

## The Vagina Dialogues

*One of the last medical frontiers - women's genital health - is finally getting specialist attention, writes Bettina Arndt.*

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IT IS 19 years since Jennifer has been able to have sex with her loving husband. The couple from regional Victoria are now in their late 50s. Until 1994, they had a very active sex life. Then, suddenly, sex left Jennifer (who doesn't want her surname used) feeling as though her vagina was on fire.

"I felt the most unbelievable heat, as if I had a red-hot poker inside me, and this burning sensation persisted for over two years, 24 hours a day," she said. The only relief came from sitting for hours in cold salt baths.

The pain lasted for two years and then disappeared, but has recurred twice since for periods of up to six months. Even when the burning sensation went away, attempting intercourse proved too painful, with the vagina being unbearably sensitive to touch.

Before she contacted me for help nearly two years ago, Jennifer had searched everywhere for answers, seeing innumerable doctors and alternative health practitioners. She was advised that her complaint was attributable to any number of skin issues, hormones, immune problems and nerve problems, with many doctors suggesting it was all in her head. "You must be promiscuous as this is a prostitute's disease," one specialist told her. Another suggested her husband should find a new woman.

There are huge numbers of women like Jennifer, searching the country for help with "things that go wrong down there". That's the phrase women sometimes use to refer to problems in the vagina and vulva (the external genitals) which cause so many of them extreme pain and embarrassment.

Now, finally, the medical profession is waking up to their plight. Vulva clinics are opening up across the country, staffed by specialists - gynaecologists, dermatologists, physiotherapists - who are newly branded "vulvo-vaginal" experts trying to solve the mysteries that cause so many women such misery.

One such expert is Deborah Coady, a New York gynaecology professor, who estimates that up to one in five women struggle with painful sex at some point in their lives.

Boston gynaecologists Bernard Harlow and Elizabeth Steward surveyed nearly 5000 women and found that 16 per cent had experienced chronic burning or pain in the vulva that lasted at least three months.

In the past five to 10 years, there's been an exponential increase in knowledge about vulval and vaginal pain - both causes and treatment - but most doctors aren't up to speed with the new developments. It turns out many problems are mighty complex, requiring the co-operation of various medical specialists to sort them out.

For example: most women will have experience with thrush, the irritating yeast infection that causes itching and vaginal discharge. If it isn't properly treated or the woman has recurrent infections, it sometimes leads to inflamed nerve endings and pain at the opening of the vagina. This, in turn, can cause spasms of pelvic floor muscles, and even compression of the pudendal nerve, the main pathway linking the vulva, the pelvic muscles and organs. The result can be severe, chronic pain.

Adelaide pelvic pain specialist Dr Susan Evans explains: "Chronic pain in the vulva or vagina can be the driver that leads to physical and chemical changes in the nervous pathways, making the pain even worse. This can mean the pain continues even when the original cause of the pain has been treated. Pain persists because the nerves have 'learnt' to transmit pain signals."

Evans is one of only two gynaecologists in Australia who is also a pain specialist. The other is University of NSW gynaecology professor Thierry Vancaillie, who runs the Women's Health and Research Institute, which deals with many complex vulvo-vaginal issues. Their clinic sees more than 300 women a year with undiagnosed pelvic pain; some of whom, like Perth woman Vanessa Watson, travel across the country for the unique treatments on offer. These treatments include surgery on pelvic nerves or botox injections for painful spasms or tension in pelvic floor muscles, the muscles which support the structures in the pelvis.

A host of factors can cause pain in pelvic muscles, including congenital high muscle tension, orthopaedic issues like hip dysplasia, childbirth-induced injuries to the pelvic floor, repetitive strain from sports such as cycling or skiing, painful bladder problems and tensing in response to sexual pain. Deborah Coady's excellent new book, *Healing Painful Sex* (co-authored by Nancy Fish), points out that research on many of these areas is very recent, which is why it is such a struggle for women to find proper help.

Vancaillie's team includes a physiotherapist who teaches women to relax these muscles, and an acupuncturist - "this works well for women recovering from birth injuries," he says.

Many women with sexual pain spend years trying to find out what's wrong with them; the women attending Vancaillie's clinic have averaged four to eight years before being properly diagnosed.

Jenny Towell's story is typical. The 67-year-old Lakes Entrance woman visited her local GP over a two-year period complaining about her painful vulva which, she says, "never felt quite right" following her hysterectomy. "It was constantly itchy, dry and sensitive." In response, her doctor did not examine her but simply suggested she use treatments, such as ointments, for thrush. It was a female locum who finally conducted a proper examination and immediately picked that Jenny had lichen sclerosus, a serious skin condition which, left untreated, can cause painful scarring that totally covers the clitoris and other organs.

"I was horrified when I realised where this could end up if left unattended," says Towell, who is slowly recovering using steroid ointments.

Vancaillie points out that very few gynaecologists, let alone GPs, have a good knowledge of sexual anatomy. "If you asked a gynaecologist about which nerves stimulate the various structures in the pelvis, most would have great difficulty telling you," he says.

Take the clitoris. It's only in recent years that the true complexity of this most sensitive of genital organs, and problems associated with it, have been revealed. We now know that a chemical imbalance in the brain marked by high dopamine levels accounts for the distressing problem known as persistent genital arousal disorder (PGAD), in which a woman feels perpetually aroused.

There are other issues causing trouble with the clitoris, as Sydney woman "Jane" discovered when she was a 29-year-old newly-wed. Out of the blue she started feeling exquisite, unrelenting pain around the clitoris. "It felt as if someone was slicing the tip of the clitoris with a razor blade. It never stopped, I couldn't wear underwear, couldn't wash or wipe myself, just couldn't function."

Jane (who doesn't want her identity revealed) sought help from doctors. She had acupuncture and took Chinese herbs before finally she turned up at her parents' home and announced that she'd kill herself unless someone helped her.

She ended up in the hands of a bevy of experts at one of Sydney's major hospitals who tried various remedies, some of which made the problem worse, until finally it was discovered she had a collapsing disc that put pressure on the base of the pudendal nerve connecting to the clitoris. She used Pilates to realign her back, and by following a strict diet, reducing stress and using meditation she controlled the chronic pain.

Such obscure problems are fortunately rare in comparison to the more common causes of pelvic pain such as endometriosis, chronic thrush infection, bladder pain syndrome, damage through labour, pelvic muscle spasm and cancer.

Evans also deals with a steady stream of young women whose pelvic pain stems back to early problems with painful periods. Those problems led to a sensitised pelvic nervous system. Here, too, proper treatment may require experts from different specialties to work together.

"The vulva is the frontier where the specialties meet," said Ross Pagano, a Melbourne gynaecologist speaking at the Australian and New Zealand Vulvovaginal Society, which is a new professional body.

Sadly, it's taken many years to get these professionals together and persuade them to take seriously the problems suffered by women in their nether regions.

Tanja Bohl, a Victorian dermatologist and vulva specialist, suggests this is now happening because women, often educated through the internet, are now demanding answers. "They are no longer prepared to be fobbed off and so we have had to raise our game," she says, mentioning the pivotal role played by women's support groups in galvanising the professions to take action.

In many countries, including Australia, there are now support groups with excellent websites covering many vulvo-vaginal problems (you can find them on my website - [bettinaarndt.com.au](http://bettinaarndt.com.au)).

Here, the major push has come from the indefatigable Kath Mazzella, who runs the Perth-based Gynaecological Awareness Information Network, which promotes these issues. She's planning awareness days across the country this year under a stirring banner: Viva la Vulva!

### **Vanessa Watson's story**

IMAGINE vulval pain so excruciating that you end up spending almost six months lying on your back with no knickers and your legs in the air.

Seven years ago, Perth mother of twins Vanessa Watson found herself doing just that to avoid the broken-glass sensation she felt when anything touched her external genitals. She had years of not even being able to sit down due to overwhelming burning pain in the genitals, bowel and bladder, and was bedridden for a year.

"I couldn't sit, couldn't have sex. I had rectal spasms that felt like hot poker and needed ice packs to cope with my constant pain in the vulva."

Watson is a gynaecological nurse and for years did the rounds of the Perth medical establishment trying to find out what was going on.

Googling her symptoms, she stumbled on the answer herself – pudendal nerve entrapment – but it took a year before she managed to convince her doctors to give her the test that proved it.

In the meantime, she had temporary relief from botox injections into the wall of her vagina. “That relieved the spasm in my pelvic muscles and gave me a few months of relief.”

The real breakthrough came when she went to a meeting run by the Gynaecological Awareness Information Network. “I heard women describing my symptoms and my life!”

There she met Professor Thierry Vancaillie, her condition was properly identified and she went to Sydney for nerve decompression surgery.

Now, four years later, she is enjoying long pain-free periods and even occasional sex with her husband Brad, who continues to shoulder much of the family responsibility. But the legacy of her condition is chronic pain syndrome, with her over sensitised nerves leading to pain all over her body.

Watson had to give up her nursing career but at least she can make it to the first few races of her children’s sports carnival before collapsing on the couch.

She is now determined to speak out to help other women avoid a similar nightmare.

### **Astris Sweres' story**

ASTRID Sweres is a happy woman as she lies enjoying the filtered sunlight in her Melbourne garden. Yet she is recovering from an operation most would find shocking – the removal of her whole vulva, from the clitoral hood to the anus.

It is an operation that finally brought some relief from 14 years of battling lichen sclerosus (LS), a skin condition that thins the genital tissues, leading to tearing and painful sores and scar tissue that can cover the clitoris and fuse the labia.

It took four years of visits to the doctor for Sweres to finally find a dermatologist who identified the condition.

She started on steroid treatment, which initially provided some relief, but problems re-emerged.

Since 2006, specialists at the vulva clinic at the Mercy Hospital in Heidelberg have looked after what she describes as her “painfully fragile and screaming vulva”.

In a small group of women (4 to 5 per cent), untreated LS leads to skin cancer, as Sweres discovered: a painful sore turned out to be cancer, leading to her recent operation.

Astrid counts herself lucky that the cancer is apparently unlikely to recur. But she is angry that she still has LS.

“I’ll need to monitor and treat this disorder for as long as I live. I’m distressed about the lack of treatment options, the lack of research and the appalling lack of awareness about these horrendous conditions.”

<https://www.theage.com.au/national/the-vagina-dialogues-20130105-2ca3g.html>