Vulvar Lichen Sclerosus

Key Information for Patients

What is lichen sclerosus?

Lichen sclerosus (LS) pronounced lye-ken skle-ROH-sus is a long-term inflammatory skin condition that usually affects the vulva (the outside part of the female genitals) and the skin around the anus.^{1,2}

It is not an infection and it is not contagious. You cannot pass it to a partner.³

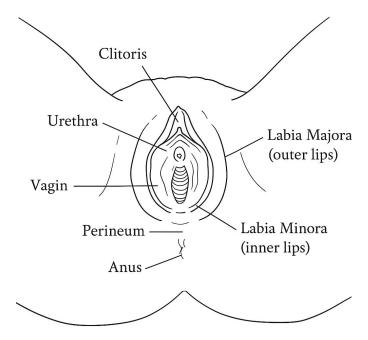


Figure 1: Diagram of the vulva and nearby skin, showing the clitoris (glans clitoris), clitoral hood (clitoral prepuce), outer lips (labia majora), inner lips (labia minora), the opening of the vagina (vaginal opening or introitus), the area between the vagina and the anus (perineum), and the anus.

What are the symptoms?

- Itching and a strong urge to scratch.^{2,3}
- Burning or soreness. Fragile skin that can tear.
- Pain during sex.^{2,3}
- Skin changes that can look white, thin, and crinkled, often in a figure-8 pattern around the vulva and anus.^{2,3}

It can affect people of all genders. More than half of women with LS report sexual problems, most often pain with penetration. ^{4,5} Overtime there may be eventual changes to the appearance of the vulva. For example, the small hairless lips can thin and flatten, and the glans of the clitoris becomes hidden under the skin. The large hair bearing lips may stick together and entry to the vagina (not the vagina itself) may become narrowed resulting in difficult inserting anything into the vagina.^{1,2,6}

How can LS affect sexual function?

LS can narrow the vaginal opening, thin the skin, and cause tears or fissures.^{2,6}

Scarring can pull tissues together, including the clitoral hood, which can limit stimulation and cause pain with arousal or penetration.^{2,6}

These changes can lead to painful sex, reduced arousal or orgasm, and avoidance of sexual activity.^{4,5}

How is LS diagnosed?

A clinician usually makes the diagnosis by looking at the skin and asking about your symptoms. A small skin biopsy is done only when the picture is unclear or there is a spot that looks worrisome. Getting diagnosed early helps protect sexual function.^{2,6}

First-line treatment that improves comfort and protects sexual function

- The most effective treatment for LS is a strong steroid ointment. Clobetasol propionate 0.05% is the gold-standard therapy. It calms inflammation, reduces itching, and helps the skin resist tearing. Many people need a maintenance plan after the first course. Your clinician will set a schedule.^{2,6}
- Non-steroid creams like tacrolimus or pimecrolimus can help some people but steroids work best for most.^{2,6,7}
- If scarring blocks the clitoris or makes the vaginal opening very tight, surgery may help. Releasing the clitoral hood can improve sensation and orgasm for some. A small procedure called perineoplasty can widen the opening and make penetration possible and less painful. Even after surgery, ongoing medical treatment is needed to control LS.^{2,6,8,9}

Given that steroid ointments are the main treatment, it helps to know how much to use and how to apply them safely.

How to use the ointment

It is recommended that patients use ½ Fingertip Unit (FTU) per application. One FTU is the amount of ointment squeezed from a 5 mm nozzle, along the length of your index fingertip. So half of that is enough each time. A 30-g jar will last you about three months with regular use. This treatment is considered safe, including during pregnancy.^{2,3,6}

You may be prescribed mometasone furoate 0.1% or clobetasol propionate 0.05%.^{2,6}

- **First month.** Once a day (morning or night), apply a thin layer of the ointment to the affected areas, not forgetting the skin around the anus if this is involved too. Your symptoms should be greatly improved after one month.2,3
- **Second month.** Apply on alternate nights.^{2,6}
- **Third month.** Apply twice a week (for example Mondays and Thursdays or on weekends Saturdays & Sundays). You should follow up with your doctor after you have finished 3 months of treatment.^{2,6}

Managing LS long-term

After 3 months of therapy, most people continue using the ointment 2 to 3 times a week. It is highly recommended that you continue to use the medication. LS cannot be cured, but it can be managed effectively. Ongoing treatment controls symptoms, protects the skin, and may reduce the risk of vulvar skin cancer.^{1,6}

Handling flare-ups

Flare-ups are common (times when symptoms suddenly get worse). If you have an increase in itch, restart a daily application for 1-2 weeks until your symptoms resolve.^{2,6} If the symptoms do not resolve after one week, or they get worse, stop the ointment and see a doctor - you may have another issue (For example, a yeast infection).^{3,6} Once your symptoms improve go back to regular 2-3 times per week application.

It is important to note that you should not use the ointment daily for any longer than 4 weeks at a time. There are alternative medications if the steroid medication is not helpful (for example, topical tacrolimus).^{2,6,7}

Support for pain, pleasure, and intimacy

- Psychosexual counseling can lower anxiety, improve communication with a partner, and support desire and pleasure. Research shows benefits for people with LS.^{2,6}
- Pelvic floor physical therapy helps if your pelvic muscles are tight or painful. This is common when sex has hurt for a while.^{2,6}

When to seek care

Contact your provider if:

- Sex is painful during or after penetration.
- You see cracks, bleeding, or tears in the skin.
- You notice new white patches, thicker skin, color changes, or new bumps.
- The opening feels too tight to allow penetration.
- Your symptoms are not improving on treatment.

Questions to bring to your visit

- Is my treatment strong enough right now?
- Do I have any scarring that needs extra care or a procedure?
- How often should I come for follow-up?
- What changes should make me book sooner?

Resources

- Vulvar skin care. Practical tips for daily comfort. Use this as your checklist - <u>Vulvar</u> Skin Care Recommendations
- For your provider. You can share this before or during your visit. It covers diagnosis, treatment planning, and follow-up. <u>Living</u> <u>with lichen sclerosus - a resource for</u> <u>healthcare professionals</u>



- 1 De Luca, D. A., Mervic, L., Hohl, D., Kerl, K., & Feldmeyer, L. (2023). Lichen sclerosus: The 2023 update. *Frontiers in Medicine, 10,* 1106318. https://doi.org/10.3389/fmed.2023.1106318
- 2 van der Meijden, W. I., Boffa, M. J., ter Harmsel, B., Kirtschig, G., Lewis, F., Moyal-Barracco, M., Tiplica, G.-S., & Sherrard, J. (2022). 2021 European guideline for the management of vulval conditions. *Journal of the European Academy of Dermatology and Venereology, 36*(10), 1761–1780. https://doi.org/10.1111/jdv.18102
- 3 British Association of Dermatologists. (2022, September 8). Lichen sclerosus in females, patient information leaflet. https://cdn.bad.org.uk/uploads/2021/12/08134523/Lichen-Sclerosus-Female-Update-08-September-2022.pdf
- 4 Pope, R., Lee, M. H., Myers, A., et al. (2022). Lichen sclerosus and sexual dysfunction: A systematic review and meta-analysis. *The Journal of Sexual Medicine*, 19(11), 1616-1624. https://doi.org/10.1016/j.jsxm.2022.08.006
- Vittrup, G., Mørup, L., Heilesen, T., Jensen, D., Westmark, S., & Melgaard, D. (2022). Quality of life and sexuality in women with lichen sclerosus: A cross-sectional study. *Clinical and Experimental Dermatology*, 47(2), 343–350. https://doi.org/10.1111/ced.14893
- 6 EuroGuiDerm Guideline Development Centre. (2023). EuroGuiDerm guideline: Lichen sclerosus (update). Swiss Society of Dermatology and Venereology. https://www.sggg.ch/fileadmin/user_upload/Dokumente/3_Fachinformationen/2_Guidelines/LSGuidelineUpdate2023.pdf
- 8 Goldstein, A. T., & Burrows, L. J. (2007). Surgical treatment of clitoral phimosis caused by lichen sclerosus. *American journal of obstetrics and gynecology, 196*(2), 126.e1-126.e1264. https://doi.org/10.1016/j.ajog.2006.08.023
- 9 Abramov, Y., Elchalal, U., Abramov, D., Goldfarb, A., & Schenker, J. G. (1996). Surgical treatment of vulvar lichen sclerosus: a review. Obstetrical & gynecological survey, 51(3), 193–199. https://doi.org/10.1097/00006254-199603000-00023

