

Patient Information Leaflet

ENDOMETRIOSIS

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What is endometriosis?

Endometriosis is a condition in which endometrial tissue, normally found only in the lining (the endometrium) of the womb (uterus), grows outside the uterus. The misplaced endometrial tissue commonly sticks to the ovaries and the ligaments that support the uterus. Less often, it adheres to the outer surfaces of the small and large bowel, the ureters (the tubes that take urine from the kidneys to the bladder), the bladder or the vagina. Rarely, endometrial tissue is found in surgical scars, in the lining of the chest cavity or even in the lungs themselves.

The misplaced endometrial tissue responds to cyclical hormonal changes in just the same way as the normal lining does. Therefore, during a menstrual period, it may bleed. This minor internal bleeding can cause irritation and pain, often with cramps. With time, scar tissue develops and can form 'adhesions'. These fibrous bands bind together structures that are normally separate and by distorting internal organs may interfere with their normal function.

What causes endometriosis and who is at risk?

Exactly what causes endometriosis is not known. It is possible that during menstruation, some endometrial tissue shed from the uterus wall fails to pass out of the body and passes backwards along the fallopian tubes towards the ovaries. It can then reach the abdominal cavity and implant under certain conditions.

It is estimated that about 10 to 15% of women have endometriosis. The condition tends to run in families and it is more common in white women.

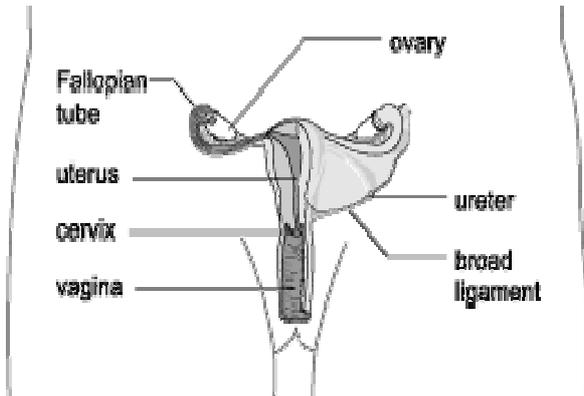
What are the common symptoms and complications of endometriosis?

The most common symptom of endometriosis is period pain (dysmenorrhoea). Often, a woman will not start to have period pain from her endometriosis until it is already well established over several years. The severity of the pain can vary greatly; some women with extensive endometriosis have no symptoms, whereas others with minimal disease have incapacitating pain. The pain may not be confined to the time of the period (pelvic pain). Pain can also be experienced during sexual intercourse (dyspareunia).

Another symptom of endometriosis is subfertility.

Less commonly, endometrial tissue and adhesions attach to the bowel or bladder causing abdominal swelling, pain during bowel movements, bleeding from the rectum (back passage) during menstruation, bowel obstruction or pain when passing urine.

Occasionally blood collections form in cysts and these can leak, rupture (haemorrhage) or twist (torsion) causing sudden severe abdominal pain, sometimes requiring emergency surgery.



Female pelvic organs

Endometriosis and fertility

There is an association between mild endometriosis and infertility but most women will be able to conceive. Medical treatment does not enhance fertility although surgical treatment sometimes can.

In moderate to severe endometriosis, distortion of the pelvic organs is more likely to affect fertility. In such cases, surgery is often required to improve the chances of pregnancy. Pregnancy itself is a good treatment for endometriosis.

How do doctors diagnose endometriosis?

To make the diagnosis, a laparoscopy is almost always necessary.

For this procedure, a general anaesthetic is given and a fibre optic viewing tube (a laparoscope) is inserted into the abdomen via a small incision just below the navel (see separate Patient Information Leaflet on Diagnostic Laparoscopy). The doctor can inspect the inside of the abdominal cavity for patches of endometrial tissue. Early implants look like spots and pimples sprinkled on the pelvic surface.

Other procedures, such as ultrasound scans, computerised tomography (CT scanning) or magnetic resonance imaging (MRI) can be used to get more information about the extent of endometriosis in severe cases.

What is the treatment for endometriosis?

Self-care action plan

When the principal symptom is lower abdominal pain, stress may make the pain worse. Therefore, some form of relaxation therapy, such as yoga or the Alexander technique may be helpful.

Choice of treatment of the condition with medicines and/ or surgery will depend on age, symptoms and pregnancy plans as well as the extent of the disease. All these factors should be discussed with your doctor.

Medicines

There are variety of medicines available, each having different advantages and disadvantages. You should discuss the options with your doctor.

Anti-inflammatory drugs may relieve pain associated with endometriosis. Other drugs (such as the oral

contraceptive pill, progestogens, danazol or gonadotrophin-releasing hormone agonists) all suppress the activity and/or hormone production by the ovaries and so slow the growth of the misplaced endometrial tissues. However, when the drug treatment is withdrawn the disease can return.

Medicines may be used in combination with surgery.

Surgery

If you have moderate to severe disease, surgery may be necessary. As much of the misplaced endometrial tissue as possible will be removed, while trying to preserve your ability to have children. This procedure can be performed either as a keyhole procedure with a laparoscope or as an open abdominal operation. Even after surgical removal of endometriosis the endometriosis may grow back later on.

Hysterectomy alone (without removal of the ovaries) leads to a 40% recurrence of endometriosis after 5 years. Only surgical removal of both ovaries can prevent endometriosis from recurring. Removal of the ovaries together with removal of the uterus (hysterectomy and bilateral oophorectomy) is only carried out in women with severe pain that is unrelieved by medicines and who do not want another pregnancy. Afterwards, hormone replacement therapy with oestrogen is necessary because the removal of the ovaries results in the same effect as the menopause.

What is the outcome of endometriosis?

Endometriosis spontaneously subsides after the menopause as the ovaries become less active.

Before the menopause, symptoms may improve considerably or even disappear after drug treatment or surgical removal of the misplaced endometrial tissue.

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