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Personal Health

A Little-Known Skin Disease That Can Disrupt People's Sex Lives

Patients deal with pain and itching and often encounter medical ignorance and mistreatment until affected tissues become irreparably scarred.



By [Jane E. Brody](#)

- May 12, 2019

You've probably heard of lichens, complex organisms consisting of a fungus and an alga (and sometimes a bacterium) that break down rocks to create soil.

Though lichens vary widely in color and form, most often seen are the white crusty varieties that colonize the surface of trees, rocks and barren soil. This type has lent its name to a little-known skin disease — lichen sclerosus — that typically manifests as white crusts on genital tissues and is often undiagnosed or misdiagnosed before it wreaks havoc on people's lives.

A related disorder, lichen planus, more often affects the skin and inside of the mouth but can also affect genital membranes, where it can be more challenging to treat than lichen sclerosus.

Although lichen sclerosus can form on any skin surface, it has a predilection for a woman's vulva and, less often, a man's penis, and it can so disrupt people's sex lives that divorce or celibacy is sometimes the outcome.

[Lichen planus](#) generally has broader targets, but an erosive form can affect the anal-genital region and other body parts and be as destructive as lichen sclerosus. In addition to pain, both conditions can cause intense itching that, lacking an accurate diagnosis, patients may mistreat with creams and other substances that only make matters worse. Doctors, too, may mistake the problem for a yeast infection and prescribe the wrong treatment.

Furthermore, people rarely talk freely about diseases that attack the vulva or penis, even to their doctors, which delays a correct diagnosis and effective treatment. But even when patients overcome their embarrassment, they often run up against medical ignorance and mistreatment until affected tissues become irreparably scarred.

“When gynecologists do a pelvic exam, they may not even look at the vulva,” said Dr. Anuja Vyas, a gynecologist at Baylor College of Medicine [who specializes in these disorders](#). “Doctors often treat the vulva like a small Midwestern town that you drive through without noticing it.”

And when a woman past menopause complains that vaginal pain has made intercourse impossible, doctors may dismiss it as normal age-related changes and miss the presence of a treatable disease, she said.

Thus, it is often up to patients to make sure they get to a knowledgeable health care provider and get treatment that relieves symptoms and halts progression of their disease.

As two nurse practitioners, Nicholas Wedel and Laura Johnson, [pointed out in The Journal of Nurse Practitioners](#), “Vulvar health is one aspect of women's health that is often not discussed,” even though “up to 20 percent of all women will experience significant vulvar symptoms at some point in their lives.”

Yet, they added, “when left untreated, vulvar lichen sclerosus can cause significant physical, emotional and sexual discomfort.” It can also result in irreversible destruction of genital tissues and, in rare cases, squamous cell carcinoma.

Women with lichen sclerosus who responded to an international survey had this to say:

“I love my husband and want to be with him sexually and when we try, the pain is unbearable. It feels like cut glass is inside me.”

“My late diagnosis at age 58 was devastating. So much marital heartbreak could have been avoided.”

“Sex is not in my vocabulary anymore. The pain is unbearable and is increased when urinating or defecating.”

A mother whose daughter from age 4 had splits and tears in her skin from lichen sclerosis said her child was “unable to sleep due to intense itching and burning,” and was terrified to use the restroom lest she experience another tear and more pain.

An affected woman echoed the girl’s plight. She said, “It makes me not drink the fluids that my body needs because I don’t want to pee. I have literally screamed when I go.”

Here’s what is important to know about these two chronic diseases.

Neither lichen sclerosis nor lichen planus is a deadly condition. Nor are they contagious or transmitted sexually. The conditions do not have an established cause or definitive cure. Lichen planus may disappear spontaneously or following treatment, but lichen sclerosis rarely improves without proper treatment that should be continued indefinitely.

Both are inflammatory skin conditions likely autoimmune in nature. That is, the body mistakes the skin and mucous membranes for foreign tissue and launches an attack. About one woman in five with lichen sclerosis is likely to have another autoimmune condition, like thyroid disease, vitiligo or alopecia areata.

Lichen sclerosis can occur at any age but most commonly affects girls before puberty and women after menopause, suggesting that low levels of sex hormones may play a role in its onset. It also seems to have a genetic component. Over the course of a lifetime, as many as one woman in 300 may be affected, Dr. Vyas said.

Several symptoms of the two conditions overlap, and both can change the architecture of genital tissues, narrowing openings to the vagina or urinary tract.

Lichen planus, which often affects younger women, may start with very itchy purplish bumps on the skin — often the wrist, shins or ankles — that can spread over the body. When it affects the mouth, painful lacy-white lesions form that can make eating a challenge. Vaginal symptoms may include discharge, pain, burning and itching.

Symptoms of lichen sclerosis include smooth white patches on the skin, intense itching, tearing of the skin, discomfort or pain that can be extreme, and in severe cases bleeding, blisters or ulcerated sores.

While neither disorder is common, vulvar lichen sclerosis can affect as many as one woman in 30 after menopause. Genital lichen disease is estimated to be 10 times more common among women than men, who are more likely to get it if they are not circumcised.

The most effective treatment for lichen sclerosis is a potent corticosteroid ointment called clobetasol (Temovate), applied in tiny amounts several times a day at first, then less and less often as symptoms improve. Dr. Vyas said that “even if the condition is advanced, it will get better if treated properly and treatment is continued indefinitely.”

Also helpful is routine use of skin moisturizers, like vitamin E suppositories, hyaluronic acid or a product called Revaree, she said. To reduce sexual discomfort, she suggested using a water- or oil-based lubricant: food-grade oils like coconut, olive, grapeseed or avocado oil, or a personal lubricant called Slippery Stuff. If scarring limits sexual penetration, dilators can be used to gently stretch the vaginal tissues to make intercourse more comfortable.

Although the risk of cancer is low, women with either lichen disease should be examined regularly for evidence of a malignancy.

Jane Brody is the Personal Health columnist, a position she has held since 1976. She has written more than a dozen books including the best sellers “Jane Brody’s Nutrition Book” and “Jane Brody’s Good Food Book.”

A version of this article appears in print on May 14, 2019, Section D, Page 5 of the New York edition with the headline: A Skin Disease Can Disrupt People’s Sex Lives.

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