

## HOW DO I MANAGE THE SYMPTOMS?

There are a few things you can do to help manage the symptoms:

- The use of a simple hypoallergenic moisturiser may help to improve the symptoms.
- If penetrative sex is painful, using a lubricant should help. It's safe to have sex but painful intercourse should be avoided as it can further irritate the affected skin or cause small skin tears. It's best to wait until your symptoms have improved to have intercourse.
- If dryness is a problem, and you are around the age of menopause, ask your health care provider about using vaginal oestrogen cream or pessaries to help with this. Hormone replacement therapy may also be helpful.
- Gently clean the vulva using water only over the skin surface, and avoiding any soap, gels, body wash etc. Some people prefer rinsing with a saline solution (a quarter of a teaspoon of salt dissolved in a cup of water).

### MANAGING THE ITCH

Itchiness is a common symptom of vulvar lichen sclerosus. This may be worse at a particular time of the day, usually at night. Scratching causes itchiness which in turn makes you scratch more. This is called the itch-scratch cycle. The itch-scratch cycle is normal and treatment with the steroid ointment will help this. Scratching the genital area is potentially harmful as it can damage the skin and continue the symptoms.

There are several strategies you can use to manage the itch:

- Most importantly, the condition needs to be managed properly. This is a shared responsibility between you and your health care provider.
- Distraction can be very useful. This is something only you can do. For example, if the itch becomes unbearable when you are in bed, don't lie there feeling uncomfortable and unable to resist scratching. Instead, get up and find something to do which occupies your hands and your attention. When you feel the tension from the itch is reduced, then try going back to bed.
- It is best to keep your nails short so scratching in your sleep does not damage the skin.
- An oral antihistamine taken at bedtime may also help to control the itching.

References: ANZ Vulvovaginal Society. <https://anzvs.org/patient-information/lichen-sclerosus> • International Society for the Study of Vulvovaginal Disease Patient Information Committee. Revised 2021 • DermNet NZ <https://dermnetnz.org/topics/lichen-sclerosus>



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### LOCATION

SHFPACT is conveniently located in the city.

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## WHAT IS VULVAR LICHEN SCLEROSUS?

Vulvar lichen sclerosus is a common long-term inflammatory skin condition that affects the genitals. Lichen sclerosus can occur anywhere on the body, but most often affects the vulva.

It can occur at any age but usually starts around menopause and affects around 1 in 20 women who have gone through menopause. It can occasionally affect men and children. If lichen sclerosus is left untreated for a long time, there can be an increased risk of skin cancer in the vulva. Lichen sclerosus does not affect the vagina which is different tissue to the vulva.

## WHAT CAUSES IT?

The cause of lichen sclerosus is unknown. It can sometimes be associated with autoimmune conditions. Autoimmune conditions occur when the cells and proteins that your body uses to fight off infection start to damage your body's own tissues and prevent their normal actions.

Your health care provider may do some blood tests to check for autoimmune conditions if they think this may be the case. Sometimes the condition may also occur in family members, but the risk of this is unknown.

Lichen sclerosus is not an infection and is not contagious. It cannot be passed onto a sexual partner.

## WHAT ARE THE SYMPTOMS?

- Itching is the most common symptom. This can sometimes be quite severe and may disturb sleep.
- Some people experience soreness and burning, particularly with intercourse.
- Small cracks in the skin (fissures) can occur because of scratching the skin. These can become very sore. It can become painful to urinate and if the skin around the anus splits, there can be pain with bowel movements.
- Scarring may occur due to the loss of vulvar tissue (the inner lips) or shrinkage of skin at the entrance to the vagina making it less flexible. This can cause pain and may interfere with sexual intercourse.
- In about 10% of people with vulvar lichen sclerosus, white patches may be seen on the skin elsewhere. The common sites for this are on the back, waist area, and under the breasts.
- About 10% of people have no symptoms, and the diagnosis is made when the area is examined for another reason.

## WHAT DOES IT LOOK LIKE?

The appearance of lichen sclerosus is different from person to person. In some people the vulval skin looks unchanged. More commonly there are changes to the appearance.

This may include pale, white, fragile skin patches that can sometimes look crinkled, but can also have a shiny smooth surface. These can be individual patches or may involve the entire vulva, extending down to the skin around the anus. In other people there may be white dots or small splotches.

Some purplish/red areas may be also seen on the white background. These are bruises due to tiny areas of bleeding into the skin, often because of scratching. Small skin tears (fissures) can sometimes appear.

There may also be changes to the vulval skin folds. The labia minora (small inner lips) can seem smaller or stuck, and sometimes may disappear altogether. The vulval skin may also flatten or close over the clitoris.

## HOW IS IT DIAGNOSED?

Health care providers familiar with the condition may diagnose vulvar lichen sclerosus by looking at the skin of your vulva. The diagnosis is sometimes confirmed by taking a skin biopsy.

A biopsy involves numbing the skin with a local anesthetic, then removing a small piece of skin. This piece of skin is then looked at under the microscope. A biopsy is a simple procedure that can be done in the doctor's office.

## HOW DO YOU TREAT IT?

While there is no cure for lichen sclerosus the symptoms can usually be very well controlled by using steroid ointments.

As vulvar lichen sclerosus is a chronic condition this treatment needs to be long-term.

With proper treatment you can expect very good results. Inflammation will settle, symptoms will lessen, further scarring and damage will be prevented, and the appearance and texture of the vulvar skin will improve. However, any changes to the skin, such as scarring, and loss of tissue that has already occurred cannot be reversed.

Steroid ointments can be used safely in the genital area. Your health care provider will instruct you on how to use it correctly.



Treatment needs to be ongoing, and it is very important not to stop your treatment, as lichen sclerosus can recur or progress without it.

Lichen sclerosus can be made worse by skin irritation, like scratching, or infections such as yeast or bacteria. Therefore, it is important to avoid skin irritation as much as possible. Any infections from yeast or bacteria need to be treated as soon as possible.

## WHAT HAPPENS IF VULVAR LICHEN SCLEROSUS IS NOT TREATED?

- Lichen sclerosus can cause significant problems and affect your quality of life if it is not treated.
- The changes to vulval anatomy that occur, such as loss of tissue and scarring are permanent and not reversible.
- Scarring can make intercourse uncomfortable if not impossible and passing urine may become difficult.
- Persistent discomfort in the vulval area can lead to a chronic pain condition in the long term.
- If lichen sclerosus is left untreated or treatment is stopped, there is a 5% (1 in 20) chance of it progressing to cancer of the vulva. Ongoing treatment reduces this risk to less than 1%.