



Endometriosis

Patient Information leaflet

What is Endometriosis?

Endometriosis is a chronic inflammatory condition in which tissue similar to the inner lining of the uterus (endometrium) grows outside of the uterus. This mostly occurs in the pelvis and can affect organs such as the ovaries, fallopian tubes, bowel and bladder. Rarely, endometriosis can spread to other parts of the body. During menstruation, this tissue can bleed, leading to inflammation, and over time scarring may develop. Endometriosis can significantly impact physical and mental health, fertility and quality of life, especially during the reproductive years.

It is estimated that 1 in 10 women are affected by endometriosis.

What are the Symptoms of Endometriosis?

Endometriosis symptoms may vary. Some of the common symptoms are:

- Painful or heavy periods. Pain may start days before and last several days after menstruation
- Pelvic pain: chronic pain, varies in severity
- Pain during or after sexual activity
- Bleeding after sex
- Painful urination or bladder issues
- Painful bowel movements or bleeding from the rectum
- Difficulty becoming pregnant
- Some women may experience pain radiating to the legs or back, fatigue, bloating, constipation, or diarrhoea
- Some women may have no symptoms

What Causes Endometriosis?

The exact cause of endometriosis is unknown. A number of theories have been suggested, but no theory explains all types of endometriosis. It is thought to involve multiple factors and is hormone-driven, causing chronic inflammation. A family history of endometriosis may increase the likelihood of developing the condition.

How is Endometriosis Diagnosed?

Patient-reported symptoms are an important clue to diagnosing endometriosis. Pelvic examinations, ultrasound scans, and MRI scans can aid in diagnosis, though a normal scan or MRI result does not rule out endometriosis.

Laparoscopy (a keyhole surgery procedure) is the most accurate way to confirm endometriosis.

What are the Treatment Options?

Treatment of suspected or confirmed endometriosis can be initiated in Primary Care by your GP. If symptoms persist or worsen despite initial treatment or if there are concerns about fertility, your GP will refer you to a gynaecologist for further evaluation and management.

Symptom Management

Physiotherapy

Physiotherapy can help manage chronic pelvic pain by

- Improving abdominal and pelvic muscle function
- reducing muscle tension and spasms
- providing pain management techniques

Physiotherapists use a range of manual therapy techniques to help get you moving with less pain. Some examples are myofascial release around the organs and muscles, trigger point release of tight muscles, dry needling, skin rolling, and scar massage. Usual areas of focus are the pelvic floor, abdomen and diaphragm. This will vary depending on the physiotherapist's assessment. Treating the pelvic floor will often involve an internal examination, if and when you feel ready for this.

Your physiotherapist will often teach you some self-treatment techniques with your hands or with tools such as a massage ball, therawand, or vaginal trainer so that you have more options to treat the pain as needed at home.

Your physiotherapist might suggest using a TENS machine: This is a small battery-operated device that may help with period pain, back pain and with general chronic pain. It is recommended to have an assessment by your GP or physiotherapist before considering TENS. Some machines have more settings to allow greater variability in treatment.

Exercise can improve function and reduce some symptoms and help with the psychological effects of chronic pain.

Medical Treatment

Pain Relief: Medications like paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) may be effective

Hormonal Treatments: These reduce menstrual flow and symptoms but may not be suitable for women trying to conceive

Hormonal therapy may reduce symptoms by suppressing ovulation and menstruation which can lead to a reduction in symptoms such as ovulation or period pain. In a recent study, hormonal treatment improved pain by 40%

Non-contraceptive hormonal treatments such as the medication Dienogest is effective reducing symptoms in some cases

GnRH-a (Gonadotropin-Releasing Hormone agonist) injections will lower oestrogen levels and induce a temporary menopause-like state, with side effects that mimic menopausal symptoms. If staying on this medication longer than 6 months, it is recommended that add-back oestrogen is considered to prevent long-term side-effects of GnRH-a, such as loss of bone density.

Non hormonal treatments

Low dose Naltrexone (LDN) has been shown in small studies to help modulate the immune/inflammatory response for patients with endometriosis and to alleviate pain. Larger studies are needed to confirm this.

N-Acetylcysteine (NAC): Small studies have shown that anti-oxidant and anti-inflammatory properties of NAC may help to may reduce the size of endometriomas (cysts of endometriosis in the ovaries) and associated pain. Larger studies are needed to confirm this.

When medical treatments are stopped, symptoms may reoccur.

Surgical Treatment

1. **Laparoscopy:** To confirm the presence and extent of disease, and to treat endometriosis by excising (removing) or ablating (destroying) lesions. Current evidence suggests that deep endometriosis is best excised, and that superficial endometriosis treatment with excision or ablation is equal. Further research is required in this area.
2. **Advanced Surgery:** Referral to an Endometriosis Centre may be needed if extensive surgery is required, such as bowel or bladder surgery.

Risks and Benefits of Surgery

- **Risks:** Pain, infection, bleeding, damage to surrounding organs (bowel, bladder, blood vessels, ureter, nerve tissue), recurrence of endometriosis
- **Benefits:** Pain relief, potential fertility improvement, and a definitive diagnosis

Recovery Time and What to Expect After Surgery:

Recovery varies, typically takes two weeks, depending on the extent of surgery, and pain relief is usually required. For certain types of endometriosis there may be a short-term improvement in fertility after surgery.

Ongoing management of symptoms may be required. You will need an appointment to see the team six weeks after your surgery for a routine post-operative check-up.

Long-Term Prognosis for Women with Endometriosis

Management: Endometriosis is a chronic condition and may require long-term management and follow-up.

Recurrence: Endometriosis and its symptoms can recur, necessitating further treatment, even after surgery.

Fertility: Many women with endometriosis conceive naturally; some may require fertility treatments. If you know you have endometriosis and you have been trying to conceive for six months, and you meet the eligibility criteria, your GP should refer you and your partner to your local fertility hub.

Is Endometriosis Curable?

There is no single cure for endometriosis. Managing symptoms, often until menopause, is the most effective approach. Treatment aims to control symptoms and improve quality of life.

Menopause and Endometriosis

Hormone replacement therapy (HRT) may reactivate endometriosis symptoms. Women with endometriosis should have progesterone HRT in addition to oestrogen, even if they have had a previous hysterectomy.

Conclusion

Endometriosis is a chronic inflammatory condition with a variety of treatment options that can be tailored to meet your specific needs and priorities. Treatment typically involves a combination of approaches, including diet and lifestyle modifications, physiotherapy, pain relief, hormonal therapy, and surgery, all aimed at improving symptoms and quality of life.

Regular follow-up appointments with either your GP or your healthcare team are recommended to ensure effective management and to support your long-term well-being. Remember, treatment choices are individual, and your healthcare provider will work with you to find the best plan to manage your symptoms and enhance your overall quality of life.

References and Resources

www2.hse.ie/conditions/endometriosis

rcog.org.uk/for-the-public/browse-our-patient-information/endometriosis

Endometriosis-uk.org

endometriosis.ie/

endozone.com.au

livewellwithpain.co.uk/resources-for-people-with-pain/ten-footsteps-to-living-well-with-pain

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