

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 gynaecological condition where tissue that resembles the uterine lining (endometrium) is growing in abnormal locations - such as the ovaries, fallopian tubes, bowel and bladder, other pelvic organs and the pelvic lining. This tissue responds to the monthly hormone cycle; oestrogen stimulates patches to thicken and form cysts or lesions, which can cause inflammation. Scar tissue and adhesions can form in response. The outcome is often pain and fertility problems.
3. 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. Many teenage girls with endometriosis report school absenteeism due to severe period pain, impairing academic achievement.
4. 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 preserve fertility.
5. Endometriosis can affect women of all ages, including teenagers.
6. Endometriosis is a leading cause of fertility problems, affecting about 40% of women with endometriosis.
7. Endometriosis is complex and can be isolating, with no definitive cure and high recurrence rates. Treatment options can be bewildering. Becoming informed and seeking family and community support can be invaluable to managing the condition and being 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. In nearly all women, small amounts of endometrial tissue are inside the pelvic cavity during a normal period (retrograde menstruation). The reason why this tissue becomes attached permanently in some women and not others is unknown. The development of endometriosis may represent a deficiency within the immune system. A healthy immune response usually prevents normal body cells implanting in unusual sites, but this system either doesn't work or overreacts with endometriosis sufferers.

3. It is widely believed that endometriosis is familial; a woman is more likely to have endometriosis if her mother, sisters or aunts are affected.
4. Endometriosis has been linked to autoimmune diseases such as coeliac, hyper/hypo-thyroid, fibromyalgia as well as melanoma and female cancers.

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 pelvic exam, where they feel for cysts and whether the pelvic organs are moving freely or have adhesions. Sometimes ultrasounds can find endometrioma (ovarian cysts caused by endometriosis).
3. Currently the only definitive way to diagnose the condition is visually by surgery - most often by an operation called a laparoscopy. This is done under general anaesthetic by a gynaecologist.
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’ the pain until it becomes overwhelming. Diagnosis often takes longer for teens.

Key points:

1. Women need to recognise that painful periods are not normal and seek medical help, either by asking their GP for a referral to a gynaecologist specialising in endometriosis, or women can self-refer.
2. Women affected by endometriosis need to take a management approach, seeking information to become expert patients.
3. Until endometriosis is publicly recognised as a serious and common health problem, thousands of women and teenage girls throughout NZ will continue to struggle with this debilitating condition. Greater awareness is needed, along with widely available access to public treatments, 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
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