

The health check THAT changed MY LIFE

It strikes one in 10 women and can cause debilitating pain and infertility. **Rebecca Wallwork** reports on her ongoing battle with endometriosis and the medical leaps providing hope to sufferers



Endometriosis left Rebecca Wallwork exhausted, irritable and in pain. After laparoscopic surgery, she had a new lease on life.

The photos from my 28th birthday do not lie. My boyfriend and I had come to Miami from New York for the weekend, but all I could think about was the vice squeezing my lower abdomen. The pressure was constant, the pain piercing. It felt like thick elastic bands were cutting me. My back ached. I'd left my heels back at the hotel because they only made each step more excruciating. At dinner, I tried to enjoy my steak and red wine, but really I was counting the minutes before I could get back to our room, pop a painkiller and go to sleep. So much for a sexy getaway.

I'd been in pain for over a year and had no idea what was wrong. It was beyond cramps – the pain never let up, no matter what time of the month it was – and it was robbing everything I had. My social life, ambition, energy – all gone. Just 18 months earlier I had been a strong, successful woman. But now I was fatigued, cranky and frustrated. Although I didn't know it yet, the culprit was something I'd already had to deal with and thought was long behind me. The cause of all this misery was endometriosis.

Endometriosis affects millions of women around the world (an estimated 1 in 10 women of reproductive age), yet it is still greatly misunderstood. Researchers at Melbourne's Prince Henry's Institute say it can take eight to 11 years for an accurate diagnosis. In my case, it took two long years of dead-end doctor appointments – and I'd already had a run-in with endometriosis. When I was 24, I had a cyst removed from my ovary, and during the laparoscopic (keyhole) surgery, the doctor found endometriosis, which she assured me she had removed. No one seemed to think it could come back as soon as six months later. Now I know better. Endometriosis is nasty and insidious, and if it gets you, it colours everything you do. I've since had two more surgeries to remove endometriosis.

Some women are genetically predisposed to it, the doctors tell me. They don't know why.

Dr Thierry Vancaillie, an associate professor at the University of NSW, treats more than 300 women with pelvic pain a year. "Endometriosis involves normal tissue and organs," he says. The tissue in question is the endometrium (the lining) of the uterus, which instead of being flushed out with menstrual blood, spreads and settles in other areas in the pelvis. Once it implants itself – on the ovaries, uterus, bladder, abdominal wall, or in the rectum – those lesions bleed every time you have a period. "The condition is erratic," says Dr

10%

of women of reproductive age have endometriosis. Some studies put the figure as high as 25%*

Vancaillie, who has had some success using Botox to help relax pelvic floor muscles in his patients. "It can cause pain one day and none the next." Also, not every woman with endometriosis has pain or other symptoms. Maybe that's why certain people who had experience with endo would tell me, "Oh, it's not such a big deal."

IS THAT ALL?

With a disease like cancer there is a public understanding of what that person may be going through. With endometriosis, it's invisible and rarely spoken about, and you can be thrown to the ground by it but no one really understands. "Our society has great difficulty in accepting that chronic

pain does exist," says Dr Vancaillie. Even among health professionals, he admits. "It is not infrequent to hear comments in the operating room during surgery for endometriosis, like, 'Is that all?'"

In an effort to find out what was wrong with me, I saw 11 doctors and was told I might have everything from irritable bowel syndrome to colon and cervical cancers. It wasn't until the twelfth doctor that endometriosis was seriously considered as the cause of my pain. It was also the first time I heard the words "interstitial cystitis". The doctor suspected I had both conditions [see "Endometriosis 101"].

I was relieved to finally have an answer. With no energy, work had become torture. In pain, or groggy from painkillers, all I could manage was travelling from the office to bed and back again. Being sick took away my confidence and strength. Meanwhile, I was being poked and prodded by doctor after doctor. Exercise hurt, sex hurt, walking hurt. Pain was the elephant that never left the room.

SCALPEL, PLEASE

Endometriosis doesn't show up on an ultrasound. The only way to tell if you have it is to have surgery. But a true specialist, one who takes a thorough medical history and does a good physical exam, can tell you if there's a high probability of endometriosis. Both doctors who treated me in the US, where I now live, were able to do this, which meant I didn't have to risk having unnecessary surgery.

When I first met my current doctor, Iris Orbuch, in her New York office, she looked at my file, asked me lots of questions, and then said, "Endometriosis is my passion." Dr Orbuch is one of a small number of gynaecologists who, as a rule, excise endometriosis, rather than burn or cauterise it. Burning it carries the risk of missing some microscopic endometriosis tissue and leaving it →

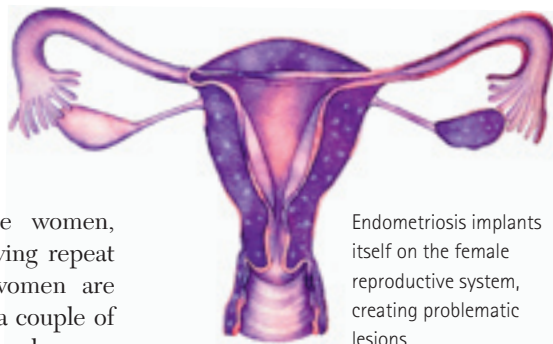
behind, leading to more pain. "If you're excising endo, it doesn't come back in the same place," she explains. "However, it can develop in other areas." That's why some women, including me, end up having repeat surgeries. While some women are back on their feet within a couple of days, my recovery was slow because of the extent of the endometriosis. But a few weeks later, I was my old self. "Look at you, you're smiling!" Dr Orbuch exclaimed at my post-op follow-up. The relief was enormous.

Not all women opt for surgery. Many doctors treat endometriosis pain medically – with continuous birth control pills and drugs known as GnRH agonists. They work by shutting the ovaries down, but the side effects can be severe. Hot flashes, night sweats, vaginal dryness, weight gain and steep mood swings – pseudomenopause, essentially – were enough to put me off that idea. Besides, if you want to get pregnant, you have to stop the medical treatment.

Fertility has not been a huge concern for me – yet. All I wanted was to stop hurting. Once upon a time, GPs would misguidedly tell women to get pregnant to cure their endometriosis. "Your pain is better when you're pregnant because you're not having that hormonal stimulation of the tissue," says Dr Orbuch. "But the endo will still be there."

Another myth that still persists is that a hysterectomy will cure endometriosis. "A lot of doctors who don't specialise in endometriosis will take the uterus out, but [mistakenly] leave the endometriosis behind," says Dr Orbuch. "And if the women still have their ovaries, they're still going to have hormonal stimulation of those endo implants, and they're still going to have pain. It's terrible, but it happens all the time."

Lots of women have surgery for endometriosis to improve fertility.



50%

of women who have surgery to excise endometriosis will have a recurrence within five years*

Even though babies were far from my mind, I felt relief when Dr Orbuch told me I would still be able to have children after my last surgery. I sure didn't want endometriosis robbing me of the *choice* to have children.

Not too long ago, about nine months after my last surgery, I started to feel those familiar twinges of pelvic pain. My back ached and some days I struggled to get out of bed. During the physical exam, I was in tears. "I'm pretty sure you have endo again," Dr Orbuch said, and my heart sank.

For now, we're holding off on surgery and trying to manage the interstitial cystitis. I expect to be back in the operating room at some point, but I know I will be in good hands.

When I asked why she decided to specialise in endometriosis, she told me, "You can make a difference for people. You see people suffering and then you can help them."

Follow Rebecca's endometriosis blog at madisonmag.com.au.

endometriosis 101

✿ The most common symptom of endometriosis is pain, often described as burning, cramping, throbbing, stabbing or pressure. Symptoms can also include painful sexual intercourse, painful bowel movements, constipation, diarrhoea, urinary frequency, heavy periods, premenstrual spotting, fatigue and depression.

✿ Researchers at Prince Henry's Institute and Monash IVF are developing a groundbreaking clinical test that will detect endometriosis without surgery. The researchers analysed uterine cells from more than 200 women, isolating different "protein fingerprints" in the women suffering from endometriosis. The test would be similar to a pap smear, performed in the doctor's office without anesthetic. Comparing samples to existing "protein fingerprints" could help doctors identify endometriosis in their patients.

✿ Some women with endometriosis also suffer from a painful bladder and increased urinary frequency. Often dismissed as a urinary tract infection, these symptoms may in fact be evidence of interstitial cystitis (IC), a chronic inflammation of the bladder. IC is treated with medicine and diet (many foods irritate the lining of the bladder). Symptoms of both conditions overlap considerably, but IC is still under-diagnosed. If IC is strongly suspected, endometriosis experts recommend working in tandem with urologists, who perform a cystoscopy during laparoscopic surgery, to determine if IC is present. See ic-network.com for more information.

✿ Check out *100 Questions & Answers About Endometriosis*, by American expert Dr David B Redwine. Or find a specialist through the Endometriosis Care Centre of Australia at ecca.com.au. **m**