

Endometriosis:

what you need to know



Royal College of
Obstetricians and
Gynaecologists

Setting standards to improve women's health

Published November 2007

The patient information review process will commence in 2014
unless otherwise indicated.

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 and around the womb, ovaries and fallopian tubes. It mainly affects women during their reproductive years. It can affect women from every social group and ethnicity. Endometriosis is not an infection and it is not contagious. Endometriosis is not cancer.

What could endometriosis mean for me?

The main symptoms of endometriosis are pelvic pain, pain during or after sex, painful, sometimes heavy periods and, for some women, problems with getting pregnant.

Endometriosis can affect many aspects of a woman's life including her general physical health, emotional wellbeing and daily routine.

Endometriosis is common and many women may have no symptoms. An estimated two million women in the UK have this condition.

Endometriosis is a long-term condition which affects women of all ages during their reproductive years (from the onset of menstrual periods to the menopause). It affects women from all social and ethnic groups.

Women who do experience symptoms may have one or more conditions:

- painful periods (dysmenorrhoea) which do not respond to over-the-counter pain relief. Some women have heavy periods.
- pain during or after sexual intercourse (dyspareunia)
- lower abdominal pain

- pelvic pain which can be long-term
- difficulty in getting pregnant or infertility
- pain related to the bowels and bladder (with or without abnormal bleeding)
- long-term fatigue.

Some women do not have any symptoms at all.

Pain is a common symptom of endometriosis. The pain can be a dull ache in the lower abdomen, pelvis or lower back. Pain affects each woman differently: where it hurts, when it hurts and how much it hurts. The pain, and the effects of endometriosis, can make you feel depressed.

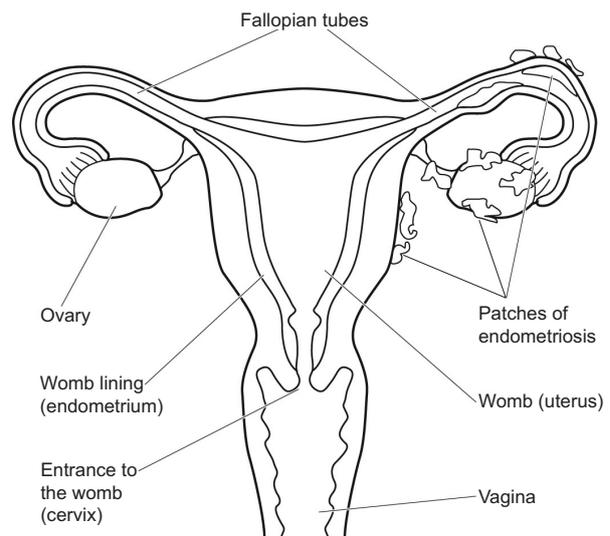
Most women with endometriosis get pain in the area between their hips (known as the pelvis) and the tops of their legs. For further information see [Long-term pelvic pain: information for you](#). Some women get pain only at certain times, such as during their periods, when they have sex or when they open their bowels. Other women have pain all the time.

Some women with endometriosis become pregnant easily while others have difficulty getting pregnant. The pain may get better during pregnancy and then recur after the birth of the baby. Some women find that their pain resolves without any treatment.

What causes endometriosis?

During the menstrual cycle, under the influence of the female hormones estrogen and progesterone, the lining (endometrium) of the womb thickens in readiness for a fertilised egg. If pregnancy does not occur, the lining is shed as a period.

Endometriosis occurs when the cells of the lining of the womb are found in other parts of the body, usually the pelvis. Each month this tissue outside the womb thickens and breaks down and bleeds in the same way as the lining of the womb. This internal bleeding into the pelvis, unlike a period, has no way of leaving the body. This causes inflammation, pain and damage to the reproductive organs.



Reproductive areas where endometriosis can be found

Endometriosis commonly occurs in the pelvis. It can be found:

- on the ovaries where it can form cysts (often referred to as 'chocolate cysts')
- in or on the fallopian tubes
- almost anywhere on, behind or around the womb
- in the peritoneum (the tissue that lines the abdominal wall and covers most of the organs in the abdomen).

Less commonly, endometriosis may occur on the bowel and bladder, or deep within the muscle wall of the uterus (adenomyosis). It can also rarely be found in other parts of the body.

Why does endometriosis occur?

It is not yet known why endometriosis occurs. A number of theories have been suggested but none has been proved. The most commonly accepted theory is that, during a period, light 'backward' bleeding carries tissue from the womb to the pelvic area via the fallopian tubes. This is called 'retrograde menstruation'.

How soon can I expect to get a diagnosis?

For many women, it can take years to get a diagnosis. Doctors say that this is because:

- no one 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) (for further information see [Acute pelvic inflammatory disease: what the RCOG guideline means for you](#))
- different women have different symptoms
- some women have no symptoms at all.

There is no simple test for endometriosis. The only way to make a definite diagnosis is by a small surgical operation known as laparoscopy (see [What treatment can I get?](#)). This is not performed on every woman.

If you have painful periods and no other symptoms, your GP may suggest that you try pain relief before having further surgical investigation or treatments.

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. They may think that they have cancer (see [Other organisations](#)).

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 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.

You should also have an opportunity to ask questions (for further information see BestTreatment NHS Direct in **Useful organisations**).

Your gynaecologist may examine your pelvic area, this will include an internal examination. Your doctor will discuss the best time to do this. This may be when you are having your period. If you have concerns about this, you should have an opportunity to discuss them.

What types of tests might I be offered?

You should be given full information about the tests that are available. These may include:

Ultrasound

You may be offered a scan. This can identify whether there is an endometriosis cyst in 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 under general anaesthesia. A small cut is made in your abdomen 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. These should be fully explained to you when you are offered the test (see **Are there any risks?**).

If you have a laparoscopy, you should be given full information about your results.

Making a decision about treatment

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

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

- how you feel about your situation
- your age
- whether your main symptom is pain or problems getting pregnant
- whether you want to become pregnant - some hormonal treatments which help to reduce the pain will 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.

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 is a range of hormone treatments to stop or reduce ovulation (the release of an egg) to allow the endometriosis to shrink or disappear.

The hormonal methods below are contraceptives and will prevent you from becoming pregnant:

- The combined oral contraceptive (COC) pill or patch

These contain the hormones estrogen and progestogen and work by preventing ovulation and can make your periods lighter, shorter and less painful.

- The intrauterine system (IUS): this is a small T-shaped device which releases the hormone progestogen. This helps to reduce the pain and makes periods lighter. Some women get no periods at all.

The hormonal methods below are non-contraceptive, so contraception will be needed if you do not want to become pregnant:

- Use of hormonal progestogens or testosterone derivatives
- GnRH agonists - these drugs prevent estrogen being produced by the ovaries and cause a temporary and reversible menopause.

Surgery

Surgery can be used to remove areas of endometriosis. Surgery including hysterectomy does not always successfully remove the 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 you may need further surgery. 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.

- Laparotomy

If the endometriosis is severe and extensive, you may be offered a laparotomy. This is major surgery which involves a cut in the abdomen, usually in the bikini line.

- Hysterectomy

Some women have surgery to remove their ovaries or womb (a 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 should 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 women with endometriosis. Your doctor should provide you with full information about your options such as assisted conception. Infertility Network provides information about this (see **Other organisations**).

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.

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

Support organisations provide invaluable counselling, support and advice (see **Other organisations**).

Complementary therapies

Complementary therapies include reflexology, traditional Chinese medicine, herbal treatments and homeopathy. They may be effective at relieving pain. Many women have found that dietary changes such as eliminating certain food types, such as dairy or wheat products, 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.

Is there anything else I should know?

- Taking the combined oral contraceptive (COC) pill or contraceptive patch treats the symptoms of endometriosis.
- If you become pregnant, endometriosis is unlikely to put your pregnancy at risk.
- Some women find that recreational exercise improves their wellbeing, which may help to improve some symptoms of endometriosis (for further information see **Recreational exercise and pregnancy: information for you**)

No treatment is guaranteed to work all the time for everyone.

- Support groups are run locally for women with endometriosis (see **Other organisations**).
- Internet forums may be the first place many women turn to for support. The quality of information can be variable.

Useful organisations

Best Treatment NHS Direct

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: 08707 743665

Website: www.shetrust.org.uk/index.html

[Also provides specific information for teenagers with endometriosis]

Hysterectomy Association

10a Acreman Close

Cerne Abbas

Dorset DT2 7JU

Tel: 0871 7811141

Website: www.hysterectomy-association.org.uk/

Infertility Network UK

Charter House

43 St Leonards Road

Bexhill on Sea

East Sussex TN40 1JA

Telephone: 0870 1188088

Website: www.InfertilityNetworkUK.com

Pelvic Pain Support Network

PO Box 6559

Poole BH12 9DP

Telephone: 01202 604 749

Website: www.pelvicpain.org

Sources and acknowledgements

This information is based on the Royal College of Obstetricians and Gynaecologists (RCOG) guideline *The Investigation and Management of Endometriosis*, originally published by the RCOG in July 2000 and revised in October 2006. The information in this leaflet will be reviewed and updated, if necessary, once the guideline has been reviewed. The guideline contains a full list of the sources of evidence we have used. You can find it online at:

www.rcog.org.uk/resources/Public/pdf/endometriosis_gt_24_2006.pdf

Clinical guidelines are intended to improve care for patients. They are drawn up by teams of medical professionals and consumers' representatives, who look at the best research evidence there is about care for a particular condition or treatment. The guidelines make recommendations based on this evidence.

This information has been developed by the Patient Information Subgroup of the RCOG Guidelines and Audit Committee, with input from the Consumers' Forum and the authors of the clinical guideline. It was reviewed before we published it by women attending clinics in Cambridge, London and Oxford. The final version is the responsibility of the Guidelines and Audit Committee of the RCOG.

The RCOG consents to the reproduction of this document providing full acknowledgement is made.

A final note

The Royal College of Obstetricians and Gynaecologists produces patient information for the public. This is based on guidelines which present recognised methods and techniques of clinical practice, based on published evidence. The ultimate judgement regarding a particular clinical procedure or treatment plan must be made by the doctor or other attendant in the light of the clinical data presented and the diagnostic and treatment options available.

© Royal College of Obstetricians and Gynaecologists 2007