woman differently: where it hurts, when it hurts and how much it hurts. Some women get pain only at certain times, such as during their periods, when they have sex or when they open their bowels; other women have pain all the time.

Sites of Endometriosis

Reproduced with permission from Royal College of Obstetricians and Gynaecologists www.rcog.org.uk
Where can endometriosis occur?

Common sites include:

- Ovary.
- Within the muscle of the uterus (adenomyosis).
- Pouch of Douglas.
- Fallopian tube.
- Bowel / Rectum.
- Vagina.
- Bladder.
- Peritoneum (tissue that lines the abdominal wall, and covers the organs in the body).
- It can also rarely be found in other parts of the body.

How soon can I expect to get a diagnosis?

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

- No single symptom or set of symptoms can definitely confirm a diagnosis of endometriosis.
- The symptoms of endometriosis are common and could be caused by a number of other conditions such as irritable bowel syndrome (IBS) and pelvic inflammatory disease (PID).
- There is no simple test for endometriosis.

The only way to make a definite diagnosis is by a small surgical operation known as laparoscopy. However not all women require this. If you have painful periods and no other symptoms, your GP may suggest that you try pain relief before having further investigations or treatments as not everyone with painful periods has endometriosis.

Depending on your symptoms and your response to simple forms of pain relief, the GP may refer you to see a specialist.
What happens when I see a specialist?

At your appointment, you may be asked specific questions about your periods and your sex life. It is important that you provide as much information as possible, as this will help your doctor to find the correct diagnosis. You may find it helpful to write down your symptoms beforehand and take your notes along to the appointment with you. In this way, you will be sure to provide all the information required. Some women find it helpful to take a friend or partner along with them as well. Your gynaecologist may examine your tummy and carry out an internal examination. If you have concerns about this, you should have an opportunity to discuss them.

What other types of tests might I be offered?

**Ultrasound**

You may be offered a scan. This can identify whether there is an endometriosis type cyst on the ovaries. A normal scan does not rule out endometriosis.

**Laparoscopy**

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. A laparoscopy is a small operation which is carried out with you asleep under general anaesthesia. A small cut is made near your tummy button (navel), 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 look for any endometriosis. This is usually carried out as day surgery. As with any surgical procedure, there are risks and benefits, which should be fully explained to you when you are offered the test. If you have a laparoscopy, you should be given full information about your operation.
Making a decision about treatment

You should be given information about your options for treatment which should include the risks and benefits of each option.

Several factors may influence the decision about treatment. These include:

- Your age
- Your symptoms
- Whether you want to become pregnant
- How you feel about surgery
- What treatment you have had before
- How effective certain treatments are
What treatment can I get?

The options for treatment may be:

**Pain relief**

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

**Hormone treatments**

There are a range of hormone treatments to stop or reduce ovulation (the release of an egg) to allow the endometriosis to shrink or disappear. Many hormonal methods are contraceptives and will prevent you from becoming pregnant. Some hormonal preparations commonly used include:

- The combined oral contraceptive (COC) pill or patch contain the hormones oestrogen and progestogen and work by preventing ovulation; your periods are likely to become lighter, shorter and less painful.

- 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

- Progestogens

- GnRH agonists prevent oestrogen being produced by the ovaries and cause a temporary and reversible menopause.
Surgery

Surgery can be used to remove areas of endometriosis. There are different types of surgery, depending on where the endometriosis is and how extensive it is. How successful the surgery is can vary and for some women further surgery is needed. Your gynaecologist will discuss this with you before any surgery.

Laparoscopic surgery

The gynaecologist removes patches of endometriosis by destroying them or cutting them out via keyhole surgery.

Laparotomy

This involves a cut in the abdomen, usually in the bikini line.

Hysterectomy

Some women have surgery to remove their womb (hysterectomy). Having this surgery means that you will no longer be able to have children after the operation. Depending upon your own situation, your doctor may discuss hormone replacement therapy (HRT) with you if you have your ovaries removed.

What if I am having difficulty getting pregnant?

Getting pregnant can be a problem for some but not all women with endometriosis. Drug treatments are unfortunately of no benefit in the treatment of infertility related to endometriosis. For younger women, especially those wanting to become pregnant, spots of endometrial tissue can be removed during laparoscopy (keyhole surgery). Where there is damage to the ovaries and fallopian tubes, leading to infertility, it may be possible that the damaged areas could be surgically removed without a hysterectomy and the ovaries and tubes reconstructed so that they are as normal as possible.
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.

Support organisations provide invaluable counselling, support and advice:

**Best Treatment**  
www.besttreatments.co.uk/btuk/conditions/13729.html  
[This site requires registration and prepayment to view the information it contains]

**Endometriosis UK**  
50 Westminster Palace Gardens Artillery Row London SW1P 1RR  
Tel: **0207 222 2781** Helpline: **0808 808 2227** Website: www.endometriosis-uk.org

**Endometriosis SHE Trust (UK)**  
14 Moorland Way Lincoln LN6 7JW Tel: **0870 743 665** Website: www.shetrust.org.uk  
[Also provides specific information for teenagers with endometriosis]

**Hysterectomy Association**  
10a Acreman Close Cerne Abbas Dorset DT2 7JU Tel: 0871 781 1141 Website: www.hysterectomy-association.org.uk/

**Infertility Network UK**  
Charter House 43 St Leonards Road Bexhill on Sea East Sussex TN40 1JA Telephone: **0870 118 8088** Website: www.InfertilityNetworkUK.com

**Pelvic Pain Support Network**  
PO Box 6559 Poole BH12 9DP Telephone: **01202 604 749** Website: www.pelvicpain.org.uk

Internet forums may be the first place many women turn to for support. The quality of information can be variable
Complementary therapies

Complementary therapies include reflexology, herbal treatments and homeopathy. They may be effective at relieving pain. Some women have found that dietary changes such as eliminating certain food types (dairy/ wheat) may help to relieve symptoms. Therapies such as TENS, acupuncture, vitamin B1 and magnesium help some women with painful periods. There is currently insufficient evidence to show whether such therapies are effective at relieving the pain associated with endometriosis. Some women find that recreational exercise improves their wellbeing, which may help to improve some symptoms of endometriosis.

NHS Constitution. Information on your rights and responsibilities. Available at [www.nhs.uk/aboutnhs/constitution]
If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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