

## Patient information – Vulvar Lichen sclerosis

**INTRODUCTION** — Lichen sclerosus (LS) is a skin disorder that causes the skin to become thin, whitened, wrinkled, and can cause itching and pain. LS usually occurs in postmenopausal women, although men, children, and premenopausal women may be affected. It can develop on any skin surface, but in women it most commonly occurs near the clitoris, on the labia (the inner and outer genital lips), and in the anal region. In 15 to 20 percent of patients, LS lesions develop on other skin surfaces, such as the thighs, breasts, wrists, shoulders, neck, and even the inside the mouth.

It is not clear exactly how many people have LS. Estimates for LS involving the female genitals vary from 1 in 30 elderly women seen in general gynecology offices to 1 in 300 to 1000 patients referred to dermatologists.

**LICHEN SCLEROSUS CAUSES AND RISK FACTORS** — The cause of LS is not clear; Medical science suspect that a number of factors may be involved.

**Genetic factors** — LS seems to be more common in some families. People who are genetically predisposed to LS may develop symptoms after experiencing trauma, injury, or sexual abuse.

**Disorders of the immune system** — People with LS are at a greater risk of developing autoimmune disorders, which develop when the body's immune system mistakenly attacks and injures normal body tissues. These may include some types of thyroid disease, anaemia, diabetes, alopecia areata, and vitiligo.

**Infections** — Researchers have tried to identify an infectious organism as a cause of LS, but no clear data have shown that there is an infectious source. LS is not contagious.

### LICHEN SCLEROSUS SIGNS AND SYMPTOMS

**Features of genital LS in women** — Some women with LS feel dull, painful discomfort in the vulva, while other women with LS have no symptoms. The most common symptoms include:

- **Vulvar itching** – The most common symptom of LS is itching. It may be so severe that it interferes with sleep.
- **Anal itching, fissures, bleeding, and pain**
- **Painful sexual intercourse (dyspareunia)** – This can occur as a result of repeated cracking of the skin (fissuring) or from narrowing of the vaginal opening due to scarring.

Typically, women with LS have thin, white, wrinkled skin on the labia, often extending down and around the anus. Purple-colored areas of bruising may be seen. Cracks (also known as fissures) may

form in the skin in the area around the anus, the labia, and the clitoris. Relatively minor rubbing or sex may lead to bleeding due to the fragility of the involved skin.

If lichen sclerosus is not treated, it may progress and change the appearance of the genital area as the outer and inner lips of the vulva fuse (stick together) and bury the clitoris. The opening of the vagina can become narrowed, and cracks, fissures, and thickened, scarred skin in the genital and anal area can make sexual intercourse or genital examination painful. LS does not affect the inner reproductive organs, such as the vagina and uterus.

**Features of LS in other areas** — LS may also cause lesions to occur in areas outside the genitals, especially the upper body, breasts, and upper arms. These lesions tend to be white, flat or raised, and are not as itchy as the affected skin of the genitals and anus.

**LICHEN SCLEROSUS DIAGNOSIS** — Providers typically use the following methods to diagnose lichen sclerosus.

**History and physical examination** — A medical history and physical examination of the vulvar and anal areas will be done, looking for the signs and symptoms of lichen sclerosus.

**Biopsy** — To confirm a suspected diagnosis of lichen sclerosus, a biopsy is recommended. A small piece of the affected skin will be removed and sent to a pathologist to be examined with a microscope.

**Excluding other conditions** — Tests may be done to exclude other conditions that could cause symptoms similar to those of lichen sclerosus, such as:

- Lichen planus (a skin disease that can also cause itching and fusing of genital skin). Lichen planus can occur together with lichen sclerosus.
- Low estrogen level (a lack of the hormone estrogen can rarely cause fusing of genital skin but is often the cause of painful intercourse)
- Vitiligo (a disorder that can cause white skin patches similar to those of lichen sclerosus). Vitiligo can occur together with lichen sclerosus.
- Pemphigoid (a blistering skin disorder that also causes scarring of the vulva) is extremely rare.
- Hemorrhoids (which can also cause cracks in the skin of the anus)

**LS and cancer** — Women with LS affecting the vulva are at increased risk for developing squamous cell skin cancer. However, it is not clear if women who are treated for LS are at the same risk as women who are not treated. Diagnosing LS early, treating it effectively, and biopsying any abnormal areas may help to reduce the risk of developing or missing a diagnosis of skin cancer. A once yearly examination of the skin of the vulva is recommended, and women should examine themselves

regularly for lumps or sores that do not heal. A biopsy should be performed if there are areas that do not improve with treatment.

LS lesions outside the genital area do not have an increased risk of cancer.

**LS and painful sexual intercourse** — Lichen sclerosus can lead to constriction of the vaginal opening and pain during sexual intercourse. Women who experience pain during sex first require treatment to suppress any active disease. Once the disease is controlled, some clinicians may recommend an estrogen cream to help to soften the skin around the vaginal opening. Devices called vaginal dilators, which patients can use at home, also may be used to slowly stretch the skin.

Pain with intercourse can also occur from other causes. Patients who notice pain during intercourse should discuss their symptoms with their healthcare providers.

**LICHEN SCLEROSUS TREATMENT** — The goals of treatment of LS are to relieve bothersome symptoms and to prevent the condition from worsening. A clinician may recommend medication for the physical symptoms, and may refer the patient for support and therapy for other issues associated with the condition, such as problems with sex.

All patients with LS, even those without noticeable symptoms, need to use medication on a regular and ongoing basis. Patients also should see a healthcare provider for reevaluation of the disease at least once or twice yearly.

Patients who are diagnosed with LS should talk to their clinician about:

- The lifelong and potentially progressive nature of LS; appropriate treatment can stop the condition from worsening
- Ways to manage the condition
- The slightly increased risk of vulvar cancer and the need for ongoing monitoring
- How to keep the genital area healthy and avoid scratching
- Persistent pain with intercourse

Depending on the severity of the condition, a healthcare provider may recommend one or more of the following treatments:

- Steroid ointments are recommended to reduce inflammation and itching.
- Steroid injections, especially if steroid ointments are not effective
- Oral or topical tricyclic antidepressants (TCAs) are sometimes recommended for vulvar pain that persists despite steroids.

- An oral medication called acitretin has been used for the treatment of LS in some resistant patients.
- Surgery is not routinely used to treat women with LS because lichen sclerosus tends to recur after the skin heals. However, patients whose genital tissues have grown together may have surgery to separate the fused tissues. Recurrence of the scarring occurs frequently.

**WHAT TO EXPECT** — The good news for patients who have been diagnosed with lichen sclerosus is that treatments such as topical steroid ointments are very effective. In one study of women and girls who were treated, 96 percent of patients showed improvement in their LS symptoms, and 66 percent of patients had relief of all LS symptoms. Thus, early treatment of LS with topical steroids can prevent scarring. Follow up is important throughout the lifetime.

## Healthy vulval hygiene practices

### AVOID

### SUBSTITUTE

Pantyhose	Stockings with a garter belt Thigh high or knee high stockings
Synthetic underwear	Cotton underwear or no underwear
Jeans and other tight pants	Loose pants, skirts, dresses
Swimsuits, leotards, thongs, lycra garments	Loose-fitting cotton garments
Pantyliners	Tampons or cotton pads
Scented soaps or shampoos	Fragrance free pH neutral soap (eg, Basis, Neutrogena, Dove soap)
Bubble bath	Tub baths in the morning and at night without additives and at a comfortable temperature
Scented detergents	Unscented detergents
Washcloths	Use fingertips for washing; pat dry, don't rub dry
Feminine sprays, douches, powders	These are not necessary products and can be omitted from personal practices
Dyed toilet articles	Toilet articles without dyes
Hair dryers to dry vulva skin without contact	Dry vulva by gentle patting