

NHS Greater Glasgow and Clyde
Gynaecology Services

Lichen Sclerosus

Patient Information



What is Lichen Sclerosus?

Lichen Sclerosus 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 Lichen Sclerosus?

Lichen Sclerosus 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 even become raw.

Who is affected by Lichen Sclerosus?

Lichen Sclerosus 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 Sclerosus?

It is not known for definite what causes Lichen Sclerosus. 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 autoimmune conditions such as thyroid disease and diabetes

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 help with condition.

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 give you treatment which will relieve the symptoms and protect your skin from further damage.

It is estimated that approximately 60% of women will have resolution of symptoms while approximately 40% will experience relapsing and remitting symptoms.

Treatment

The mainstay of treatment for Lichen Sclerosus is topical steroid ointments or creams in combination with liberal use of topical emollients. We also recommend simple creams for washing and general good care of the vulval skin. These measures aim to reduce the chance of the skin flaring.

Operations are not usually helpful as Lichen Sclerosus can re-appear in the skin left behind. Occasionally we may suggest an operation if scarring and tightening of the skin causes problems with passing urine

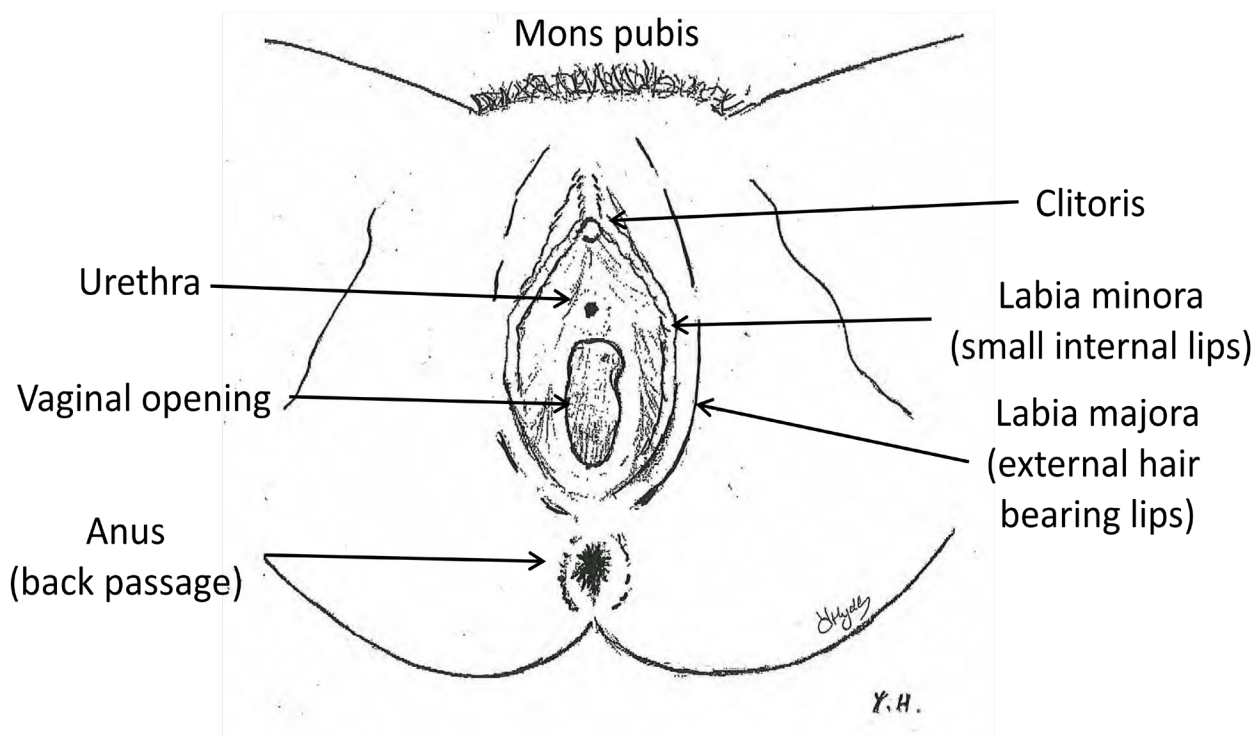
Are there any risks with Lichen Sclerosus?

There may be a small approximately 3-5% lifetime risk of developing a skin cancer in the vulva on a background of Lichen Sclerosus.

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

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

Self Examination of your vulva



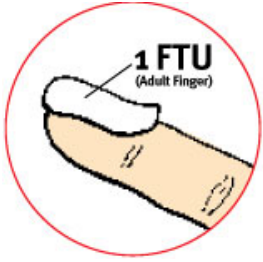
If you are comfortable it is helpful to check the area yourself with a mirror. The self examination diagram above labels the areas which you can inspect during your examination.

For further support with self examination ask for help from your medical practitioner or consult the self-examination area at

<https://vulvalpainsociety.org.uk>

How to use topical steroid therapy

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



First month - apply to affected area once nightly

Second month - apply to affected area alternate nights

Third month - apply to affected area twice a week

After the three month course, you can use the cream or ointment every night for 2 weeks to treat the flare-up and control the itch, then try to reduce the frequency as above.

If symptoms keep coming back quickly when you stop using the cream, you may prefer to use the cream 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.

Stinging for a few minutes after application is quite normal. However, if it persists for greater than 1-2 hours after application, you may be sensitive to the cream or ointment. If this occurs, wash the area thoroughly and STOP using the cream. There are several alternative creams 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 cream or ointment if required.

Where can I get more information?

Web links to patient information leaflets:

www.bad.org.uk/for-the-public/patient-information-leaflets/lichen-sclerosus

www.niams.nih.gov/Health_Info/Lichen_Sclerosus/default.asp

dermnetnz.org/immune/lichen-sclerosus.html

Web link to patient support groups:

National Lichen Sclerosus Support Group (NLSSG)

www.lichensclerosus.org

The Vulval Pain Society

<https://vulvalpainsociety.org.uk>

Useful contact numbers

The numbers below can be used if you are finding treatment difficult and are still attending the specialist vulval clinic.

Stobhill Gynaecology Clinic (Clinic F)

0141 355 1209

Alternatively, if you have been discharged from gynaecology follow up, you should seek advice from your own GP or Practice Nurse in the first instance.