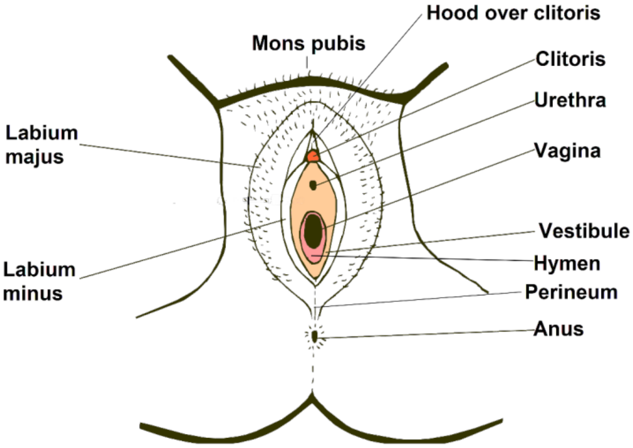
# Lichen Sclerosus

## What is lichen sclerosus (LS)?

**Lichen sclerosus (LS)** is an **autoimmune disease** of the vulva that starts when cells that normally fight infection attack your own skin cells by mistake.

- We do not know what causes LS. People with lichen sclerosus often have a personal or family history of another autoimmune disease, such as thyroid disease.
- LS is not contagious, meaning that it cannot be passed to another person by skin contact.
- LS is most common in people who have gone through **menopause** (when people stop getting their monthly period), but it can happen at any age.

LS affects the skin of the **vulva**, or the part of the body that includes all the external (outside the body) genital parts. It covers the area from where pubic hair grows (the **mons pubis**) to the opening that stool comes out of (the **anus**). The vulva includes the large outer lips of skin (**labia majora**), small inner lips of skin (**labia minora**), the clitoris, the opening that urine comes out of (**urethra**), and the opening to the vagina.



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## What are the symptoms of lichen sclerosus (LS)?

- LS most commonly causes itching, discomfort, or pain. Sexual activity may be uncomfortable or painful, as LS can cause the vaginal opening to narrow.
- LS may affect a small area or involve the entire vulva, from the hood of the clitoris to around the anus.
- Skin affected by LS often has a white color and looks thin, shiny, and crinkled. The skin is fragile (weak) and tears easily.
    - Scratching or rubbing the skin can cause small cracks in the skin (**fissures**) that are painful. A fissure near the anus can cause pain during bowel movements.
- LS does not typically involve the skin inside the vagina. About 10% of patients have lichen sclerosus on other parts of their bodies or are affected by many skin conditions at once.

## How is LS diagnosed?

- Often, your provider can diagnose LS based on the way your vulva looks during your exam.
- Sometimes your provider may do a **biopsy** (removing a small piece of skin for lab testing) to confirm an LS diagnosis if typical treatments aren't working for you or if your provider thinks your skin condition might be a sign of something more serious. You will get an injection of numbing medicine before the skin is removed.

## What are long term effects of LS?

- Untreated LS can cause scarring and changes in the way your vulva looks. The labia minora (inner labia) can stick to the labia majora (outer labia) and shrink. The opening to the vagina can get smaller. The hood over the clitoris can become scarred so that it does not move.

- **Chronic inflammation** seen with LS can cause long-lasting redness, heat, swelling, and pain. Patients with LS also have a slightly higher risk of developing skin cancer in the affected area. LS can cause abnormal growth of skin cells called **HPV-independent neoplasia** (also called **differentiated vulvar intraepithelial neoplasia, or dVIN**). If this growth is untreated, it can develop into vulvar cancer.
    - Treatment that prevents inflammation lowers your risk of getting abnormal growths and cancer.

## How is LS treated?

LS is a chronic (long-term) disease that cannot be cured, but it can be effectively treated. LS treatment has 2 main goals:

- Stop your itching and other symptoms.
- Stop the chronic inflammation that leads to scarring and increases your risk of cancer.

### Symptom relief

While you are waiting for the treatment to take effect, symptoms can be reduced by:

- **Comfort measures:** Comfort measures are things you can do to decrease irritation, itching, and pain to your vulva. We have created a handout with information on comfort measures that you can read online at: bit.ly/MM-ComfortMeasuresVulvarDisease.
- **Treatment for yeast or bacterial infections:** We may check for these and prescribe treatment for you if needed.
- At times, we may prescribe an oral medication (medication you take by mouth, like a pill) to take at bedtime to prevent itching so that you do not scratch yourself while you're asleep.

- **Vaginal lubricants:** You can use a lubricant to increase comfort during sexual activity. For more information, read the "Vaginal Lubricants" section of our Vulvar Diseases booklet (www.med.umich.edu/1libr/Gyn/VulvarDiseasesBooklet.pdf) or the "Improving Sexual Health: Vaginal Lubricants, Moisturizers, Dilators, & Counseling" handout (bit.ly/MM-VaginalLubricants).
- **Vaginal estrogen:** After menopause, vaginal tissue can become thin, dry, and easily irritated. If we think this is part of what is causing your symptoms, we may prescribe vaginal estrogen to treat this.
    - There are different kinds of vaginal estrogen products including creams, suppositories, and a long-acting silicone ring. We will help you choose one to start with.
    - Research has shown that using vaginal estrogen does not increase the risk of getting breast or uterine cancer for people with no personal history of these cancers.

### Topical steroid treatment

We usually start LS treatment with a strong steroid ointment called clobetasol that you will put on your vulva using your finger. We will show you what part of the vulva you should treat.

- Squeeze a small, pea-sized amount on your finger and gently spread it on the affected skin.
- Usually, after you are first diagnosed with LS, you will put this on once a day for 3 months. It is very important to continue treatment on this schedule even after itching stops. The symptoms you feel will stop before the inflammation is fully treated.
- After your symptoms (itching, burning, pain, etc.) have stopped and we have seen that your vulvar skin has responded well to the treatment, we will give you a schedule for ongoing treatment. This may be daily use of a weaker topical steroid (**topical** means that it is a medication that is put

on the skin, like a cream or ointment) or a different schedule for using the clobetasol ointment (like 3 times every week).

  - It is important to continue this treatment to prevent your symptoms from returning. This will also reduce your risk of developing skin cancer in the affected area.

### Other medications

If treatment with a topical steroid is not effective, there are other options. These include:

- Topical medications that target a specific part of your immune system
- Steroid shots
- Oral steroids

### Surgery

Sometimes you may need surgery to open scar tissue. Scar tissue may make it hard to urinate (pee) or have sex. If you need surgery, we will talk with you about the plan for surgery and how to prevent scar tissue from reforming after your surgery.

## What kind of follow-up do I need to do for LS treatment?

- We will continue to meet with you as needed until your treatment is working. After that, you should get an exam of your vulva done every 6 months. This can be done by your gynecologist or primary care provider (if this is something they feel comfortable doing). If not, we will help you find a Michigan Medicine doctor to see. The purpose of the exam is to:
  - Make sure the treatment is still effective
  - Look for changes (raised, bleeding, or non-healing areas) that should get biopsied to check for cancer
- We want you to do regular self-exams of your vulva. Call us, or use the online patient portal to send us a message, if:

  - You see something new (raised, white, bleeding, or non-healing areas)
  - Your symptoms come back
  - You get new vulvar symptoms

## Where can I find more information on lichen sclerosus (LS)?

| Resource | QR code |
|---|---|
| International Society for the Study of Vulvovaginal Disease<br>www.issvd.org/resources/vulvar-lichen-sclerosus | |

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