



FAQ

FREQUENTLY ASKED QUESTIONS

Endometriosis

How common is endometriosis?

Endometriosis affects at least 1 in 10 Australian women. 30-40% of women with endometriosis suffer its effects from their very first period. 50-60% of women endure pelvic pain from their early 20s.

These figures are very conservative - the true number of women affected by this disease remaining unknown due to difficulties with diagnosis.

Endometriosis is a condition that's progressive and chronic. The symptoms are many and varied both over time and between sufferers. For some women, there are few and even no symptoms at all. For others, multiple severe symptoms need to be managed through to menopause.

An overwhelming number of women suffer this disease in silence, allowing the pain to become a way of life even as it interferes with education and career throughout their reproductive years. Studies have revealed that, for 50% of women with endometriosis, the debilitating nature of this condition has led to them missing 18 days a year of school and/or work on average.

A decline in fertility may be attributed to diagnostic delays, as indeed can a negative flow-on both for the individual's socio-economic situation and that of the wider community.

What are the current diagnostic criteria of endometriosis?

A detailed pain and menstrual history is vital in the diagnosis of endometriosis.

One of the clearest indications that a younger patient should be treated as having this disease is if the pain they experience before and during menstruation forces them to take 2-3 days off school or work every month. This is information that cannot be derived from closed-ended questions. It takes good listening skills, astute clinical reasoning, empathy and sensitivity to overcome the stigma that has for too long surrounded any problems concerning the reproductive organs.

The importance of achieving greater success in diagnosing and managing endometriosis in younger women is emphasised by the revelation that as many as 80% of women undergoing treatment for infertility have this disease: even those who do not present with symptoms such as pain and menstrual irregularities.

What causes endometriosis?

At this stage, it is impossible to know with any certainty what causes endometriosis. A number of factors are recognised as increasing the instance of the disease, like higher estrogen levels and more periods, but the two theories regarding its origin are most widely noted as retrograde menstruation and familial inheritance.

Retrograde (backwards) menstruation

According to Sampson's Theory, endometriosis occurs as a result of menstrual blood with retrograde flow, leaking back up the fallopian tubes to enter the pelvis instead of draining out vaginally. The problem with this theory is that retrograde menstruation is more common than not, and, for 90% of women, does not end in endometriosis. In the majority of cases, the blood containing endometrial cells is broken down and absorbed by the body without causing any harm.

Familial inheritance

While thought to have a genetic predisposition, only 60% of diagnosed cases have been found to be hereditary. For those who fall into this group, however, the fact other family members may also suffer the same symptoms makes them less likely to identify as having a problem. Girls with close relatives who accept and explain away their endometriosis symptoms as normal rarely seek help for their own symptoms.



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What are the presentation patterns for endometriosis?

Endometriosis typically presents with one or more of:

- intermenstrual bleeding;
- dysmenorrhea;
- dyspareunia;
- dyschezia; and
- dysuria.

Pelvic pain may present before menstruation begins.

It can lead to chronic fatigue, migraines, poor self-esteem and moodiness.

It can also be asymptomatic, only being detected during evaluation for infertility.

What are the diagnostic options?

- **Clinical examination**

A pelvic examination can reveal localised tenderness or nodules in the vagina.

- **Blood test**

While a protein CA-125 may help track the course of the disease in more severe cases, it is not a reliable indicator in the early stages of endometriosis.

- **Ultrasound**

Ultrasound cannot detect superficial lesions, but is helpful both in preoperative diagnosis and preparation for surgeons and patients. A number of Australian sonologists and sonographers have developed an ultrasound technique enabling diagnosis of deep infiltrating endometriosis with a high degree of accuracy. While less invasive than laparoscopic investigation/ surgery, however, the transvaginal ultrasound is not advised as an investigative tool for young women.

- **Laparoscopy**

Laparoscopy is the most reliable way of diagnosing all forms of endometriosis; indeed, it is the only way to detect superficial deposits. In younger women, however, visual detection is often limited given that lesions are quite subtle in this age group. Further, for women of all ages, it can cause not only localised pain but also trigger the dorsal root ganglion, creating heightened sensitivity to pain more generally.

What are the appropriate management pathways for endometriosis?

Irrespective of a definitive diagnosis, the clinical focus should be on managing the pain indicative of endometriosis before it becomes chronic - activating visceral and somatic sensitisation via the dorsal root ganglion - and alters the trajectory of the patient's life. Too many young women endure severe pelvic pain without seeking help, the absenteeism this causes too often resulting in an abbreviated education which in turn leads to diminished career opportunities and ultimately a lower socio-economic status.

Medical management to this end might include NSAIDs to reduce the pain and contraceptives to suppress periods. Hormonal treatments combining oral contraceptives and progestogens can also stop the cyclical nature of menstruation and thus halt the bleeding in order to suppress the growth of endometrial cells, while use of the combined oral contraceptive pill has been proven to reduce the symptoms in girls who are not sexually active (or not trying to overcome fertility issues/ get pregnant).

These more conservative management pathways for endometriosis are potentially more effective than heading straight down the path of surgery.

Despite being regarded as the gold standard in identifying endometriosis and facilitating the removal of nodules, referring your patient for laparoscopic surgery is not always the best option. Arguments against the use of laparoscopies include the fact that removal of endometriosis does not prevent recurrence and tends to lead to repetitive surgeries. This becomes an issue in terms of fertility. Even though the initial surgery can help reduce inflammation and thus increase fertility, this is negated by the need to repeat the process, with patients finding their egg numbers dropping after each procedure.

Where surgery is unavoidable, better pain outcomes are found by combining this with physiotherapy targeting the stretching of pelvic muscles.

Effective management of endometriosis requires a long-term, multidisciplinary approach. Members of the multidisciplinary team might include any or all of the following:

- Gynaecologist / gynaecological surgeon
- Pain specialist
- Physiotherapist
- Dietician
- Psychologist
- Exercise Physiologist

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How do I prepare an effective referral for tertiary management of endometriosis?

The GP plays a central role both in selecting the right people for the patient's multidisciplinary team, and as the information disseminator for and on behalf of their patient. The more detailed and up-to-date the patient's history, the greater the effectiveness of tertiary management of the disease.

Where can I find more information about endometriosis?

Endometriosis Australia: <https://www.endometriosisaustralia.org/>

Jean Hailes for Women's Health: <https://www.jeanhailes.org.au/health-a-z/endometriosis>

Pelvic Pain Foundation of Australia: <https://www.pelvicpain.org.au/>

Endo Active: <https://endoactive.org.au/>

Endometriosis Association (Qld) Inc: <https://www.qendo.org.au/>