



The Reality Of Having Endometriosis in New Zealand

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SASHA BORISSENKO • 1 March 2023



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On the first day of Endometriosis Awareness Month WOMAN+ investigates an appalling debilitating disease that affects as many as 1 in 10 women in New Zealand. Sasha Borissenko finds there are barriers to getting a diagnosis and testing can be extreme.

Tara Forde, 34, once taped four boiling hot water bottles around her abdomen to cope with the pain. Initially, the 34-year-old thought she'd wet herself only to find that one of the water bottles had burst. The third-degree burns were no comparison to the suspected endometriosis.

Endometriosis is a chronic inflammatory disease where tissue akin to lining in the uterus can be found on the pelvic, ovaries, bowel, diaphragm, scar tissue, bellybutton, and even lungs. Research has shown that the lifetime effects on a person's work, education, and fertility can be just as destructive as cancer.

Despite two laparoscopic surgeries at 19 and 28, doctors couldn't find anything so she has never had a formal diagnosis. Doctors equally haven't ruled it out. Forde was on waiting lists for almost a decade.

Globally, delays range from seven to 12 years. In New Zealand, a recent EndoCost study found patients experienced 8.7 years of delays.

Exploratory key-hole surgery has traditionally been one of the only ways to get a formal diagnosis. If endometrial tissue outside of the endometrium is found on other parts of organs they can be cut out or burnt off.

The results of the surgeries were a relief at first for Forde, but nothing has been able to explain the pain that's continued into her adult life. "I had about seven hospital admissions and I'd be screaming to the point where they'd have to sedate me. Because there's no testing, you start to think that you're crazy and it's all in your head."

UK research suggests 60% of people who have surgery will go on to have another. Half of those will have surgery within five years.

The ‘walking womb’ effect

Doctors have regularly told Forde to have a baby for pain relief. “Choosing to have a baby is a pretty life altering decision. You should want to have a baby not just to alleviate your period pain but because you’re in a good position to do so.” Eventually, she gave birth to her son and she’s got another child on the way.

“Having a child has relieved some of the pain so maybe they were right, but I also resented the suggestion,” she says.

One of the problems is that endometriosis is seen as a fertility or women’s issue, she says.

“It feels like no one really understands what’s going on and there’s no one to really help you navigate it. The lack of research and wraparound support seems like it’s just another way of controlling women’s bodies.”

The gender pain gap thanks to Endometriosis

Endometriosis is an enigma and there’s lots of things the scientific community still doesn’t understand, he says.

It stems from misogyny in medical research. “The majority of research has been done by men on men, particularly around pain. It’s why we don’t know a lot about women’s bodies. It’s historical, but it’s changing slowly,” he says.

Coined ‘the gender pain gap’, studies show men wait an average of 49 minutes before receiving pain medication in instances of acute abdominal pain. Women wait an average of 65 minutes, for example.

While there are increasingly strong theories around genetics, immunological and environmental factors abroad, there’s virtually no New Zealand based research or funding for research, Wynn-Williams says.

“We need to know about our own population, particularly in terms of equity and accessing services. We also need long-term data where we look into lots of patients – collect their data and histories, and what happens to them long term.

“When patients come to us we’re essentially the ambulance at the bottom of the cliff. Investing in research would eradicate this issue.”

Forde’s found solace in wraparound services including going to a pelvic physio, nutritionist, counselling for pain management, exercise services, and fertility specialists. They should be available and embraced to all endometriosis sufferers because “there’s nothing to lose by doing all of the things to take care of yourself”.

Equally, the costs are a barrier, she says. The public health system may be free but the waiting times and referrals are tedious, and there are costs associated with going to multiple GPs, childcare, ambulance fees, taking time off, travelling to appointments, and annual leave when you’ve surpassed your sick day entitlements.

“I feel it’s too easy for people to fall through the cracks. You’re either engaging with the hospital system or waiting for specialists that are impossible to access. Then there still aren’t any answers. You just kind of get kicked around until it resolves itself, you keep trying, or you give up and spend your life on opioids.”

Some bare facts of Endometriosis

According to a recent Endometriosis NZ study:

- Respondents required 5 visits to the doctor before receiving a diagnosis.
- 67% of respondents said their pelvic pain symptoms caused significant problems with their partner.
- 81% of respondents avoided sex because of chronic pelvic pain.
- 32% of respondents said their pelvic pain symptoms prevented them from attending work and carrying out basic life tasks in the last 3 months.
- 73% of respondents were scared to tell their employer about their pelvic pain because of fear it might affect their prospects.