

Information for you

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Endometriosis

This information is for you if you wish to know more about endometriosis. It may also be helpful if you are the partner or relative of someone with endometriosis.

What is endometriosis?

Endometriosis occurs when cells that normally line the womb (the endometrium) are found elsewhere, usually in the pelvis around the womb, ovaries and fallopian tubes. It is not cancer and it is not infectious. It is a very common condition, affecting between 2 and 10 women out of 100. You are more likely to develop endometriosis if your mother or sister has had it.

Endometriosis usually affects women during their reproductive years. It is a long-term condition that can have a significant impact on your general physical health, emotional wellbeing and daily routine.

What are the symptoms?

Common symptoms include pelvic pain and painful, sometimes irregular or heavy periods. It can cause pain during or after sex and can lead to fertility problems. You may also have pain related to your bowels, bladder, lower back or the tops of your legs, and experience long-term fatigue. Some women with endometriosis do not have any symptoms.

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 pain may get better during pregnancy and sometimes it may disappear without any treatment. For more information, see the RCOG patient information Chronic (long-term) pelvic pain (www.rcog.org.uk/en/patients/patient-leaflets/long-term-pelvic-pain).

What causes endometriosis?

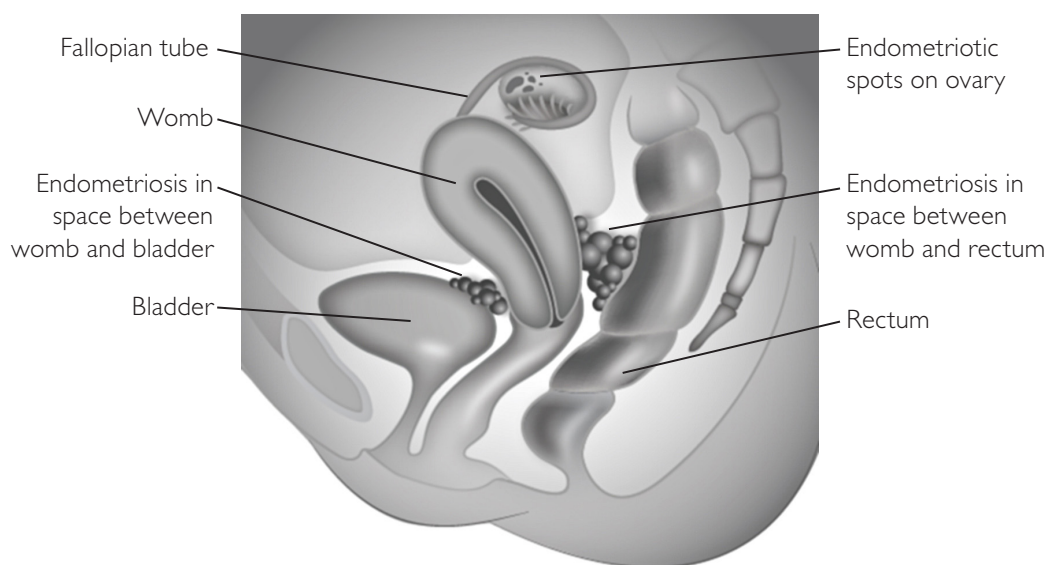
The exact cause of endometriosis is not known. It is thought to happen when cells that line the womb are carried to the pelvis via the fallopian tubes during your period. These cells respond to your hormones and bleed. Unlike the cells

in the womb, which leave your body through the vagina, this blood has nowhere to escape. This can cause pain, inflammation and possibly damage to your pelvic organs.

Endometriosis may be found:

- on the ovaries, where it can form cysts (often referred to as '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 may sometimes be found in other parts of the body, but this is rare.



How is it 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); for further information, see the RCOG patient information *Acute pelvic inflammatory disease: tests and treatment* (www.rcog.org.uk/en/patients/patient-leaflets/acute-pelvic-inflammatory-disease-pid-tests-and-treatment)
- different women have different symptoms
- some women have no symptoms.

What will happen if I see a gynaecologist?

You will be asked:

- about any pain you have and whether it has a pattern or is related to anything, in particular your periods
- about your periods – are they painful and how heavy are they?
- whether you have any pain or discomfort during sex
- about problems with your bowels at the time of your period.

The doctor may carry out an internal examination with your consent. This helps to localise the pelvic pain and the doctor can feel for any lumps or tender areas. You will be offered a chaperone during this examination. You will be able to discuss any concerns and you will have an opportunity to ask other questions.

What tests might I be offered?

Tests usually include a pelvic ultrasound scan. This may be a transvaginal scan to check the uterus and ovaries. It may show whether there is an endometriotic (chocolate) cyst in the ovaries or may suggest endometriosis between the vagina and rectum.

You may be offered a laparoscopy, which is the only way to get a definite diagnosis. This is carried out under a general anaesthetic. Small cuts are made in your abdomen and a telescope is inserted to look at your pelvis. You may have a biopsy to confirm the diagnosis and images may be taken for your medical records.

The doctor may suggest treating the endometriosis at the time of your first laparoscopy, either by removing cysts on the ovaries or treating any areas on the lining of your pelvis. This may avoid a second operation. Sometimes, however, the extent of endometriosis found means that you may need further tests or treatment.

The procedure, including any risks and the benefits, will be discussed with you. After your operation you will be told the results. You can often go home the same day after a laparoscopy. For information about recovery following a laparoscopy, please see the RCOG patient information *Laparoscopy* (www.rcog.org.uk/en/patients/patient-leaflets/laparoscopy).

An MRI scan may be suggested if the condition appears to be advanced.

What are my options for treatment?

The options for treatment include those listed below.

Pain-relieving medication

This works by reducing inflammation. There are several different ways of helping you relieve your pain. This can range from over-the-counter remedies to prescribed medications from your health practitioner. In more severe situations, you may be referred to a specialist pain management team.

Hormone treatments

These treatments reduce or stop ovulation (the release of an egg from the ovary) and thus allow the endometriosis to shrink or disappear by decreasing hormonal stimulation.

Some hormone treatments that may be offered are contraceptive and will also stop you becoming pregnant. They include:

- the combined oral contraceptive (COC) pill or patch given continuously without the normal pill-free break; this usually stops ovulation and temporarily either stops your periods or makes your periods lighter and less painful
- an intrauterine system (IUS/Mirena®), which helps to reduce the pain and makes periods lighter; some women using an IUS get no periods at all
- progestogens in the form of injection, the mini pill or the contraceptive implant.

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 are given as injections, implants or a nasal spray. They are very effective but can cause menopausal symptoms such as hot flushes and are also known to reduce bone density. To help reduce these side-effects and bone loss, you may be offered 'add-back' therapy in the form of hormone replacement therapy (HRT).

Surgery

Surgery can treat or remove areas of endometriosis. The surgery recommended will depend on where the endometriosis is and how extensive it is. This may be done when the diagnosis is made or may be offered later. Success rates vary and you may need further surgery. Your gynaecologist will discuss the options with you fully.

Possible operations include:

- laparoscopic surgery – when patches of endometriosis are destroyed or removed
- laparotomy – for more severe cases. This is a major operation that involves a cut in the abdomen, usually along the bikini line. Sometimes other surgeons, such as bowel specialists, will be involved. If needed, a laparotomy can be used to remove the ovaries with or without performing a hysterectomy (removing the womb). You will not be able to have children after a hysterectomy. Longer term pain relief is more likely if your ovaries are removed. However, because of the health risks associated with removal of ovaries, your doctor will discuss this and the possible need for hormone replacement therapy (HRT) with you.

If you have severe endometriosis, a specialist team that could include a gynaecologist, a bowel surgeon, a radiologist and specialists in pain management may discuss your treatment options. You may be referred to an endometriosis specialist centre.

Fertility treatment

Getting pregnant can be a problem for some women with endometriosis. Your gynaecologist can provide you with information about your options.

Other options

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.

Complementary therapies

Although there is only limited evidence for their effectiveness, some women may find the following therapies help to reduce pain and improve their quality of life:

- reflexology
- transcutaneous electrical nerve stimulation (TENS)
- acupuncture
- vitamin B1 and magnesium supplements

- traditional Chinese medicine
- herbal treatments
- homeopathy.

Key points

- Endometriosis occurs when cells that normally line the womb are found elsewhere, usually in the pelvis around the womb, ovaries and fallopian tubes.
- It is not cancer and it is not infectious.
- Endometriosis can sometimes be a difficult condition to diagnose.
- Common symptoms include pelvic pain and painful, sometimes irregular or heavy periods. It can cause pain during or after sex and can lead to fertility problems.
- Treatment options include pain-relieving medications, hormones and/or surgery.

Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85



<https://www.aquanw.nhs.uk/SDM>

Further information and support

NHS Choices: www.nhs.uk/conditions/Endometriosis/Pages/Introduction.aspx

Endometriosis UK: www.endometriosis-uk.org

Infertility Network UK: www.infertilitynetworkuk.com

British Society for Gynaecological Endoscopy: bsge.org.uk

British Society for Gynaecological Endoscopy Accredited Centres: bsge.org.uk/centre_

RCOG *Recovering Well* series:

- Laparoscopy: www.rcog.org.uk/en/patients/patient-leaflets/laparoscopy
- Abdominal hysterectomy: www.rcog.org.uk/en/patients/patient-leaflets/abdominal-hysterectomy
- Laparoscopic hysterectomy: www.rcog.org.uk/en/patients/patient-leaflets/laparoscopic-hysterectomy

Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the European Society of Human Reproduction and Embryology (ESHRE) clinical guideline *Management of Women with Endometriosis*, which you can find it online at: www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline.aspx.

This leaflet was reviewed before publication by women attending clinics at the Royal Infirmary of Edinburgh, Aberdeen Royal Infirmary, Royal London Hospital, Princess Anne Hospital, Countess of Chester Hospital, Stepping Hill Hospital and Wrexham Maelor Hospital, by the RCOG Women's Network and by the RCOG Women's Voices Involvement Panel.

A glossary of all medical terms is available on the RCOG website at: www.rcog.org.uk/en/patients/medical-terms.