Patient Information: Endometriosis

What is endometriosis?
Endometriosis refers to the presence of cells that normally line the womb, but abnormally occur outside the womb cavity. Typically, this occurs in the lower tummy area but it may occur in virtually any part of the body. The most common locations for endometriosis are the outer surface of the ovaries, the pelvic peritoneum (the tissue that lines the abdomen), the uterus, fallopian tubes, bowel or bladder.

How common is it?
Endometriosis is found in around 40% of women who are having difficulty getting pregnant and around 15% of all women.

Is all endometriosis the same?
Endometriosis most likely represents a varied range of disease, which affects different women in different ways. Some women may have quite severe endometriosis and are virtually without problems whilst others have milder endometriosis and can suffer from bad symptoms, difficulty getting pregnant, or both. There is a complex interaction between the endometriosis tissue and the woman’s body, which is not completely understood.

Endometriosis is classified into one four stages (I-minimal, II-mild, III-moderate, and IV-severe) depending on location, extent, and depth of endometriosis tissue; presence and severity of scarring; and presence and size of ovarian endometriomas.

Endometriomas are areas of endometriosis that are large enough to form a cyst on the ovaries. The endometriosis cyst contains a brown liquid that has the appearance of melted chocolate, hence the alternative name “chocolate cysts”. Chocolate cysts have a characteristic appearance on ultrasound scan however unless cysts or very major endometriosis is present, ultrasounds are not good at diagnosing endometriosis as a general rule.

Deep infiltrative endometriosis (DIE) is a name given to endometriosis that has spread through the lining of the pelvis or other tissues and is growing into the structures beneath such as the ligaments supporting the uterus, the bowel, bladder or other structures. If DIE is found, then the stage is moderate (III) or severe (IV).

Why would I get endometriosis?
The following factors may increase your chance at developing endometriosis:

• No pregnancies resulting in the birth of a child
• Endometriosis in a woman’s mother or sister
• Regularly having less than 27 days between periods
• Heavy bleeding during periods and periods lasting longer than five days
• First period before 11 years of age
• Partial or complete obstruction of normal menstrual flow, e.g., from uterine abnormalities such as a tight cervix, vaginal septum or uterine fibroids
• White or Asian race
• Changes in the immune cells (this possibly cause needs further research and understanding)
• Low body weight
• Alcohol use

Conditions that decrease how often or how heavy your periods are may also lower the risk of endometriosis, e.g., pregnancy or prolonged use of the oral contraceptive pill.

**Causes of endometriosis**

We don’t really know what causes endometriosis, and possible causes or factors may be different from person to person.

• **Family history:** women who have a close relative with the condition are up to 7-10 times more likely to get endometriosis. Also, it is common with twins that both may get endometriosis, particularly if they are identical twins.

• **Retrograde (backwards) menstruation:** When a woman has a period, the blood flows out of the vagina, but also backwards along the fallopian tubes into the pelvis. In most women (90%) the blood, which will contain endometrial tissue, just gets absorbed or broken down and causes no symptoms; however, in women with endometriosis this endometrial tissue starts to grow.
## Symptoms of endometriosis

Endometriosis symptoms vary greatly between individuals. For example, some women may experience no symptoms whilst others may experience many symptoms.

| Pain | • Pain before and during your period  
|      | • Pain during or after sex  
|      | • Tummy, back and/or pelvic pain  
|      | • Pain when going to the toilet or passing wind  
|      | • Ovulation pain, including pain in your thigh or leg (this can also happen normally in some women) |

| Bleeding | • Heavy bleeding, with or without clots  
|          | • Irregular bleeding, with or without a regular cycle  
|          | • Bleeding longer than normal  
|          | • Bleeding before your period is due |

| Vagina | As the muscle walls of the vagina close tightly or spasm in response to attempted insertion, for example, with a tampon or penis. This can be mildly uncomfortable or it may cause searing or tearing pain. |

| Bladder & bowel problems | • Change in pattern of bowel habit e.g. constipation, diarrhoea  
|                          | • Bleeding from your bladder or bowel  
|                          | • The need to urinate more frequently or some other change from your normal habit |

| Bloating | Increase in your tummy area, with or without pain at the time of your period. |

| Tiredness | Tiredness or lack of energy, especially around the time of your period. |

| Mood changes | Anxiety, stress and depression due to ongoing pain. |

| Reduced quality of life | Taking days off work, study or school because you can’t function normally. |
Diagnosis of Endometriosis

There are unfortunately no blood tests or scans that can definitely diagnose endometriosis, rather this is done by keyhole surgery and sending off a sample of endometriosis to the pathology service. Endometriosis is rarely diagnosed before a girl’s periods start or after the menopause. Keyhole surgery for finding endometriosis and taking a biopsy is the only definite way of diagnosing endometriosis. Without this, the diagnosis is only assumed.

Treatment of endometriosis

There are several treatment options for women with endometriosis and the kind of treatment chosen depends purely on a woman’s wishes, her desire for fertility, the desired effects and the wish or not to be on long-term medication.

Analgesics

I would consider it unsatisfactory to use these as my first line treatment after a positive diagnosis of endometriosis. Most women come to me having already tried the oral contraceptive pill in combination with analgesics to free themselves from pelvic pain. Once a diagnosis is made then an attempt should be made to cure the endometriosis.

Oral Contraceptive Pill

The oral contraceptive pill contains both oestrogen and progesterone. When taking the pill for a while the effect on the lining of the uterus is generally to cause it to thin which results in much lighter periods. However, it never really disappears. The same effect occurs with endometriosis in that the endometriosis is suppressed without ever really disappearing. Nonetheless, if disease is mild, the oral contraceptive pill can be a useful way of suppressing pain symptoms without causing any real harm. The therapy can be continued for a long time, generally without side effects.

Other Forms of Hormonal Therapy

Other forms of hormonal therapy similarly seek to suppress endometriosis. This would include progesterone tablets, progesterone injections or Goserelin (a gonadotropin releasing hormone analogue). None of these are without significant
side effects and none are generally taken for a long period of time for reasons of cost, convenience and side effects.
Surgery

In my hands, surgery is the mainstay of treatment for diagnosis and treatment of endometriosis. Many treatment modalities have been described in the past and all have their advantages and disadvantages. The exact type of surgery that is required depends on the extent of a woman’s symptoms, her desire for fertility, the site and radiation of the pain and the potential risks and benefits of surgery.

Excisional Surgery

Excisional surgery refers to cutting out the deposits of endometriosis. This requires greater time and skill and is ideally suited to those in whom the endometriosis is severe, resulting in adhesions, sticking together of tissues and distortion of anatomy. If the endometriosis is deep then excisional surgery is really the only kind that can be carried out with the hope of obtaining adequate cure.

Ablative Surgery

Ablation refers to burning or destroying endometriosis deposits. This can either be done with electrical energy or laser. Ablative therapy typically works best where lesions are small and superficial however in the presence of deep disease, clearance is much less likely. Ablative therapy is often used for disease on the surface of the ovary.

Other Issues in Surgical Treatment

The vast majority of endometriosis should be treated by laparoscopic approach. In rare cases laparotomy (opening of the abdomen through a large incision) may be necessary when dealing with extremely extensive adhesions or invasive endometriosis involving the ureters, bladder or rectum. Indicating for removing endometriosis on such structures really depends on a patient’s symptoms and plans for fertility. Removal of deep, infiltrative endometriosis involving the bowel is an extensive procedure requiring removal of a short section of bowel and often has associated bowel disturbance thereafter for many months. Pain relief is achieved in most patients who undergo laparoscopic resection of endometriosis however the risk of recurrence is estimated to be up to forty percent at ten years follow up and around twenty percent of patients may undergo additional surgery within two years. Success rates in relieving pain are most marked in those who have severe, e.g., stage IV
disease and such women often feel a reduction in pain in the immediate post-operative period.

**Definitive Surgery**

Definitive surgery involves a hysterectomy with or without removal of the fallopian tubes and ovaries. Removal of the ovaries in a pre-menopausal lady is a matter not to be taken lightly however if they are heavily involved with endometriosis and are likely to form adhesions resulting in ongoing pain or the requirement for further surgery, then removal of the ovaries is sometimes required. The decision to proceed to a hysterectomy is primarily dependent on the patient’s interest in having (more) children.

**Hormone replacement after hysterectomy for severe endometriosis**

If the ovaries are removed in a premenopausal lady then oestrogen replacement with or without progesterone to prevent menopausal symptoms and loss of bone density, should be considered even if surgery has not removed all the endometriosis. There is a very low likelihood of symptom recurrence in these cases (less than five percent) except if endometriosis involves the rectum. It is not known whether the use of progesterone will reduce the chances of any residual endometriosis growing again. This theoretical benefit of avoiding a small risk of recurrent disease must be balanced against a small increase in the incidence of breast cancer.
Reasons for combination medical and surgical therapy

Pre-Operative Medical Therapy

Hormonal suppression such as with GnRH analogues (Zoladex and others), has been used prior to surgery to try to decrease the amount of adhesions and make the endometriosis less biologically active ("sticky") thereby facilitating the surgery. However, there is no evidence that this results in a better operation and in the vast majority of cases a competently performed primary operation with attention to detail in clearance of disease, is far preferable.

Post-Operative Medical Therapy

Previously, progesterone or tablets such as Danazol or GnRH analogues have been used in conjunction with surgical clearance of disease to try to reduce disease recurrence. If, after surgery a woman still has pain with periods then certainly suppressing the menstrual cycle may be of benefit in reducing pain. However there is no increased chance of pregnancy (obviously impossible whilst the periods are stopped by tablets) and upon ceasing medical suppressive therapy, endometriosis will recur. My own approach is that if the woman requires contraception or if symptomatic relief has been incomplete after surgery, the most physiological approach is to commence and remain on the oral contraceptive pill. This is as good as more aggressive and expensive medications. There is evidence that insertion of a Mirena IUCD gives an additional benefit to a well performed operation in terms of pain relief.

Endometriosis and infertility

About 30% of women with endometriosis report difficulty getting pregnant, however most women with mild endometriosis can have children naturally. As endometriosis tends to worsen with time, it is best to start trying to get pregnant as soon as possible.

In mild endometriosis there is no obvious reason why infertility occurs. It may be because the endometriosis cells release chemicals that interfere with the ability to conceive or affect early normal development of the embryo.
In moderate to severe endometriosis, scarring may cause interference with ovulation and the passage of the egg along the tube because of damage or blockage. It can also prevent the sperm from reaching the egg.

Surgery can remove and repair the endometriosis and any organs affected, and increase the chance of pregnancy in women with reduced fertility due to endometriosis. Especially in moderate to severe endometriosis, keyhole surgery to remove large areas of endometriosis has been shown to increase the chance of pregnancy. If you are in your late 30s or early 40s, or have been trying to fall pregnant for some time, IVF treatment may be recommended.

**Conclusion**

Endometriosis can be a confusing and difficult to treat condition. The mainstays of assessment are careful history, detailed examination and ultrasound scan and a well performed operation plus or minus post-operative medical therapy by the most simple and physiological means possible. Treatment of endometriosis in the presence of infertility must be tailored to a patient’s individual needs. Complete removal of known endometriosis definitely enhances spontaneous (natural) pregnancy rates however chasing more severe endometriosis that may involve operations with their potential for prolonged recovery phases, may not necessarily be required before embarking on fertility treatment. Pregnancy itself may improve the symptoms of endometriosis but does not cure it. Pregnancy provides a similar hormonal picture as remaining on the oral contraceptive pill and hence endometriosis is suppressed but not removed. During pregnancy a woman has no periods and so pain from endometriosis may stop or be improved.