

## **Campaigners and scientists work towards faster diagnosis and treatment of endometriosis**

By [Melissa Brown](#)

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Endometriosis campaigners say diagnostic surgery should be prioritised to cut waiting times. *(Supplied: Pexels)*

Kimberley Gardiner spent her 20s suffering from painful periods and ovarian cysts.

She had surgery to remove her first cyst at the age of 22.

Despite the intervention and continuing pain, she said doctors missed her signs of endometriosis for another eight years.

It was then a 12-month wait for Ms Gardiner to receive a laparoscopy — a keyhole surgery commonly used to diagnose endometriosis — to confirm the diagnosis and begin treatment.

"I was waiting on the public system. I had multiple hospital admissions for pain and was prescribed [painkillers] to help me get through," she said.

"I couldn't wait any longer so went privately."

[Around 1 in 9 Australians of reproductive age develop endometriosis](#), according to the federal health department which says it can take an average of seven years to be diagnosed.

Symptoms including debilitating pain, migraines, bladder and bowel dysfunction, depression and infertility.



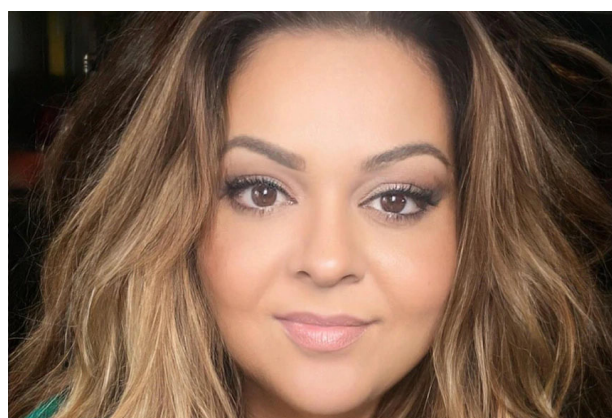
Endometriosis is a painful condition that affects up to one in nine women. (Source: *Unsplash, Yuris Alhumaydy*)

The federal government was recently told [the condition was costing the Australian economy \\$9.7 billion a year](#) in medical costs and lost productivity, prompting [more than \\$50 million dollars to be set aside in the budget](#) for treatment and research.

The Fight ENDO Foundation is preparing a campaign to highlight and address endometriosis surgery waiting lists.

Executive director and founder Maria Kyriakou said women going through the public health system for both diagnosis and treatment faced waits of between 12 months and two years — sometimes longer.

"Women with endometriosis face a dilemma: they must decide whether to go public and wait, or to go private and choose the surgeon but incur considerable out-of-pocket expenses," she said.



Marina Kyriakou says the Fight ENDO Foundation understands it is a difficult time to push for the elevation of surgery for endometriosis. (Supplied: *Marina Kyriakou*)

"Out-of-pocket surgery expenditures range from \$3,000 to \$10,000 regardless of whether patients use the public or private healthcare system."

Mrs Kyriakou said [waiting times grew substantially during the pandemic](#) due to delays in elective procedures.

The national support group, Endometriosis Australia, said it would support a campaign to diagnose and treat patients within 90 days.

"Most women or individuals affected by endometriosis will present [to a doctor] because they are having pain so, by definition, their conditions should no longer be a category-three or an elective admission, but it should actually be a category-two or a semi-urgent one," Endometriosis Australia medical director Anusch Yazdani said.

The associate professor said waiting lists varied according to the state, but, on average, between 5 and 8 per cent of all patients were waiting more than a year for intervention.

"Rural or Indigenous or First Nations Australians often have to wait much longer than other areas in order to get access not only to surgery, but in fact care in general," he said.

Internationally recognised women's reproductive health expert Caroline Gargett said delays in diagnosing endometriosis could allow the disease to progress.

"It gets worse and worse and so there's much more fibrosis and lesions growing in the pelvic cavity and there are big ovarian cysts that can occur, they just get bigger and bigger and so it's much more difficult to treat," Professor Gargett said.

"It compromises a woman's chances of getting pregnant."

## **Research could help reduce diagnosis time**

Nicole Fernley knew something was wrong from the moment her first period arrived.

She was 13 years old and suffering excruciating pain before fainting and having convulsions.



Nicole Fernley suffered agonising periods, collapses and convulsions before being diagnosed with endometriosis. *(Supplied: Nicole Fernley)*

She said doctors and a gynaecologist had fobbed her off over the years, even when she had emergency surgery for an ovarian cyst the size of a grapefruit when she was 16.

"The doctor said 'oh well, this is just all part of growing up'," Ms Fernley said.

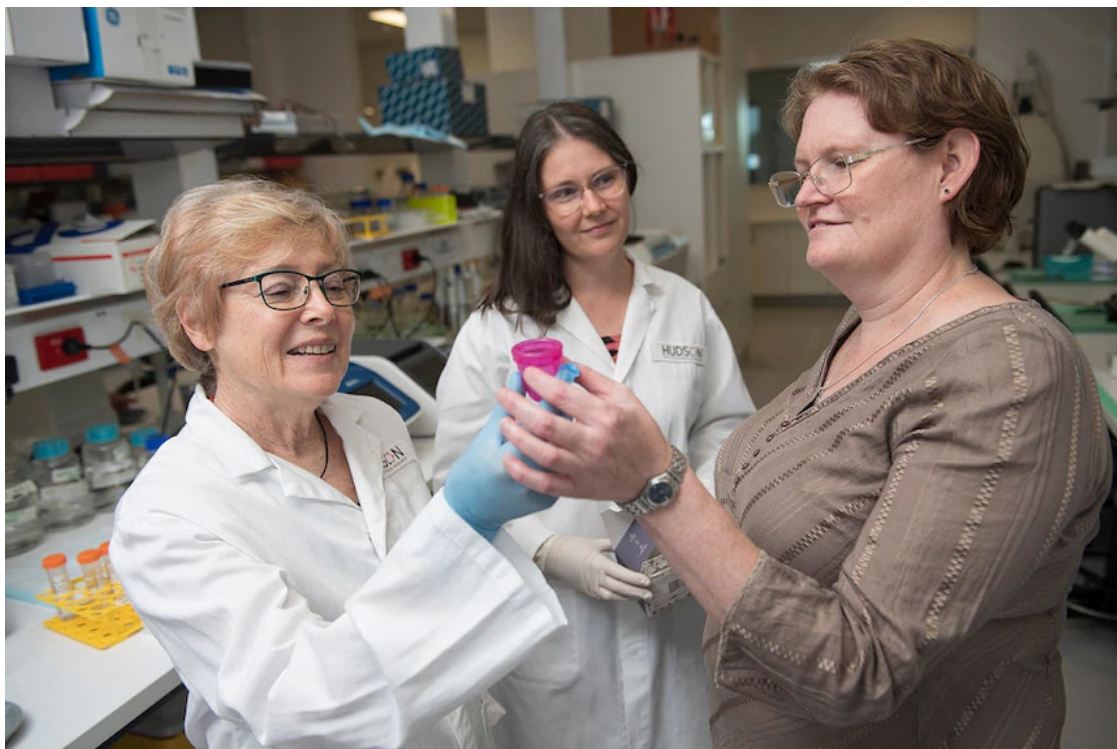
It took another 20 years of agonising pain and physical collapses, including one that resulted in a broken foot that required five operations to fix, before Ms Fernley was diagnosed with endometriosis.

"That's kind of scary when you go to a GP and you're saying 'look, something's wrong, it's not right' and you're kind of dismissed as just being a woman," she said.

**"I've had a doctor tell me it's all in my head. 'You're bringing it upon yourself' were his actual words."**

There is currently no early or non-surgical diagnostic test that detects all types of endometriosis.

But Professor Gargett and scientists at the Hudson Institute of Medical Research in Melbourne say an early stage concept trial is providing hope of slashing the time to diagnose the condition and reducing the need for invasive surgery.



Professor Caroline Gargett (left) and Nicole Fernley (right) hope a new study will allow for early intervention for endometriosis patients. *(Supplied: Hudson Institute)*

In a study [published in the journal of Reproductive Biomedicine Online](#) in 2021, the team furthered the established theory that endometriosis was caused by tissue fragments flowing back into the pelvic cavity, where cells could establish new growths of endometrial tissue.

The researchers are now looking at whether comparing endometrial tissue in a woman's menstrual fluid over several cycles can diagnose whether she has endometriosis.

"It's kind of looking quite good," Professor Gargett said.

"We're very keen to look at things associated with the endometrium itself that may actually even target not only being able to diagnose the disorder, but perhaps even detect abnormalities that may relate to the infertility aspect as well."

Professor Gargett said the concept was still in the early stages but, if subsequent trials were successful, could do away with the need for a laparoscopy to confirm the condition.

"That would be the ultimate goal because that's really the reason why it takes so long, because no-one wants to put a teenage girl in for laparoscopic surgery," she said.

Ms Fernley also hoped more research, along with the prominence of the issue in the media, would mean girls are diagnosed at 13, not 33.

"I hope in 2023 that the idea that people can be diagnosed with a common women's disorder is not a fantasy," she said.



"I do have hope, but it starts with, first of all, doctors being educated about endometriosis and our GPs understanding the symptoms and getting onto it early.

"That's really all it takes, that one doctor saying 'oh that sounds like endometriosis!'."