

What is endometriosis?

1. Endometriosis is a very common and significant condition affecting women and teenage girls and can dramatically impair quality of life.
2. Endometriosis is a condition where tissue resembling the uterine lining (endometrium) grows in abnormal locations such as the ovaries, fallopian tubes, bowel and bladder, other pelvic organs and the pelvic lining (peritoneum). This tissue responds to the monthly hormone cycle; oestrogen stimulates patches forming superficial, lesions or endometrioma (ovarian cyst) which can cause inflammation. Adhesions (scar tissue) can form in response. The outcome is often pain and fertility problems.
3. More unusually it can be found elsewhere, creating a range of symptoms which are generally cyclical - for example on liver, kidneys, diaphragm, heart, lungs and nose. Rarely, there have cases found affecting men.
4. Some women with the condition are relatively unaffected by it, while a great many others suffer severe pain and distress from problems associated with it. Teenage girls with endometriosis often report school absenteeism due to severe period pain, impairing academic achievement.
5. Endometriosis tends to be a chronic, progressive condition – left untreated it tends to worsen over time (with each period). Early diagnosis and treatment can alleviate symptoms and may preserve fertility.
6. Endometriosis can affect all ages, including teenagers and menopausal women. Rarely, endometriosis has been found in girls before puberty.
7. **Endometriosis is New Zealand's leading cause of fertility problems**, affecting about 40% of women with endometriosis. About 40% of women presenting for fertility treatments have endometriosis.
8. Endometriosis is complex and can be isolating, with no definitive cure and potentially high recurrence. Treatment options can be bewildering. Becoming informed and seeking family and community support helps to manage the condition and to be assertive when seeking treatment.

What causes endometriosis?

1. At present, no-one knows what causes endometriosis. There are several theories and ongoing international research into its cause and treatments.
2. It is widely believed that endometriosis is familial; a woman is more likely to have endometriosis if her mother, sisters or aunts – either maternal or paternal - are affected.
3. Endometriosis has been linked to autoimmune diseases such as coeliac, hyper/hypo-thyroid, fibromyalgia as well as melanoma, bowel and other cancers, leading to theories that the development of endometriosis may be due to immune system issues.

How is endometriosis diagnosed?

1. Endometriosis is often diagnosed after a long search for the cause of pain or infertility. It is frequently confused with Irritable Bowel Syndrome (IBS), Pelvic Inflammatory Disease (PID) and similar illnesses, which may also be present. Sometimes it is diagnosed when having tests for fertility problems or during pelvic surgery for other complaints.
2. Symptoms may indicate further investigation. Initially the doctor may do a simple exam, where they feel for cysts and whether the pelvic organs are moving freely or have adhesions. Ultrasounds can show endometrioma (ovarian cysts caused by endometriosis) or other causes of symptoms such as fibroids and cysts.
3. Currently the only definitive way to diagnose the condition is visually by surgery - most often by an operation called a laparoscopy (keyhole surgery). This is done under general anaesthetic by a gynaecologist, usually as day surgery or an overnight stay.
4. The extent of the disease found can be classified into stages: 1 (minimal) 2 (mild) 3 (moderate) and 4 (severe). The extent of the disease is often not reflected in the severity of pain symptoms.
5. Internationally, the average time from first symptoms to diagnosis is a staggering 9-11 years – often because women normalise pain until it becomes overwhelming. Diagnosis often takes longer for teens.

Key points:

1. Women need to recognise that pain at time of periods is not normal and seek medical help, asking their GP for a referral to a gynaecologist specialising in endometriosis, or women can self-refer.
2. Outcomes can be improved with a management approach, seeking information to become an expert patient.
3. Until endometriosis is publicly recognised as a significant and common health problem, thousands of women and teenage girls throughout NZ will continue to struggle with this debilitating condition alongside fertility issues. Greater awareness is needed, along with widely available access to public treatments, quality endometriosis education and community support.

Suggested reading:

Fact Sheet: Endometriosis Symptoms (*Insight Endometriosis*)

“Endometriosis: A New Zealand Guide” by Andrea Molloy (2006)
– *Insight Endometriosis has copies in the lending library*

For more information: visit www.InsightEndometriosis.org.nz or [www.Facebook.com/InsightEndometriosis](https://www.facebook.com/InsightEndometriosis) or contact our Educator, Annette ph 07 8555 123 | email info@InsightEndometriosis.org.nz | FB message.
