Endometriosis

What is endometriosis?

Endometriosis is the presence of tissue similar to your womb lining, outside your womb (uterus). This tissue can implant in many places in your pelvis including your ovaries, bladder, and bowel, on the ligaments attached to the back of your uterus and the space between your vagina and bowel. Endometriosis may also develop outside the pelvis in abdominal surgical scars, the lungs, and kidneys, in fact in almost any other organ in the body.

What is the risk of getting endometriosis?

Endometriosis is a common condition and occurs in about 5-10% of the female population. 1 in 6 women with pelvic pain and 20% of women with fertility problems will have endometriosis. Furthermore, if your sister or mother has endometriosis then your risk of endometriosis increases.

What are the symptoms of endometriosis?

There are a number of different symptoms associated with endometriosis, although some women may not experience any symptoms at all. Symptoms that may be caused by endometriosis include: - painful periods, painful intercourse, chronic pelvic pain, and ovulation pain. Pain (usually worse during your period) may also be felt when opening the bowels or on passing urine and occasionally blood may be passed from these organs during your period. Some women may only experience non-specific symptoms such as bloating, nausea and vomiting. Endometriosis can also make it more difficult to become pregnant.

How does it produce symptoms?

Just as the endometrial tissue inside the uterus bleeds monthly, from menstrual periods, so does the endometrial tissue of endometriosis. Endometriotic tissue bleeds, irritating the surrounding tissue and then heals over by scarring. The scar tissue may form into a tender nodule or, if the endometrial tissue is in the bladder or bowel, it may cause bleeding when passing urine or stools during your period. Adhesions, (scar tissue) formed as a result of endometriosis, may obstruct the normal movement of some organs such as the bowel and this will usually result in pain.

How is the diagnosis made?

Internal (vaginal) examination revealing a non-mobile uterus, tender support ligaments of the uterus or enlarged painful ovaries suggest endometriosis. Visible endometriotic nodules can also sometimes be seen in the vagina or on the cervix (the neck of the uterus).

Ovaries that are enlarged by endometriotic deposits (called endometriomas) can usually be diagnosed by ultrasound or other imaging techniques. However, visual inspection of the pelvis by a laparoscopy, (an operation during which a miniature telescope is inserted into the tummy while you are under a general anaesthetic), is the best way to make a diagnosis of endometriosis.

What does endometriosis look like?

At laparoscopy endometriosis may appear as dark brown or black powder burn patches on the peritoneum (the lining of the inside of the abdomen or tummy), and endometriotic cysts can swell your ovaries. A biopsy of any of these lesions may help to establish a diagnosis of endometriosis but may not always be conclusive.

How is endometriosis treated?

Endometriosis may be treated by medication or surgery. The aims of treatment are to try to reduce endometriosis associated pain, improve quality of your life, or to help you try and get pregnant, when appropriate.

Medical Therapy
Drug treatment may include analgesia (pain relief tablets) or hormone therapy.

Analgesia
Analgesia helps to control pain in endometriosis. These tablets should be taken as per the manufacturer's instructions.

Hormone therapy
Hormonal medication prevents monthly menstrual periods and can make endometriosis tissue become inactive. Hormones may be administered in the form of progesterone tablets or the oral contraceptive pill. Either of these is usually taken for 6-9 months without a break. This may mean you do not have a monthly bleed which is not abnormal. Hormonal treatment for endometriosis can also be delivered by the Mirena® intrauterine coil.

Another type of hormone treatment prevents ovarian stimulation of endometriotic tissue. These drugs are called Gonadotrophin–Releasing Hormone Agonists or Antagonists (GnRHa). GnRH agonists are injections administered on a monthly basis for 6 months in the first instance. Alternatively, GnRH antagonists are administered daily orally. Longer use may result in thinning of your bones though this can be prevented by the additional administration of hormone replacement therapy (HRT).

HRT may also help to make some of the side effects of GnRHa treatment, which are similar to the menopause, less intrusive. These include hot flushes, night sweats, mood swings and headaches.

Up to 7 in 10 patients will have improvement of their endometriosis-associated pain. However, the benefits from medical treatment may be short lived.

Surgical therapy
The aim of surgery is to remove or reduce as much or all of the visible / palpable endometriosis to improve pain or help fertility. Surgery offers a longer-term effective treatment for endometriosis without the unpleasant side effects of medical therapy.

Conservative (uterine and ovarian sparing) surgery for endometriosis is ideally performed by laparoscopic (keyhole) surgery. Occasionally, open surgery via an abdominal incision (cut) may be discussed with you.

Endometriotic deposits that infiltrate the peritoneum (the skin covering the inside of the abdomen) Superficial Peritoneal Endometriosis (SPE) can be cut out with diathermy (heat) or laser. Endometriosis that affects the ovaries (ovarian cysts or endometriomas), are normally treated by drainage of the cyst or by drainage and stripping of the cyst wall. Occasionally your gynaecologist may advise the removal of an affected ovary as the best option. When endometriosis affects your bowel or bladder or when deep pelvic endometriosis is present, treatment may need a joint surgical procedure with other specialty doctors. This will be discussed with you at your gynaecology clinic consultation.

For some patients who have severe endometriosis and have completed their families a hysterectomy to remove the womb and both ovaries may be the most appropriate treatment. Hysterectomy is usually combined with removal of all endometriotic tissue to improve the benefits of surgery.

Your gynaecologist will discuss all treatment options with you at your clinic consultation.

Endometriosis can be quite a difficult condition to treat. Even though medical or surgical treatment may initially cure your symptoms, it is not unusual for similar presenting symptoms to return after a while.

If this happens to you, you will probably need further treatment and should make an appointment to see your General Practitioner for another referral to your gynaecologist.

Conclusion
Endometriosis affects many women and usually presents with pain or reduction in fertility. It may significantly affect quality of your life, but the symptoms can be treated by either medication or surgery. Your doctor will discuss the best management option with you depending on your individual circumstances.

Useful Contact Numbers

Stoke Mandeville Hospital
Ward 16A 01296 418107 or 01296 418108 (24 hours)

Wycombe Hospital 01494 526161

Please Note:
This leaflet explains some of the most common side-effects some people may experience. However, it is not comprehensive. If you experience other side-effects and want to ask anything else related to your treatment, please speak to the Gynaecology Nurses on Ward 16A 01296 418107 or 01296 418108.

How can you help reduce healthcare associated infections?
Infection prevention and control is important to the well-being of our patients and for that reason we have infection prevention and control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections.

More help or advice
Contact our patient advice and liaison service (PALS) on 01296 316042 or bht.pals@nhs.net

Division of Women, Children & Sexual Health Services

Approvals:
Gynae Guidelines Group: June2010, V3 Mar 2014, V4 Feb 2018, V5 Oct 2023
Divisional Board: Jun 2010, V3 Apr 2014, V4 Apr 2018, V5 4.10.23
Clinical Guidelines Subgroup: 26 Aug 2010, V3 Sep 2014, V4 Aug 2018, V5 8 Aug 2023
Patient Evaluation forms: completed
Equality Impact Assessment: Apr 2010, V5 29 Aug 2023
Communications Advisory Panel: V1 May 2009, V4 not required, V5 Nov 2023