

Patient Information

Endometriosis

What is Endometriosis?

Endometriosis is a disease affecting millions of women throughout the world. It is not cancerous. It is a condition where tissue similar to the inside lining of the womb is also found in places outside the womb. The inside lining of the womb is called the endometrium. The endometrium reacts to the hormones released by the ovaries. It prepares itself each month for pregnancy. If the woman does not become pregnant, the endometrium is shed as a period. Endometriosis also goes through the monthly cycle. If it is present outside the womb there is no escape for the blood, which remains and irritates the surrounding tissues.

Endometriosis can be found on the ligament supports of the womb and nearby organs such as the ovaries, the bladder and the bowel. It can sometimes be found in the more distant sites such as the lungs or navel. Endometriosis can appear as spots or patches or as cysts on the ovaries. It may be present in only a few small isolated areas or in some more severe cases it may be present throughout the pelvis.

In most women endometriosis grows slowly and can remain stable for years. It may remain unchanged, become scar tissue or disappear over a period of months. It can also form cysts on the ovaries called endometriomas (also known as “chocolate” cysts because of the presence of altered blood within the cyst). A woman may suddenly feel pain when an endometrioma bleeds or bursts. In severe cases, adhesions (web-like scar tissues) may be formed which may bind the womb, tubes ovaries and nearby intestines together.

Causes

It is not known why some women develop endometriosis. It is not known to be inherited but a woman with an affected close relative is more likely to have endometriosis herself. One possible cause is that during a period some blood may pass backward through the fallopian tubes into the abdominal cavity. Contained within the menstrual blood are fragments of endometrium and these can seed and grow in the peritoneal cavity. It is not known why these cells seed in some women and not in others. It may be that endometriosis develops as a result of several years of uninterrupted periods.

Symptoms

Some women with endometriosis are without symptoms but others may experience some or all of the following symptoms to varying degrees:

- Painful, heavy, prolonged periods.
- Pain during intercourse.
- Infertility.
- Irregular vaginal bleeding.
- Pain on opening bowels.

It is known for some women with mild disease to have severe symptoms, while some women with severe disease occasionally have none.

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Treatment

Your doctor will recommend the most appropriate treatment to improve pain and/or fertility based on your personal circumstances. It may involve treatment, surgery or a combination of both.

It has been claimed that pregnancy and the menopause are two 'natural cures' for endometriosis. In pregnancy there are sustained high levels of hormones and in the menopause the levels of hormones are low. Hormone treatment involves mimicking one or other of these conditions. Both types of treatment lead to changes in the endometriotic tissue, which encourage its healing.

If you were planning to start a family in the near future the doctor may advise you to go ahead. However, some women with endometriosis have difficulty falling pregnant. Surgical treatments, rather than medical treatments, are usually recommended for women with endometriosis who are trying to become pregnant. Other fertility treatments for women with endometriosis include assisted conception therapy such as In Vitro Fertilisation (IVF) or Intra Uterine Insemination (IUI) may be an option.

Hormone Treatment

Danazol – Combined Oral Contraceptive Pill

Reduces hormone levels. Taken in tablet form for up to six months. Periods will stop. Endometriosis shrinks and painful symptoms improve in 90% of women.

Progestogens

Pills or injections usually for six months. The injections are contraceptive and may have a prolonged effect of up to one year after the last injection. Progestogen hormone may also be released inside the womb via a special coil (e.g. Mirena Coil) over a period of 4 to 5 years, which provides both treatment for endometriosis and contraception.

Gonadotrophin - Releasing Hormone Agonist

Nasal spray or injection usually for up to six months. Endometriotic tissue shrinks and pain improves in 90% of women.

There are side effects with all these treatments, which should be discussed with your doctor.

Surgery

Some forms of severe endometriosis do not respond to drug therapy. Surgery may be required to remove scar tissue (adhesions) or ovarian cysts (endometriomas) to relieve pain or improve fertility. Mild to moderate cases may be treated by electrocautery (burning with electric current) via laparoscopic surgery (keyhole surgery). Laser surgery through laparoscope is also possible. The tissue is evaporated rather than burned. Pain is improved but it may take up to six months after surgery to feel the benefit.

For women with severe endometriosis, who have had not success with other treatments and have completed their families, a hysterectomy and removal of ovaries may be necessary to relieve severe pain.

Patient Information

Sources of information

Your GP or Practice Nurse

NHS Direct

www.nhsdirect.nhs.uk

Telephone: 0845 4647

Patient UK Website

Comprehensive, free, up-to-date health information - www.patient.co.uk

Important information

The information in this leaflet is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments please contact our Patient Advice and Liaison Service (PALS) – details below.

Hand hygiene

The trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

This information is available in alternative formats such as large print or electronically on request. Interpreters can also be booked. Please contact the Patient Advice and Liaison Service (PALS) offices, found in the main reception areas:

Conquest Hospital

Email: palsh@esht.nhs.uk - Telephone: **01424 758090**

Eastbourne District General Hospital

Email: palse@esht.nhs.uk - Telephone: **01323 435886**

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

Reference

The following clinicians have been consulted and agreed this patient information:

Consultants in Obstetrics and Gynaecology

Paula Smith, Clinical Matron

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Responsible clinician: Paula Smith, Clinical Matron