



## VULVAR LICHEN SCLEROSUS

### What is it?

Lichen sclerosus (LS) is a long term skin disease that mainly affects the genital skin. It usually starts around the age of menopause but may occur in children. It occurs in 1 in 1000 women and less often in men and can occur in children. The skin outside the genital region is less commonly involved. This condition appears as white, fragile, skin patches that can sometimes look crinkled, but can have a shiny and smooth surface.

### What causes lichen sclerosus?

The cause of LS is unknown. It can be associated, in some patients (and/or their close relatives), with autoimmune diseases, such as thyroid disorders or vitiligo. Autoimmune diseases occur when the cells and proteins that the body uses to fight off infection start to damage the body's own tissues and prevent their normal actions. Your health care provider may do blood tests to check for these autoimmune diseases. It can be made worse by skin irritation, like scratching, and any infection on open skin from yeast or bacteria.

LS is **not** an infection and is **not** contagious. It cannot be passed on to a sexual partner. Sometimes, the disease may occur in family members but the risk of this is unknown.

### What are the symptoms and what do I see?

- Itching is the most common symptom. This can be severe and may disturb sleep.
- Some people experience soreness and burning particularly on intercourse. Small cracks in the skin (fissures) and ulcers can occur as a result of scratching the skin, and these can be very sore. If the anal skin is split there can be pain with bowel movements.
- The skin becomes pale and white in appearance. This may be patchy or involve all the vulva extending down to the skin around the anus.
- Small purplish/red areas may be seen on the white background. These are bruises due to tiny areas of bleeding into the skin, often because of scratching.
- There may be scarring that causes loss of vulvar tissue (eg. the inner lips) or shrinkage of the entrance to the vaginal area, which can cause pain and interfere with sexual intercourse and rarely even cause problems with urination.

- It does not involve the vagina.

Some people have no symptoms and the diagnosis may be made when the area is examined for another reason.

In about 10% of women with vulvar LS, white patches may be seen on the skin elsewhere. The common sites for this are on the back, waist area and under the breasts.

### **How is it diagnosed?**

Health care providers familiar with the condition may diagnose it by looking at the skin and seeing the usually characteristic appearance. The diagnosis is usually confirmed by taking a skin biopsy. This involves taking a small piece of skin, first numbing the skin using a local anesthetic to be. The skin is then looked at under the microscope looked at microscopically. This is called a biopsy. This is a simple procedure that can be done in the doctor's office with a local anesthetic.

### **What is the treatment?**

There is no total cure for LS but the symptoms can be controlled extremely well by the use of strong steroid ointments. The appearance of the vulvar skin can usually be improved but if there is a lot of scarring, changes may not be reversed. Appropriate treatment is aimed at trying to prevent the development of further inflammation and scarring.

The most effective treatment for LS is a very strong topical steroid ointment such as clobetasol propionate or halobetasol. These can be quite safe to use in the genital area for this condition. In general, a pea sized amount of the ointment is sufficient to treat the vulvar skin. Your health care provider will tell you how to use your treatment. Just a small tube is needed, 15 to 30g, which should last 3 months and usually longer. Treatment should not be stopped unless advised by your doctor as LS *can* recur. Many patients find that simple moisturizers such as plain petrolatum can be helpful in addition to the strong cortisone/steroid ointments.

All skin irritation should be avoided as far as possible, as irritation may increase the symptoms of will increase LS. Any infections from yeast or bacteria must be treated. Soaps and shower gels are best avoided in the genital area. The genital skin can be washed with plain warm water or a gentle soap substitute. It is ideal to clean the vulva just using one's fingertips and warm water over the skin surface. Some people find that a saline solution (a quarter of a teaspoon of salt dissolved in a cup of water) is helpful.

You may feel itchy at times. This may be worse at a particular time of the day, usually at night, and many women wake themselves scratching. Many women cannot help scratching. The itch-scratch response is normal but treatment with the steroid ointment and the emollient will help scratching the genital area is potentially harmful as it can damage the skin and keep symptoms going for quite some time. There may only be 2 strategies we can use to help the itch. Firstly, the condition needs to be managed properly (this is a shared job between you and your doctor). Secondly, distraction which is something only you can do. For example, if the itch is unbearable in bed, don't lie there feeling uncomfortable and unable to resist scratching. Instead, get up, find something to do which occupies your hands and your concentration. When you feel the tension from the itch is reduced, then try to go back to bed. Hopefully there will only be a short time before you begin to feel better. A first generation antihistamine such as hydroxyzine taken at bed

time may help to control itching. It is best to keep your nails short filed down so that scratching in your sleep will not cause too much damage.

If intercourse is painful intercourse can be helped with natural gentle lubricants may help, if dryness is a problem and you are around the time of the menopause ask your doctor about vaginal estrogens such as plain petrolatum. Painful sexual penetration should be avoided.

### **What should I watch for?**

Patients with LS may be a little more likely to develop skin cancer in the genital affected areas. However, it only occurs in about 3-4% of patients with LS and early treatment may reduce this risk even further. Any new lumps or non-healing sores or a major change in your symptoms should be reported to your doctor if they do not respond quickly to the steroid ointment. It is a good idea to get used to examining the genital skin yourself at least monthly if you are able. We advise patients with LS to have a genital examination by their health care provider at least once a year.