

Lichen sclerosis and me: the male perspective

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Patient viewpoint

I had never heard of lichen sclerosis (LS) before my symptoms appeared, which wasn't particularly surprising; I'm a writer, not a doctor. What was surprising was the depth of the rabbit hole of research I had to go down before I even encountered the term. What was even more surprising was that the first two medical professionals I consulted were also unfamiliar with LS.

Upon the onset of my symptoms, I was alarmed and scared; I had no idea what was happening. However, because of the timing, I strongly suspected that it was related to a pre-existing, unidentified condition, the symptoms of which had recently returned.

Until late 2012, at age 43, I had been quite healthy. Then, literally overnight, I experienced an onslaught of disturbing symptoms throughout my body: numbness, tingling, burning, twitching, and more.

My fingers also developed a propensity for turning blue in the cold; I was later diagnosed with secondary Raynaud disease. That would be my only official diagnosis, despite a slew of tests administered by a handful of specialists over the next year or so. Their best guess: I had an autoimmune disease that the tests hadn't yet reflected.

In time, the symptoms faded, and I decided to leave well enough alone. In the ensuing years, I'd occasionally experience a tenacious twitch, nagging numbness, or some other anomaly, but it would soon cease. So, I ceased worrying about it.

In the late spring of 2021, my extended range of symptoms returned in full force. Approximately 2 weeks later, there was an alarming development: my penis suddenly sported a white ring. Comprising about one-third of the glans, it encircled the area closest to the shaft. In addition, it was painful.

After countless hours of online sleuthing, I finally found a promising lead on Reddit. In the 'lichen sclerosis' subreddit, interspersed among the scores of posts from women, were a couple from men describing their experiences. Now armed with the name of a condition, I conducted a more pointed search. The more I read, the likelier it seemed that LS could be the culprit. The one potential snag was that males with LS are typically uncircumcised, which didn't apply to me.

Still, LS seemed like a worthwhile theory to float with my general practitioner. Having no familiarity with the term, he brushed it off and settled on a diagnosis of venous blood, saying it should resolve itself in due time. I wasn't sure if the diagnosis I had proposed was correct, but I knew in my heart that his wasn't. I decided to see a urologist.

Taking a different tack, this time I didn't mention LS. Neither did she. Baffled, she agreed that the timing indicated a likely correlation with my other symptoms but had no answers. Emotionally spent and recalling the extensive and ultimately fruitless series of appointments in my past, I hit the pause button on seeking further treatment.

In January 2022, I ventured back into my research. One key learning was that many diagnoses of LS are made by dermatologists. I set up an appointment; if it turned out that this wasn't LS, perhaps my dermatologist could still provide some insight.

It took her mere seconds to say she believed it was one of two things: vitiligo or LS. However, she was confused, because, in her understanding, neither condition should be painful. This was inconsistent with what I'd learned about LS, but as she wanted to schedule a biopsy from which I'd get a definitive answer, the point wasn't worth debating.

Once the results came back positive for LS, I was relieved to have a diagnosis and a course of action. That said, with there being a dearth of useful information available, I thought I could benefit from learning more about LS from other people who were battling it. I found an online community, but it was understandably focused on vulvar LS. However, it was the only game in town, so I emailed the administrator asking if the group would be comfortable with me joining their ranks. Thankfully, she and others in the community were extremely welcoming.

As a man, the odds of my having LS were low. As a man who was circumcised at birth, without any additional factors that are recognized to contribute toward LS, such as weight gain, diabetes, procedures or piercings, the odds were infinitesimal. Given what I know now, I'm no longer surprised that doctors have trouble identifying LS, but that needs to change.

I feel fortunate that my journey to diagnosis took just months, not years, as is the case with too many LS sufferers, both male and female. We need more cohesive clinical

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research, with standardized outcomes.¹ Furthermore, there should be concerted education efforts to ensure healthcare providers can more readily identify this pernicious disease and start patients on a standardized treatment plan, helping to improve lives and ideally preventing permanent damage.

Clinician's comments

LS is a chronic inflammatory skin condition that predominantly affects genital skin and is historically thought of as primarily affecting 'postmenopausal females'. However, LS can occur at any age in either gender. The incidence of male genital LS (MGLS) has been reported to be 0.07%.² However, some experts believe LS to be as common in men as in women. The incidence of LS in women by age 80 is estimated to be 1.6%.³

MGLS affects the glans penis and sometimes the foreskin. Symptoms include difficulty urinating due to the narrowing of the urethra, difficulty in retracting the foreskin due to scarring, and pain during sexual intercourse.⁴ LS in boys usually leads to a tight foreskin (phimosis). Anatomical changes from LS are often irreversible and affect mental health in addition to physical function. Men with LS are at risk of serious urethral disease. All individuals with LS also have an increased risk of genital cancer.

Circumcision is often required in patients with MGLS, especially when symptoms are poorly controlled by topical treatment. Urine is potentially involved in the pathogenesis of LS, as supported by several observations and studies.^{5,6} The exact mechanism remains to be further investigated, although occlusion caused by genital skin is believed to be implicated in both genders.^{5–7} LS is extremely rare in men who were circumcised early in life, making this patient's story unusual and possibly responsible for the confusion during his journey to a diagnosis.

It is very important that this patient has told his story. There have been far fewer studies of MGLS than vulval LS and even fewer reports of the lived experience of men with LS due to the lower engagement of men in survey-based and qualitative research.⁸

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Patient consent

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