

# 1 in 10 women are affected by endometriosis. So why does it take so long to diagnose?

August 11 2020, by Caroline Gargett, Caitlin Filby, Fiona Cousins

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Credit: AI-generated image ([disclaimer](#))

Endometriosis is a debilitating, chronic condition that affects [1 in 10 women](#) worldwide. It occurs when tissue [which has similar properties to the womb lining](#), ends up in the body and attaches to organs, forming a patch of tissue called a [lesion](#).

The condition can cause [chronic pelvic pain](#), bowel and bladder dysfunction, and pain during sex. Painful symptoms can often make it hard for women to work or study, which has long-term socioeconomic impacts.

Unfortunately, women with endometriosis can wait up to [10 years](#) for a diagnosis. But why does it take so long?

## Diagnosis is difficult

Endometriosis can only be diagnosed through surgery, and in Australian public hospitals it is common to have to wait [up to a year](#) for this procedure. This is partly because surgery for endometriosis is classified as category 3—the lowest-priority elective surgery in Australia.

To diagnose the condition, lesions need to be surgically removed and analyzed by a pathologist. The operation is performed by keyhole surgery, but it can have significant financial and health impact on sufferers.

Surgery costs are covered in public hospitals, but long wait times mean women who can afford it [are more likely to use private hospitals for endometriosis surgery](#) than for other diseases.

Then, to have a pathologist analyze the lesions removed during surgery and provide a diagnosis [can cost A\\$5,546](#) with only [a fraction covered by Medicare](#), leaving patients out of pocket.

Non-invasive imaging by ultrasound and magnetic resonance imaging (MRI) can often detect lesions on the ovary (endometrioma), and deep lesions that invade the bowel or bladder. But while this *indicates* endometriosis, lesions analyzed by a pathologist are still considered the gold standard for a formal diagnosis.

Ultrasounds and MRIs also can't detect lesions that are on the surface of organs (superficial) and are thought to be an early stage of the disease.

A prior lack of endometriosis research funding in Australia has hampered progress towards developing non-invasive screening tests. But newly developed tests may incorporate emerging evidence that endometriosis has several [distinct subtypes](#), each with a specific diagnostic and treatment profile. Recognition of distinct subtypes has [improved and informed the treatment of breast cancer](#), and this might also be true for endometriosis.

Until such tests are developed, some clinicians are advocating for a [diagnosis based on symptoms instead of lesions](#), but this hasn't been standardized or validated yet.

## **"It just comes with being a woman..."**

Normalization of period pain means women often wait [two to three years](#) from the onset of symptoms before seeking medical help. And public awareness of endometriosis and its symptoms are low. This explains why only [38% of women](#) with suspected endometriosis present to their GP each year.

Even if a woman does present to her GP with symptoms, a lack of education in GPs and general gynecologists can result in late referral and misdiagnosis. This can add more than [two years](#) to a diagnosis journey. While Australian data is lacking, European women with suspected endometriosis have [very low rates of GP referral](#) for diagnostic testing (12%) or to a gynecologist (44%).

## **Biases come into play**

In the diagnosis and treatment of endometriosis gender, race and socioeconomic biases come into play.

If a man reported to his general practitioner (GP) with severe pelvic pain, he would likely be sent for tests immediately. This is because there probably isn't a "normal" underlying reason for his [pain](#). But in cases of endometriosis, pelvic pain can be confused with menstrual cramps, resulting in delays for further tests.

A woman's annual salary may impact her diagnosis time too. Those who can afford private healthcare can access specialist gynecologists quickly, and can avoid the long waiting lists for diagnostic surgery.

In fact, [65% of endometriosis hospitalisations](#) in Australia are either self-funded or funded by private healthcare. But even with private healthcare, [women](#) with endometriosis pay, on average, [\\$3,670 a year in out-of-pocket expenses](#) for tests, treatments and surgeries.

Despite a having a similar disease incidence, [women of colour](#) are less likely to be diagnosed than Caucasians. In fact, [Australian Indigenous women](#) are 1.6 times less likely to be admitted to hospital for endometriosis. This may be due to difficulty accessing health care, the costs associated with treatment, and cultural differences in health-seeking behavior.

## Hope for the future

The Australian government's [National Action Plan for Endometriosis](#) outlines a roadmap to overcome many of these diagnostic hurdles.

It was developed in consultation with the [Australian Coalition for Endometriosis](#) and includes public health campaigns and educational resources for both the general public and GPs. It also supports research

into the innovation of new diagnostic tools and the development of centers of excellence for diagnosis and treatment of endometriosis. These centers will enable early access to specialized care and appropriate screening and [diagnosis](#).

The Action Plan was accompanied by the greatest investment to date in Australian endometriosis research by [Australian](#) and [international](#) funding bodies.

The current research investment (totalling A\$14.55 million) for Australian endometriosis research is only 0.2% of the annual cost of endometriosis in Australia (A\$7.4 billion). But it is an important start to transform endometriosis patient outcomes.

## **Steps to take if you think you have endometriosis**

1. Know the many and varied [symptoms of endometriosis](#). Period pain that cannot be relieved by over-the-counter anti-inflammatories such as naproxen is not normal. Nor is painful sex
2. document your menstrual cycle and symptoms—several apps are available, but a diary also works
3. ask your GP for a referral to a specialist endometriosis gynecologist
4. if a pelvic ultrasound is needed, ensure it is done by a sonographer who specializes in detecting deep infiltrating [endometriosis](#)
5. if your concerns are not addressed, seek a second (or third) opinion.

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