What is endometriosis?
Endometriosis is a condition in which the tissue that normally lines the inside of the womb (endometrium) becomes deposited and begins to grow in tissues outside the womb. This abnormally located tissue continues to respond to menstrual cycle hormones, meaning that it is shed every month (just as the endometrium is) during the woman’s menstrual period. This abnormal bleeding into those tissues is responsible for the pain and other symptoms of endometriosis.

How common is endometriosis?
We know that endometriosis is common among women who have a gynaecological operation, since the typical deposits have been found in up to 2 in 5 (40%) of these women. What we do not know for certain is how common the condition is in all women. Our best estimates suggest 1 in 20 women (5%) have endometriotic deposits. The vast majority of these women will however suffer no ill effects from the condition, and it might only ever be found incidentally during other surgical procedures. Endometriosis is found more often in certain groups of women, particularly those who have difficulty conceiving.

What causes endometriosis?
We do not know for certain what causes endometriosis. We, however, know that all women shed a bit of their menstrual blood through the fallopian tubes, into the pelvis during each period. It appears that some endometrial cells contained in this shed blood remain alive, attach to the tissues in the pelvis or abdomen, and are able to continue growing in certain women. This, we believe, is what gives rise to endometriosis. There appears to be a genetic predisposition to the condition, meaning that close relatives of affected women are more likely to develop it. We believe this explains why it occurs in some women and not in others.

How does endometriosis manifest?
The vast majority of women with endometriosis do not have any symptoms, and we only discover the condition incidentally during other gynaecological operations. Endometriosis can affect virtually any part of the body, but the most commonly affected sites (see diagram) include:

1. The pelvic wall: the pelvic wall is by far the commonest site of endometriosis. Any of the walls of the pelvis can be affected, especially the wall behind the womb and around the ovaries. Endometriosis of the pelvic wall is mainly responsible for the pelvic pain, painful and heavy periods, and painful sexual intercourse associated with this condition. Endometriosis of the back wall of the pelvis can extend deep into the tissues between the vagina and rectum (endometriosis of the rectovaginal septum), a very painful condition and one that is difficult to treat. This form of endometriosis can occasionally affect the wall of the bowel (see below). Endometriosis of the front wall of the pelvis can very occasionally extend deep enough to affect the bladder (see below). Endometriosis of the wall of the pelvis can also cause infertility (difficulty conceiving) in ways that we do not fully understand.

2. Uterus, tubes and ovaries: endometriosis can affect any of these pelvic organs. The condition commonly affects the outer wall of the uterus, fallopian tubes and ovaries. Ovarian endometriosis often extends deep into the ovary, leading to the collection of a blood-filled cyst (called an endometrioma) inside the ovary. All of these also cause pelvic pain, painful and heavy menstrual periods, and painful sexual intercourse. Endometriosis around the tubes and ovaries can cause adhesions (fibrous tissue that forms between different organs in the abdomen). These adhesions might interfere with the free movement of the tube or cause its blockage, thereby causing infertility.
3. Bowel: endometriosis can affect any part of the bowel, but most commonly the parts of the large bowel located in the pelvis (sigmoid and rectum). Bowel endometriosis might cause cyclical bleeding from the anus (coinciding with the menstrual periods), pain when passing stool, constipation, and ultimately bowel obstruction in long-standing cases.

4. Bladder and ureters: endometriosis can affect the bladder as well as the tubes that take urine from the kidneys to the bladder (ureters). These might cause the passage of blood in urine in a cyclical fashion (coinciding with the menstrual periods), as well as pain on passing urine. These women are also more prone to developing urine infections. Endometriosis can lead to narrowing and even blockage (in severe cases) of the ureters, with the risk of kidney failure.

5. Other tissues: endometriosis rarely occurs outside of the sites described above, although it can theoretically affect every type of body tissue. The other observed sites of endometriosis include the belly button, operation scars from previous abdominal operations and episiotomies, the liver, the lungs, and the brain. These all give rise to symptoms due to bleeding into the various tissues.

Diagnosing endometriosis
When a woman comes to hospital with suspected endometriosis, the doctor will usually go about confirming the condition by:

1. History and examination: a detailed history of the woman's complaint helps to diagnose endometriosis. Particularly suggestive symptoms include painful and heavy menstrual periods, painful sexual intercourse, pre-menstrual spotting of blood, and specific symptoms due to effects on particular organs. Examination of the pelvis is similarly helpful, as it might reveal tell-tale signs of endometriosis at the top-end of the vagina, irregularity of the tissues behind the womb, and/or painful and immobile pelvic organs.

2. Pelvic ultrasound scan: a pelvic ultrasound scan might reveal the presence of endometriotic cysts of the ovary or deposits of endometriosis in the recto-vaginal septum or bladder.

3. Laparoscopy: the technique of inspecting or operating on the inside of the abdomen through small keyhole cuts on the abdomen. This is the firm way of confirming the diagnosis of endometriosis, and it is usually undertaken as a day case procedure. The extent of the endometriotic deposits seen at laparoscopy allows the doctor to grade the severity of the condition into mild, moderate or severe. These guide the choice of appropriate treatment.

Management of endometriosis
Depending on the severity of symptoms and extent of the endometriotic deposits, the condition can be managed as follows:

1. Conservative management: the presence of mild endometriosis does not always necessitate treatment, as quite a few of the affected women have no symptoms at all, the condition only coming to light during the investigation and/or treatment of other conditions. However, because endometriosis is a progressive condition that might get worse with time, the doctor will continuously monitor its extent in these women (especially those in younger age groups).

2. Medical management: although medical management (treatment with medication) does not completely eradicate (cure) endometriosis, it can remarkably lessen and control the symptoms for prolonged periods. Medical management is therefore useful for women with symptoms of the condition who for some reason are unable to undergo or wish to defer surgical treatment. The standard medical treatment uses an injection to suppress the ovaries (GnRH agonist) and a tablet to prevent hot flushes (Livial), a combination that can be used for up to 18 months each time. Other forms of medical treatment include continuous use of certain hormones, such as the combined oral contraceptive pill or progestogens. These medications are likely to temporarily stop women having menstrual periods whilst being used. A few women might remain completely free of the symptoms of endometriosis after stopping medical treatment, but for the vast majority, the symptoms are likely to begin again after a few months of relief.

3. Surgical management: surgery is the definitive treatment of endometriosis, and the only form of treatment with a good chance of curing the condition. This treatment is usually undertaken through keyhole or laparoscopic surgery (see above), but open abdominal surgery (laparotomy) is occasionally used. The following section details the different forms of surgical treatment:
A) **Ablation** - this refers to the procedure of burning off the endometriotic deposits. It can be achieved using diathermy (heat energy generated from an electric current), harmonic scalpel (heat energy generated from ultrasound), helium or laser. Ablation can be a very successful treatment for superficial (surface) endometriosis, especially when the deposits cover a wide area. It is not very successful with deep endometriosis, as the destructive effect of the treatment does not penetrate deep enough into tissues.

B) **Excision** - this refers to the procedure of cutting away the endometriotic deposits, and it is the most successful form of treatment for endometriosis. It can be used to treat both superficial and deep endometriosis, and is the only form of treatment suitable for deep endometriosis of the recto-vaginal septum and endometriotic cysts of the ovaries. These surgical treatments aim to cut away the endometriotic deposits, leaving the pelvic organs in as functional a state as possible.

4. **Hysterectomy and removal of both ovaries:** this might be the only option for women with severe endometriosis who have not been helped by or are unsuitable for treatment using the other types of surgery. This treatment is therefore only used as a last resort, when all other forms of treatment have failed, and is mostly recommended to women who have completed their families. Very occasionally, it might be offered to younger women, even those who have never had children, in situations where other forms of treatment fail to control the symptoms of severe endometriotic disease.

The doctor will discuss the details of the various treatment methods suitable for individual patients (including their benefits and dangers), before recommending the most appropriate form of treatment.

**Recurrence of endometriosis**
Irrespective of how successfully endometriosis is treated, there unfortunately remains a small chance that it might recur (return). The risk of recurrence appears to be greater with more extensive endometriotic deposits, and surgical excision carries the smallest risk of recurrence. It is therefore not unusual for treated women to be monitored for a few years afterwards.

**Endometriosis and infertility**
Endometriosis is found more often in women who have difficulty conceiving, irrespective of whether they have damage to their fallopian tubes or not. We know from research studies that these women have a higher chance of conceiving spontaneously following surgical treatment. This benefit of surgical treatment is not replicated by medical treatment, hence.

We would normally advise women not to become pregnant until they have had three normal menstrual cycles after the operation. This allows enough time for the womb to heal completely and for the woman to recover both physically and emotionally from the operation. On the other hand, we encourage women planning future pregnancies not to delay them too long because of the risk of recurrence of the fibroids.

This information has been put together to help patients better understand the nature of endometriosis and any treatment that has been recommended for it and to hopefully address some of their queries. Like all patient information sheets, it cannot cover every little detail of this condition and we encourage patients to discuss any further queries they have with their doctor.

For further information, please contact the Joint Endometriosis Service on 0161-276-6279/6358.

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