

NHS Greater Glasgow and Clyde  
Gynaecology Services



Information about

# Vulval Lichen Sclerosus



## What is Vulval Lichen Sclerosis?

Lichen Sclerosis (LS) is an inflammatory skin condition. In women, it mainly affects the skin in around the vulva and perianal regions (front and back passage). Less commonly, it can affect the thighs, underneath breasts, neck, shoulders and wrists.

## What are the symptoms of Vulval Lichen Sclerosis?

Lichen Sclerosis often causes intense itching, irritation and soreness of the skin of the vulva. This can cause problems with passing urine, opening bowels and can make sex painful and difficult.

The skin may be red and inflamed, but can also appear white, thickened and scarred. The skin may also develop tiny purple blood blisters or have a 'raw' appearance to the skin.

## Who is affected by Vulval Lichen Sclerosis?

Lichen Sclerosis usually affects adult women, but it can also affect children and men to a lesser extent. It is often first seen in women in their forties and fifties.

## What causes Lichen Sclerosis?

It is not known for definite what causes Lichen Sclerosis. However, we believe it may be an autoimmune skin disease where our body produces antibodies which can react against the skin of the vulva. It may also be associated with other automimmune conditions such as thyroid disease.

Lichen Sclerosus is not due to an infection, it is not contagious, and your sexual partner cannot pick up the skin condition from contact with you.

Lichen Sclerosus is not caused by the menopause, hysterectomy, the oral contraceptive pill or HRT (hormone replacement therapy). HRT or oestrogen creams do not treat lichen sclerosus but can help if there are associated menopausal changes to the skin.

Friction or rubbing of the skin can bring about the condition (Koebner response).

Exposure to urine can make the skin more irritated.

Lichen Sclerosus may occur in family members.

## Can Lichen Sclerosus be cured?

At present there is no cure for Lichen Sclerosus, but we can offer you treatment which will relieve the symptoms and protect your skin from further damage.

It is estimated that approximately 75% (3 out of 4) of women will see their symptoms resolve, but some may have symptoms that will come and go (relapsing and remitting symptoms).

## Treatment

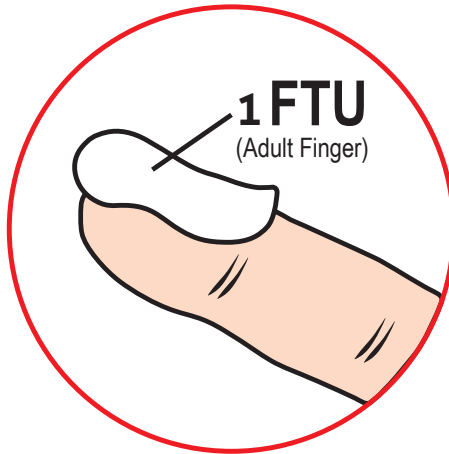
The main treatment for Lichen Sclerosus is topical steroid ointments or creams. The most commonly used steroid for the treatment of vulval Lichen Sclerosus is Clobetasol Propionate ointment. Your doctor will discuss which steroid type you should use. A guide to how to apply the steroid topically is outlined in this information leaflet.

You should also use topical emollients regularly to help protect and moisturise the skin. We also recommend simple ointments or creams for washing and general good care of the vulval skin.

These steps help reduce flare-ups and keep your skin healthy. Surgery is not usually helpful as Lichen Sclerosus can re-appear in the skin left behind. Occasionally we may suggest surgery if scarring and tightening of the skin causes problems with passing urine or having sex.

## How to use topical steroid therapy

Apply one fingertip unit of the ointment or cream to affected area.



**First month** - apply to the affected area every night

**Second month** - apply to the affected area second (alternate) night

**Third month** - apply to the affected area twice a week

After the three-month course of treatment, you should use the topical steroid regularly, once or twice a week in the long term. **This is called maintenance therapy.** Long-term use is safe as long as one 30g tube last at least 3 months.

You may experience a flare in symptoms over time. If your symptoms get worse, use the steroid cream every night for 2 to 4 weeks. Once things improve, go back to your usual routine for keeping it under control (maintenance therapy)

It may sting for a few minutes after applying the topical steroid, this is normal. However, if it lasts longer than 1-2 hours after applying, you may be sensitive to the cream or ointment. If this happens, wash the area thoroughly and stop using it. There are several alternative treatments which you may be able to use, and you should contact your GP or clinic for advice.

It is best to apply the steroid at night before you go to bed onto clean skin. An emollient can be applied over the steroid ointment if required.

## Advice for managing your Condition

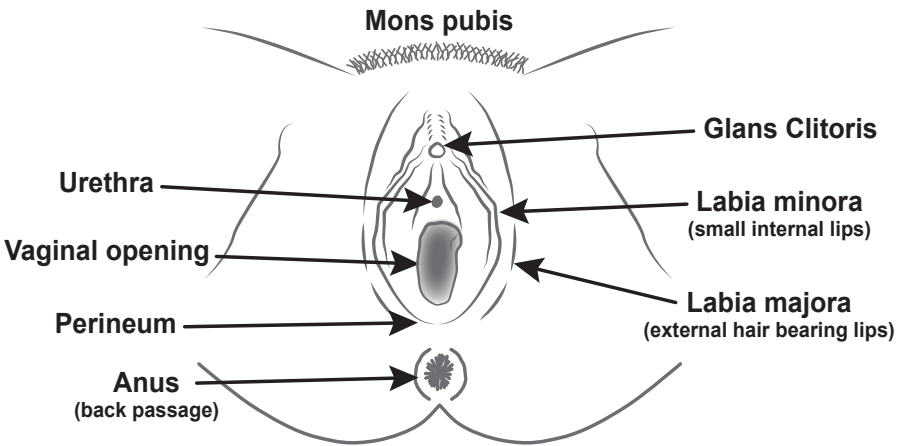
We will also give you advice on how to care for the skin around your vulva. This usually includes the use of soap substitutes for washing and applying oily moisturisers to protect and moisturise the skin.

## Are there any risks with Lichen Sclerosus?

There is thought to be a small less than 3-5% (3 to 5 out of 100) lifetime risk of developing a skin cancer in the vulva if you have Lichen Sclerosus. However, emerging evidence suggests that using steroid creams regularly as part of long-term care, can help keep symptoms under control and may also lower the risk of cancer.

Although this is a small risk, we would advise that you check the area yourself with a mirror on a regular basis (please see the self-examination diagram below). If you are unsure, our staff in the clinic can help.

## Self-examination of your vulva



If you feel comfortable, you can use a mirror to check the area yourself. The diagram above shows the parts you can look at during your self-check.

If you need more help with self-checks, speak to your doctor or visit the self-examination section at [www.vulvalpainsociety.org](http://www.vulvalpainsociety.org)

You should always let your doctor know if you have any ulcer, warty areas or bumps which are not healing with treatment or are growing bigger.

## Where can I get more information?

### Web links to patient information leaflets:

 [British Association of Dermatologists \(bad.org.uk\)](http://bad.org.uk)

 [Lichen sclerosus: Causes, Diagnosis, and Images - DermNet \(dermnetz.org\)](http://dermnetz.org)

### Web link to patient support groups:

The Vulval Pain Society (UK based)

 [www.vulvalpainsociety.org](http://www.vulvalpainsociety.org)

Lichen Sclerosus Support Network (North America)

 [www.lssupportnetwork.org](http://www.lssupportnetwork.org)

## Useful contact numbers

If you are concerned about your skin or you are finding treatment difficult, you should contact your GP first.

Alternatively, you can contact the reception at the Gynaecology Clinic where you were reviewed.

If you attend the specialist vulval clinic at Stobhill Hospital you can contact:

**Stobhill Gynaecology Clinic (Clinic F) -  0141 355 1209**

- If you have been discharged from gynaecology clinic, your GP or Practice Nurse is your first point of contact.

## Useful notes from clinic

Use this area to write any notes regarding your condition, treatment or contacts for clinic.