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**IT'S A CONDITION PUTTING
PRESSURE ON WOMEN WORLDWIDE,
AFFECTING THEIR MENTAL HEALTH,
THEIR CAREERS, THEIR FERTILITY.
AND MANY DON'T EVEN KNOW
THEY HAVE IT. BUT WITH A NEW
SPOTLIGHT ON ENDOMETRIOSIS,
IS THAT ALL ABOUT TO CHANGE?**

By Alex Davies



WORD

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Thessy Kouzoukas' breaking point came one day at work, when the agony that felt like month-long period pain became too much. "I'd lie on the floor holding a heat pack, asking colleagues to bring me painkillers," says the 28-year-old co-founder of fashion brand Sabo Skirt. "Most days I could only work until 1pm, and once I remember one of the girls saying to me, 'Do you think it might be in your head?' It was starting to look bad that I couldn't do a full day of work. I needed to get checked out." After convincing her GP that it felt like more than "just her period", Thessy was referred to an expert gynaecologist. A scan and laparoscopy later, she had a diagnosis: stage IV endometriosis, the most severe kind.

One in 10 women live with this chronic condition you may not have even heard of – although experts suspect the actual number is higher. The problem? Lack of understanding and awareness about endometriosis has left many people undiagnosed, suffering in silence or not getting the help they need.

But the tide is turning. The likes of Lena Dunham, Daisy Ridley and Olympian Emily Seebohm (see over page) have brought endo into the global spotlight by sharing their stories. Then, in December 2017, a watershed moment happened on our shores. After hearing from a coalition of researchers, patients and groups including EndoActive and Endometriosis Australia, health minister Greg Hunt formally apologised to women with endometriosis for not helping sooner. He announced the government would create Oz's first national action plan, with more research funding, education and an awareness campaign. So, are we seeing the start of a new era for women with endometriosis?

UNDER THE MICROSCOPE

Let's backtrack for a science lesson. Endometriosis occurs when tissue similar to the lining of your uterus is found *outside* of the uterus, in places such as the abdomen and pelvis. It can affect teenage girls as well as women, and is complex – experts aren't entirely sure what causes it, although a major theory is related to a little something called "retrograde menstruation".

"When you have a period and the blood comes out through your vagina, it can also flow *backwards* along the tubes, and then slip down behind the uterus into the pelvis," explains Dr Elizabeth Farrell, medical director at Jean Hailes. "In the majority of people, these cells will all get mopped up by the normal mechanisms and there won't be any issue, but in women who have endometriosis, there is some difference in their endometrial cells – they don't function in the same way. They have a capacity to stick onto the inner lining of the abdomen and pelvis, and then something triggers mechanisms in the body to keep these cells functioning [and growing]."

A factor that makes endo trickier than a *Game of Thrones* character: it doesn't present the same way in everybody. "During a laparoscopy – the only way we can properly diagnose [endometriosis] – we might see black or pink spots, clear blisters, scarring, or perhaps it's thick, like a hard ball," says Farrell.

While cause is still a slightly grey area, risk factors seem to include family history and getting your first period at a young age. As for symptoms? They range from pain (around periods or more often; during sex; while going to the bathroom), bleeding and bowel problems to bloating and fatigue. Sometimes

there are zero symptoms (told you it was complicated), with about a third of cases discovered during an unrelated operation or because a woman is having trouble getting pregnant. In a cruel twist, endometriosis can impact fertility, sometimes because of damage caused by the tissue.

Then there are the potential repercussions: anxiety and depression because of chronic pain, and relationship issues if sex is painful, as well as missed days of school, uni or work. A University of Oxford study found the condition reduced job productivity and impacted areas from childcare to exercise, while women with endo told Monash University researchers they'd love to see more flexibility in their careers, such as the option to

work around medical appointments.

"Endometriosis causes hell for so many women," according to Sylvia Freedman, who co-founded EndoActive and was diagnosed herself at 21 years old. "Many of them feel that they're not believed, sometimes by family but also health professionals, because people don't necessarily understand the level of pain they're in and all the connected symptoms. It's a tough, isolating and confusing disease to have."

UNEXPECTED OBSTACLES

Frustrating fact: Thessy's story about having to convince her GP to take her symptoms seriously isn't unusual. "[Endometriosis] has been under-recognised [in the medical space]," says Dr Robert Markham, senior lecturer

in obstetrics and gynaecology at The University of Sydney. "In this country, the time it takes to be diagnosed is around seven years, which is a long, long time. If women are diagnosed earlier, then treatment can start earlier and diminish the effects of the disease."

Diagnosis hold-ups can come when things like pain, bloating and fatigue are dismissed as a normal part of life by health professionals or women themselves. "If you're taking time off from school, work and your life every month because of pain and your periods, that's not normal," says Professor Jason Abbott, medical director of Endometriosis Australia. "There are fantastic GPs

ONE IN 10

THE NUMBER OF WOMEN LIVING WITH
ENDOMETRIOSIS, ACCORDING TO
ENDOMETRIOSIS AUSTRALIA. THAT'S
176 MILLION WORLDWIDE

SUSS SYMPTOMS

What's worth flagging with your doc? Good question! Professor Jason Abbott of Endometriosis Australia breaks it down

PAIN STOPS YOU IN YOUR TRACKS

"Most women get some uncomfortable periods. But, if you can't go to school or work and actually need to take time off your usual activities, then get checked out."

IT'S NOT JUST WITH YOUR PERIOD

"Symptoms include pain at other times of the menstrual cycle, as well as pain with intercourse or even when you go to the bathroom, plus lower back and thigh pain."

THERE'S A PATTERN

"There tends to be a more cyclic pattern with back pain that's due to endometriosis. It's the rise and fall in hormones that can be responsible for the symptoms – it ups the inflammatory response in those abnormal tissues."

YOU HAVE A COMBO

"Fatigue often comes with chronic pain, so if it's ongoing and in conjunction with other symptoms, it's important to find the cause. There's no one symptom that is absolutely classic for endometriosis, so it's the combination we need to try to [spot]."

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THIS PERCENTAGE OF AUSSIES HAS NEVER HEARD OF ENDOMETRIOSIS, REVEALS A YOUGOV GALAXY SURVEY

who do amazing jobs, but there are also GPs who don't know a lot about [endometriosis]. They've got a big burden - they've got to understand so much about all of these diseases - and that's where that awareness and education component would come into the national action plan, to help make GPs more aware."

Suspect something's up but getting nowhere with your doc? Get another opinion. See a GP with a specific interest in female health or ask for a referral to a gynaecologist.

TAKING CHARGE

There's currently no cure for endometriosis, but approaches to symptom management fall under three categories. There's medical, such as painkillers, as well as forms of hormones to control the menstrual cycle, like the contraceptive pill or other types of progestogen. Then you have complementary therapies ranging from acupuncture to seeing a psychologist. There are also surgical routes. Usually this means an op to remove the disease (though it can come back), and it can include - in severe and carefully assessed cases - a hysterectomy. "I start with conservative treatments wherever possible," says Abbott. "We work with a woman depending on what she wants and how she's dealing

with a variety of treatments."

Thessy and Sylvia both agree self-management is key when you're living with endo. "It's really important to have your health team, but [also] think about what aspects of your lifestyle make you feel better or worse," says Sylvia. "Take care of your body and get enough sleep. You [often] experience more pain if you're very tired." Use a diary to track things such as alcohol intake, food, fatigue and mood, she suggests, to help you suss out any patterns and triggers over time.

Thessy, who shares #endowarrior videos and posts with her 141k Insta fans, adds, "I think it's really important to not let endo control your life. Take exercise for example: don't *not* do it because you're in pain, but maybe scale it back. Try not to sit and dwell on the disease. Do things to get your mind off it."

THE NEXT CHAPTER

As Sylvia and the rest of the coalition meet with politicians to get the action plan moving, three

priorities top her wish list: increasing awareness, so women know what sets endo symptoms apart; changes to clinical guidelines so docs are better informed and able to help; plus more money for research.

That third one is on scientists' wish lists, too. Their mission? To develop a simpler, less-invasive diagnostic tool so endometriosis is caught sooner. Researchers at The University of Sydney are looking at protein biomarkers in the urine of women with endo, with the hope these can eventually be screened for. "It's a long way off, but in an ideal world, we'd like to see dipsticks [for testing urine] on every GP's desk, and every woman who comes in there is tested," says Markham.

Meanwhile, a team at The Royal Women's Hospital in Melbourne is on the hunt for genetic mutations that impact our risk of endo. Associate Professor Martin Healey, head of the endometriosis clinic there, explains, "The long game is once you've found that [genetic] pathway, can you then develop treatment that can modify that pathway to either stop endometriosis developing or improve the symptoms?"

There's real hope the government spotlight on endo will be a game-changer, but advocates know they need to keep the momentum going. "This is the first time I've heard the government talking about endometriosis," says Healey. "This is an opportunity and we've got to absolutely make the most of it."

Thessy's excited about her own future, too. After having her fallopian tubes removed in late-2017 because of endo-induced damage, she and fiancé Georgio began IVF. She became pregnant on her second round, and the couple is expecting their first baby in September. "IVF had its ups and downs, but I'm so glad we decided to stick with it. I've never wanted anything more than to be a mum," Thessy says. The main thing she wants us to do? "Listen to your body and stay on top of health issues." Your future self may thank you. **WH Want more? Find other stories at womenshealth.com.au/endo**



"I BLAMED SYMPTOMS ON TRAINING"

Olympic swimmer Emily Seebohm became an Endometriosis Australia ambassador after she was diagnosed in 2016

PRE-DIAGNOSIS, I'D PUT MY SYMPTOMS DOWN TO TRAINING.

I had a lot of pain, fatigue, cramping and really bad back pain. Most days I'd go home after training and just lie in bed because I was so tired. It wasn't until it got pretty bad that I started telling people, which got me thinking I should see someone.

I THOUGHT SURGERY WAS A MAGIC CURE.

I felt better for a while [after a 2016 procedure

to diagnose and remove the endo], but then it started growing again. Now when I'm not feeling good, I drop some training outside the pool - I try not to change my training in the water. I have to be understanding of the fact there's a lot going on in my body. I use an app to track my cycle, so I can plan around it.

ENDOMETRIOSIS WASN'T ON MY RADAR BEFORE.

It wasn't until a

gynaecologist said I could have it that I started researching [endo]. I want girls to be educated and feel free to talk about their cycles with their mums, friends, whoever. I think a lot more people would be diagnosed if we opened up [more].

THE FUTURE'S BRIGHT.

Swimming and life after swimming make me excited. It could be a struggle to start a family, but I'm totally willing to give it a shot.