

# Vulva health conditions: It's time to shatter the silence

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"I didn't know I had a vulva until I was diagnosed with lichen sclerosus and stage three vulval cancer."

These are the words of Clare Baumhauer, co-founder of [Vulval Cancer Awareness UK](#). She spoke of her anger at how, despite numerous doctor appointments, her cancer was not spotted until it was at an advanced stage. Baumhauer had had symptoms since the age of five, feeling burning [pain](#) "like razor blades" when going to the toilet. Despite undergoing [58 rounds of radiotherapy](#) in 2016–2017, Baumhauer experienced a recurrence in 2023 and had to have further surgery.

Public understanding of female genital anatomy is [poor](#). For the uninitiated, the vulva refers to the external female genitalia, including the labia minora and majora (the inner and outer lips), the clitoris and the entrance to the vagina.

Many vulval conditions cause itchiness and pain (often described by patients as "burning"). An itchy vulva may be mistaken for thrush by patients [and even health care professionals](#). But it could be common dermatological conditions such as eczema and psoriasis as they can affect the vulva too.

Another condition often mistaken for thrush is [lichen sclerosus](#), a progressive condition which can lead to distressing changes to the anatomy of the vulva, and can develop into vulval cancer.

Vulvodynia is the term used to describe vulval pain that must be experienced over a period of at least three months before it can be officially diagnosed, with some people experiencing pain from even a light touch. Some people with vulvodynia have continuous pain. Up to 16% of women and people with vulvas [will experience vulvodynia](#) at some point in their lives. But research has shown GPs [rarely recognize vulvodynia](#) and women [often feel dismissed](#) by their doctor.

There is a darker side to the silence that surrounds vulva health conditions. According [to a survey](#) by the British Association of

Dermatologists, one in five people with a vulval disorder have considered suicide or self-harm as a result of their condition.

## A disturbing silence

Vulval disorders are not a new phenomenon. There are accounts of women experiencing dyspareunia (pain during sex) [in ancient Egyptian papyri](#). Yet today there is still an [oppressive silence](#) around the vulva and vulval disease.

The [media](#) and the public still often refer to the vulva as a vagina. This misunderstanding makes it harder for women to talk about their symptoms. Poor understanding of vulval conditions also silences sufferers. If no one has heard of lichen sclerosus, for example, that means sufferers may have to describe it in graphic detail if they want support from others.

The term "pudendum," which refers to the vulva, was [recently removed](#) from the Terminologia Anatomica (the international standard for human anatomical terminology), because the Latin root of the word (pudere) means "to be ashamed." The media, in particular pornographic media, presents an unrealistic standard of women's genitalia. This has led to women and girls asking for cosmetic surgery, seeking an "ideal" [created by pornography](#).

Many women have internalized this genital stigma. Most vulval disorders are not sexually transmitted, but people still report a sense of shame or feeling "unclean." Shame is [a key dimension](#) of the experience of vulvodynia which leads some women with the condition to feel as though they are "not real women." This is because of the widespread narrative that penetrative sex equals "real" sex, so women who are unable to have penetrative sex due to vulva or vagina pain feel "unreal."

We also know that women's accounts of pain, especially gynecological pain, are less likely to be believed, less likely to receive appropriate pain relief, and [women often struggle](#) for many years to get diagnosed. For a progressive condition such as vulval lichen sclerosus, this delay can have dire consequences.

Recent research suggests menstrual and gynecological pain is [normalized through conversations](#) during childhood and young adulthood. So young women and those who menstruate grow up thinking gynecological pain is just something to be accepted, even expected. While children probably don't need to know every condition that's out there, it would help if we all grew up knowing there are several disorders than can affect your genitals.

Instead, we receive the message that we shouldn't be surprised when we experience pain or itching, but we also shouldn't talk about it.

## **Breaking the silence**

Perhaps we can look to breast cancer for a way forward. In the 1970s and 1980s, women began to break the silence and share their breast cancer experiences with the public. These stories raised the profile of the disease. Until then, breast cancer was the territory of doctors and surgeons. The disease claims tens of thousands of lives a year, but a silence surrounded it meaning many missed the early signs.

The increase in conversations about menopause is another recent example, with TV presenter [Davina McCall](#) leading the charge for [women](#) who are outraged that no one prepared them for it.

And recently singer Meghan Trainor [shared her experience of vaginismus](#), a condition causing the pelvic muscles to tense up painfully during sex. We need more well-known people to speak openly about

vulval conditions.

Meanwhile, patients are supporting each other. There is an online community of people with vulval lichen sclerosus, sharing experiences and tips for managing the condition, as well as memes and jokes. The [Lost Labia Chronicles](#) is an online blog by a patient describing her journey and explaining [scientific research](#) in accessible language.

Visual, literary and performing arts can be powerful tools for breaking down stigma. The short film, [Living with Lichen Sclerosus](#), uses real words from research participants to depict the experience of living with a chronic vulval condition.

Vulval disease is an under-researched field and more funding is needed to discover treatment options and ways to support patients.

Every conversation about vulva conditions adds another fracture to the taboo. The more we talk, the harder it will be to ignore the millions who are suffering.

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