

MOVING THE NEEDLE

*One in 10 women suffer from endometriosis, a chronic,
often debilitating affliction of unknown cause.*

Could Botox be the solution to their agony?

By Alexandra English

EARLIER this year, attention-grabbing headlines beamed around the world: “A World-First Study Found Botox Can Help Treat Endometriosis”; “Endo the Line: Hope for Millions with Endometriosis as Botox is Found to Ease Agony”; and the clickbait-y “I Got Botox Injected into My Vagina”. Along with the headlines came some radical claims about a study that has shown “the first time Botox has been used to treat endometriosis”, and references to it being a “novel treatment”. Could the same muscle-freezing compound we use to deny ageing really treat such a painful disease?

Endometriosis is a condition in which lesions or clusters of cells similar to the lining cells of the uterus (endometrium) grow in other parts of the body. “When your body recognises the cells shouldn’t be there, it sets up an inflammatory response,” explains Dr Erin Nesbitt-Hawes, a gynaecologist and obstetrician at Sydney’s Royal Hospital for Women. “The cells are very responsive to the hormonal ups and downs of the period cycle, and so a lot of women will get pain around the time of their period, but, equally, a lot of women get pain outside of their period.” The cells are usually found under the ovaries or behind the uterus, but there have also been reports of them implanting themselves on the bladder, the diaphragm and even in brain tissue.

So what’s the deal with Botox, aka botulinum toxin? “It is definitely not a cure,” Dr Nesbitt-Hawes says. “It’s a helpful extra treatment for one of the side effects of the condition, but, unfortunately, it’s not going to do anything to the endometriosis itself.” In fact, the study, conducted by the US’s National Institutes of Health, never predicted Botox would have any effect on endometriosis. “Some women with endometriosis have chronic pelvic pain,” it reads. “This pain may be caused by spasms of the pelvic floor muscles. ... Researchers want to see if botulinum toxin injections into the pelvic floor muscles can decrease pain and spasms.”

“When all the stories in the media came out recently about Botox being a novel treatment, we were sort of like, ‘Hmm. That’s not novel, it’s actually well used,’” Dr Nesbitt-Hawes says. Australia has been at the forefront of endometriosis research, particularly at The Royal, where a pilot study into the botulinum toxin treatment was conducted in the early 2000s. It is currently the only dedicated women’s hospital in New South Wales that provides specialised endometriosis treatment, and has been providing botulinum toxin since a randomised control trial in 2006 showed it could be effective in reducing endo-associated pelvic floor pain.

The thing to note about Botox is it is only recommended for women who have exhausted all other treatment options. “We work on the different components of pain,” Dr Nesbitt-Hawes explains. “We can use hormone suppression — like the pill or the hormonal IUD — to try to make the lesions less active and therefore less inflammatory. We can also do surgical interventions to remove the lesions, but for about a third of women, endometriosis can recur and they eventually need more treatment.” There are other, less intrusive, pain management mechanisms that some women find helpful. “Some women respond well to dietary changes and exercise; meditation and mindfulness can help women get into a better headspace to be able to deal with their symptoms,” Dr Nesbitt-Hawes says.

Jessica* is a nurse who experienced chronic and debilitating pelvic floor pain years after having a hysterectomy to eliminate her endometriosis. Her journey for diagnosis began when she was 26,

and now at 46, she lives relatively pain free thanks to Botox. “My periods weren’t very regular and they were extremely heavy and extremely painful, but that was all put in the [same] bag as polycystic ovary syndrome [PCOS], which a lot of women have hand-in-hand with endo,” she says. “It was only when my doctor went to do [a different procedure] that he saw I had grade three or four endometriosis.” Jessica was further diagnosed with adenomyosis (whereby the lesions embed themselves into the uterine wall) and had a hysterectomy when she was 32. Ten years later, the pain came back and she began the gruelling task of pelvic floor physio. “I had physio every week for a year, where we’d have to try to manually dilate my vagina, which was horrendous and horrific and all the things you can imagine,” she says. “But it was the emotional pain as well, because I had to prepare myself. If you’re going for ankle physio, you can tell people at work what you’re doing, but being like, ‘I’ve just gotta go get my vagina stretched’ ... we’re not there yet,” she says with a laugh.

“I felt like we were doing a lot and not getting very far, so that’s when the physio suggested the Botox treatment. The relief of knowing I could go in for a general anaesthetic, be asleep, have them do whatever they needed to do and wake up potentially pain free was such a gift,” Jessica says. “When I woke up, I had no back pain. It was incredible. It was absolutely life changing.”

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“The thing with botulinum toxin is it’s not a long-acting treatment,” Dr Nesbitt-Hawes explains. Jessica’s Botox window is 18 months to two years. “I’ve had three lots of Botox, and each time it costs me up to \$4000 because it’s not covered by Medicare,” she says. “It’s an extremely expensive ‘cosmetic’ procedure, but I wouldn’t not do it. It’s given me not only my physical life back, but also my emotional and sexual life back.”

Aside from the personal fiscal and emotional expense, another problem with endometriosis remains diagnosis. “As a health professional, a woman and a feminist, I was a bit cranky with myself that I didn’t know the prevalence and impact of endo,” Jessica laments. Syl Freedman, co-founder of EndoActive, a health promotion charity that raises awareness of the condition, says a lack of information at her end is what caused the delay in her diagnosis. “I had excruciating periods from day one, and my mum was just one of many women who said periods are meant to be painful. Then I started to get fatigue, chronic sinusitis, chronic pelvic pain, back pain, migraines and chronic UTIs. I had never heard the word ‘endometriosis’ when I was diagnosed — I just always thought my pill was a bit dodgy.”

At the moment, the only way to get an official diagnosis is through laparoscopy, and even reaching that point takes, on average, seven to 10 years, according to Dr Nesbitt-Hawes (although she is confident this is improving with increased awareness on both sides). Thanks in part to initiatives such as EndoActive; Instagram accounts such as @endogram, which is run by Triple J’s *Good Nights* host and Endometriosis Australia ambassador Bridget Hustwaite; plus vocal celebrities including Lena Dunham, women can at least have their health taken more seriously. “Previously, endometriosis wasn’t as well recognised by the medical community,” Dr Nesbitt-Hawes says, “but I think the fact that there has been quite a lot of media [focus] makes for a situation where women are more empowered to push for a more specialised view. That is definitely a good step for women.” ■

*For more information and treatment options, visit thewomens.org.au/health-information/periods/endometriosis. *Name has been changed.*