

## Plain language summary

# The Assessment and Management of Endometriosis

### Who is this summary for?

This summary is relevant to all women who are suspected to have or have been diagnosed with and treated for endometriosis. We note that there are people affected by endometriosis that do not identify with the terms “woman” and “women” used in this document. The use of these terms is not meant to be exclusionary or to diminish any person’s experience.

### What is this summary about?

The National Women and Infants Health Programme (NWIHP) recently developed/updated the National Clinical Practice Guideline (CPG) on endometriosis. This Guideline is for healthcare professionals who care for women and covers all aspects of care for women with endometriosis. The purpose of this plain language summary (PLS), using non-medical terminology, is to provide an overview of the national Guideline.

### What is endometriosis?

Endometriosis is where tissue that is similar to the lining of the womb is located outside of the womb. This tissue, called endometriotic lesions, are stimulated by the hormone oestrogen. This causes inflammation and the formation of scar tissue in the areas where the endometriosis is located, most commonly in the pelvis. This can cause a range of symptoms, most commonly pain or difficulty getting pregnant.

### What causes endometriosis?

The cause of endometriosis is still unknown, though there are several theories.

Some of these theories are:

- Retrograde menstruation – where during menstruation, some small pieces of the lining of the womb travel via the fallopian tubes to enter the abdominal cavity and form endometriotic lesions
- Genetic cause – endometriosis may run in some families, though no exact gene has been found to be linked to endometriosis
- Immune cause – some researchers have suggested that an immune response may be a cause of the inflammation seen in endometriosis

<https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/clinical-guidelines/>

<https://www.rcpi.ie/faculties/obstetricians-and-gynaecologists/national-clinical-guidelines-in-obstetrics-and-gynaecology/>

## How does endometriosis affect women?

Symptoms of endometriosis can range from no symptoms at all, to severe pain that interferes with the woman being able to carry out her day-to-day activities.

These symptoms can include:

- Painful periods
- Pelvic pain, which may occur during the periods or not
- Pain during or after sexual intercourse
- Painful urination, with or without blood in the urine
- Pain having a bowel movement, with or without blood in the stool
- Shoulder tip pain
- Chest problems around the time of the period (cough, chest pain, coughing of blood, or collapsed lung)
- Scar swelling or pain during the period
- Fatigue
- Difficulty getting pregnant

## What tests are available to check for endometriosis?

Making the diagnosis of endometriosis should start with a healthcare professional taking a history of the symptoms and performing an examination. This examination usually includes an internal examination of the vagina to check for tenderness or nodules.

Transvaginal (internal) ultrasound and MRI scans can be used to support the diagnosis of endometriosis, though they don't always detect endometriosis lesions. Even if no lesions are seen on imaging, medical treatment can be started to see if it will reduce symptoms.

A laparoscopy (keyhole surgery) operation can provide a definitive diagnosis if imaging did not detect endometriosis and if medical treatment did not resolve the symptoms. Surgery allows the opportunity for treatment of endometriosis. If there is evidence of deep endometriosis on imaging, the woman may be referred to a specialised centre for treatment.

## What are the treatment options for endometriosis?

Endometriosis is a chronic condition. While there are no known cures for endometriosis, there are methods for managing its symptoms.

Treatment of endometriosis can be divided into treatment aimed at reducing pain due to endometriosis, or treatment aimed at improving fertility. A doctor will discuss treatment options with the woman, taking into account factors like pain symptoms, fertility issues, age, the woman's intentions to become pregnant (now or at a later stage), how likely different treatments are to work, risks and side effects of treatments, and the type of endometriosis present.

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Treatment of pain symptoms can involve analgesic medication (pain killers), hormonal treatments (including the contraceptive pill, mini pill, intra-uterine devices, progestogen implants or injections, and GnRH agonists/antagonists), as well as surgery.

Involvement of other healthcare professionals such as physiotherapists, dieticians, and psychologists may be recommended. Often a combination of these treatments will be used to reduce pain symptoms.

60-70% of women with endometriosis will conceive naturally. If the woman is trying to get pregnant, hormonal treatment for endometriosis is not recommended as it will act to prevent conception. Surgery may be recommended to improve chances of conceiving, or to address pain symptoms that may be occurring. This will need to follow a discussion with the doctor about the woman's wishes, as well as her medical history, symptoms, and the type of endometriosis present. Particularly of importance is endometriosis of the ovaries (endometriomas), as surgery to remove this can cause damage to the ovary. Referral to fertility services for assisted reproductive therapies (such as IVF) may also be discussed.

### Where to go for more information?

<https://www2.hse.ie/conditions/endometriosis/>

Endometriosis Association of Ireland: <https://www.endometriosis.ie>

European Society of Human Reproduction and Embryology (ESHRE) guideline 2022:  
<https://www.eshre.eu/Guideline/Endometriosis>

<https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/clinical-guidelines/>

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