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Patient Information: Endometriosis

What is Endometriosis?Endometriosis patient information leaflet AUG 25.docx

Endometriosis is a long-term condition where tissue similar to the lining of the uterus (endometrium) grows outside the uterus, commonly affecting the ovaries, fallopian tubes, and pelvic lining. This tissue responds to hormonal changes, leading to inflammation, scarring, and often severe pain. Many women experience significant delays in receiving a diagnosis, sometimes waiting years before their symptoms are recognised and properly investigated. The condition is frequently misunderstood, and its symptoms can be mistaken for other conditions, leading to frustration, emotional distress, and a sense of being unheard. If you are struggling with persistent pain and symptoms, know that you are not alone, and support is available to help you navigate your journey towards diagnosis and treatment.

Symptoms

Endometriosis symptoms can vary widely from person to person. Some may experience debilitating pain, while others have mild or no symptoms at all. The severity of pain is not always an indicator of disease progression, and symptoms can fluctuate over time. Many women find their symptoms worsen during their menstrual cycle, while others have persistent discomfort throughout the month. The impact on daily life can be significant, affecting work, relationships, and emotional well-being. Some experience the symptoms below:

- Pelvic pain (often worsening during menstruation)
- Painful periods (dysmenorrhoea)
- Pain during or after intercourse
- Heavy or irregular periods
- Bloating, nausea, and fatigue
- Bleeding or Painful bowel movements or urination (especially during menstruation)
- Infertility
- Cyclical chest or shoulder tip pain

Investigations

Diagnosing endometriosis can sometimes take time, as symptoms may vary widely between individuals and can overlap with other conditions. Your doctor will start by asking about your symptoms and medical history, especially if you experience pelvic pain, painful periods, pain during or after sex, or difficulty getting pregnant. In many cases, a **working or empirical diagnosis** of endometriosis may be made based on your symptoms alone, particularly if they are typical. In such cases, your doctor

might suggest starting treatment without needing further tests, especially if symptoms are well controlled.

If symptoms persist or are more complex, further investigations may be recommended. **Imaging tests**, such as a transvaginal ultrasound scan, can help identify ovarian cysts (known as endometriomas) or signs of deep endometriosis, particularly when performed by an experienced clinician. Occasionally, an **MRI scan** is used to get a more detailed view, especially when planning surgery.

In some cases, the only way to confirm endometriosis is with a surgical procedure called a **laparoscopy**. This is a keyhole operation where a thin camera is inserted into the abdomen to look directly at the pelvic organs. If any areas of endometriosis are seen, they can sometimes be treated or biopsied at the same time. Laparoscopy is not always necessary for diagnosis, especially if symptoms can be managed without surgery, but it remains the gold standard for confirming the condition. Laparoscopy comes with risk, including anaesthetic risk, pain, bleeding infection and injury to internal structures, so the decision to proceed with surgery must be a considered one.

- **Pelvic examination** – To check for cysts or tender areas.
- **Ultrasound scan** – Transvaginal scan which can detect signs of endometriosis such as ovarian endometrial cysts (endometriomas) or endometriosis plaques or lesions.
- **MRI scan** – Detailed imaging for deep endometriosis.
- **Laparoscopy** – A keyhole surgical procedure that can confirm endometriosis, but it is not always required for diagnosis and it is not without risk. Diagnosis is often based on clinical suspicion, and treatment may be initiated without surgical confirmation. If first-line treatments do not provide symptom relief, a laparoscopy may then be considered to excise superficial endometriosis. If invasive endometriosis is found, then the laparoscopy would assess the extent of the disease and allow planning for further surgery.

Differential Diagnosis

Endometriosis shares a close relationship with several other conditions, as many of the symptoms overlap. This can make diagnosis challenging, and in some cases, endometriosis may be misdiagnosed as another condition. If endometriosis is not identified at laparoscopy, it is important to consider other potential causes of symptoms. Some of the most common conditions that mimic endometriosis include:

- **Irritable Bowel Syndrome (IBS)** – Bloating, diarrhoea, or constipation. IBS and endometriosis often have an interplay, with many women experiencing symptoms of both conditions simultaneously. Endometriosis can exacerbate bowel symptoms, while IBS may worsen pelvic pain. Because of this overlap, a combined treatment approach addressing both conditions may be necessary to achieve symptom relief.

- **Painful Bladder Syndrome (PBS)** – Chronic bladder pain and urinary urgency. Many women with endometriosis also experience PBS, as both conditions can contribute to pelvic pain and urinary symptoms. The inflammation and irritation caused by endometriosis in the pelvic region may exacerbate bladder sensitivity, leading to frequent urination, discomfort, and pressure. Treatment may involve a combination of dietary changes, bladder training, pelvic floor physiotherapy, and medications to manage symptoms effectively.

Management Options

Managing endometriosis requires a personalised approach that considers symptom severity, fertility goals, and overall well-being. Treatment options range from lifestyle modifications and medications to surgical interventions, depending on individual needs.

Lifestyle & Alternative Approaches

Many women find that making lifestyle changes can help manage symptoms alongside medical treatments. Regular physical activity, maintaining a healthy diet rich in anti-inflammatory foods, and stress reduction techniques such as mindfulness or yoga may improve well-being. Heat therapy, such as using heating pads, can provide temporary relief from pain, while acupuncture and physiotherapy may help musculoskeletal pain associated with endometriosis.

Endometriosis can lead to chronic pain, a condition in which pain persists for three months or longer, often affecting daily activities, emotional well-being, and overall quality of life. Chronic pain is complex and involves more than just the physical presence of endometriosis lesions; it can also be influenced by nerve sensitisation and central pain processing changes in the brain.

Effective chronic pain management is often based on three key pillars:

1. **Medical Management** – Using pain relief medications and hormonal treatments to address endometriosis-related pain.
2. **Physical Therapy & Lifestyle Adjustments** – Engaging in physiotherapy, exercise, dietary modifications, and stress-reduction techniques to improve function and reduce discomfort.
3. **Psychological Support** – Addressing the emotional and mental impact of chronic pain through counselling, cognitive behavioural therapy (CBT), or mindfulness techniques.

Medical Management

Medical treatments aim to reduce pain and improve quality of life by suppressing the hormonal influences that stimulate endometriosis growth. First-line treatments

typically involve pain relief medications and hormonal therapies, which may be adjusted based on individual responses.

1. **Pain Relief Medications:** Over-the-counter analgesics such as paracetamol and nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen or naproxen can help manage mild to moderate pain. However, some individuals may require stronger prescription pain relievers or nerve pain medications.
2. **Hormonal Treatments:**

Hormonal therapies are a cornerstone of endometriosis management as they help to suppress the growth and activity of endometrial-like tissue outside the uterus. These treatments work by altering hormone levels, particularly oestrogen and progesterone, which influence the menstrual cycle. The choice of hormonal therapy depends on factors such as symptom severity, treatment goals, and potential side effects. These medications aim to reduce the hormonal fluctuations that drive endometriosis growth and inflammation. Options include:

- **Combined Oral Contraceptives (COCs)**: These provide symptom relief and help regulate menstrual cycles, reducing pain and heavy bleeding. They work by suppressing ovulation and stabilising hormonal fluctuations. COCs are available in different formulations, and their effectiveness can vary from person to person. While generally well tolerated for long-term use, some women may experience side effects such as nausea, breast tenderness, and an increased risk of blood clots. Symptoms may return once treatment is stopped.
- **Progestins and Progesterone Therapy**: These therapies are more effective in reducing pain compared to COCs and can be administered in various forms such as oral tablets, intrauterine devices, or injections.

- They work by sometimes suppressing ovulation and by thinning the endometrial lining (and therefore the endometriosis) which reduces inflammation and prevents further lesion growth.

  The intrauterine system (IUS), such as the levonorgestrel-releasing device, provides localized hormone release, minimising systemic side effects while offering long-term symptom control. The most common side effect is unscheduled and erratic bleeding. Other side effects such as bloating and mood changes are more common with oral agents. There is limited evidence that progesterones cause weight gain except those used in the injectable form (depoprovera)

  Most side effects occur particularly in the initial months of use and will settle by 6 months. Long-term safety is generally well-established, making progestins a viable option for women seeking effective, continuous management of endometriosis-related pain.

- **Dienogest**: is another progestin that has shown high efficacy in controlling endometriosis-related pain while being well tolerated over long-term use. It is currently licensed in the Uk for treatment of disease and has been shown to be as effective as medications that induce menopause without some of their side effects. Dienogest can affect your menstrual cycle, and you may have irregular bleeding or no periods at all while taking it. However, it is **not licensed as a contraceptive**, so it's important to use barrier contraception to avoid becoming pregnant. Dienogest is **not considered safe during pregnancy**, so you should avoid getting pregnant while taking it.
    - **GnRH Agonists and Antagonists**: These drugs have been considered the medical gold standard and offer strong symptom relief by significantly suppressing oestrogen levels, which helps reduce the growth of endometrial lesions and alleviate pain. However, they induce a low oestrogen state, leading to side effects such as hot flashes, mood changes, vaginal dryness, and bone loss, which limits their duration of use. To mitigate these side effects, they are typically prescribed with hormone replacement therapy (HRT) add-back, which involves small doses of oestrogen and/or progestogen to protect bone density and alleviate menopausal symptoms while maintaining therapeutic effectiveness against endometriosis. They are licensed for use for a limited period depending on the type. However, in some cases use may be extended with bone scans every 24 months.

Surgical Treatment

Surgical intervention may be recommended when medical management fails to control symptoms or when endometriosis significantly impacts quality of life or fertility. However, surgery alone is not a cure for endometriosis, and there is a risk of recurrence. To prolong the improvement in quality of life, it is often recommended that medical treatment, such as hormonal therapies, be continued after surgery. This approach helps to suppress any remaining endometrial-like tissue. The extent of surgery depends on disease severity and the patient's reproductive goals.

Surgery for Diagnosis and Treatment of non-invasive endometriosis

A laparoscopy allows surgeons to confirm the presence of endometriosis and, in many cases, perform minor excision or ablation of lesions during the procedure. This approach may provide symptom relief and may improve fertility outcomes.

In cases of ovarian endometriomas (chocolate cysts), surgery may be performed to remove the cyst while preserving ovarian function as much as possible.

Multidisciplinary Surgery for Invasive Endometriosis

In cases of severe or deeply infiltrating endometriosis, a multidisciplinary surgical approach may be necessary to ensure complete and safe excision of endometriotic

lesions. This often involves collaboration between gynaecologists, colorectal surgeons, and urologists to manage complex cases where the disease affects the bowel, bladder, and surrounding structures.

Surgical intervention may include bowel resection for deeply infiltrating endometriosis affecting the intestines, bladder surgery for urinary tract involvement, and hysterectomy with or without removal of the ovaries when symptoms are debilitating, and all other treatments have failed. Each procedure is carefully planned to balance symptom relief with the preservation of function and quality of life.

While surgery can significantly improve symptoms and fertility outcomes, it is crucial to continue post-operative medical management to reduce recurrence rates and maintain long-term symptom control. Your specialist team will work with you to determine the most appropriate approach for your individual needs.

Fertility & Endometriosis

Endometriosis is very common in patients with fertility issues. The severity and location of endometrial lesions can influence fertility outcomes, with moderate to severe cases more likely to impact reproductive function. Endometriosis may cause scarring, adhesions, and inflammation, leading to blocked fallopian tubes, impaired egg quality, and disrupted implantation.

Many women with endometriosis can still conceive naturally, but some may require medical or surgical intervention to improve fertility. Treatment options depend on the severity of the disease, the woman's age, and other reproductive factors. Surgery to remove endometriosis lesions can improve fertility by restoring normal pelvic anatomy, particularly for those with moderate to severe disease. However, surgery carries risks, including ovarian reserve reduction and adhesion formation.

Cancer & Endometriosis

Endometriosis is a benign condition, i.e. it is not cancerous. However, women with endometriosis have a slightly increased risk of developing certain types of ovarian cancer. While the overall lifetime risk of ovarian cancer in the general population is about **1.3%**, studies suggest that women with endometriosis may have a lifetime risk of approximately **1.8%**. This means that while the risk is elevated, it remains low.

The increased risk is more pronounced in women with severe forms of endometriosis, such as deep infiltrating endometriosis or ovarian endometriomas. It's important to note that most women with endometriosis will not develop ovarian cancer.

Support Services

- **Endometriosis UK** – www.endometriosis-uk.org
- **Pain Management Clinics**
- **Counselling & Psychological Support**
- **Peer Support Groups -** https://www.endometriosis-uk.org/support-group/36591

For further information, please consult your healthcare provider.