# **Patient information**



# **Lichen Sclerosus**

#### **Lichen Sclerosus**

Lichen sclerosus is a skin condition that most commonly affects the vulva (genital) skin area, but can affect other areas of skin. It is often unreported especially in mild cases, so it is thought to be fairly common. It can occur at any age including childhood but, it is more common in post-menopausal patients.

### What are the symptoms of lichen sclerosus?

#### Women and girls-vulva and anal area

In a typical case, small "pearl white" spots develop on the vulva, which are usually itchy and shiny. The skin around the anus is also affected, in 3 out of 10 cases. Sometimes only the skin around the anus is affected. Typically, the itch and irritation become persistent and distressing. The itch tends to be worse at night which can disturb sleep. Sometimes soreness rather than an itch is the main symptom. Lichen sclerosus is a skin condition only and does not extend into the vagina or inside the anus.

Overtime, the white spots may become larger and join. The whole of the vulva/anal skin area may then become white and be more fragile than normal. The fragile skin may become damaged, inflamed, raw and prone to painful splitting and cracking. If the anal skin is affected, passing faeces (stools) may cause pain or splitting of the skin.

If left untreated over months or years, the vulva may atrophy (shrink). In some cases, the changes of the vulva skin may make the entrance to the vagina (labia) narrower. This can make it difficult or painful to have sex. Also, thrush and other infections tend to be more common if the vulva is sore or cracked.

Symptoms may slowly get worse but not all the above symptoms may occur. It can take months or years for the first spot to progress to more severe symptoms. At first the symptoms maybe mistaken for thrush or other problems of the vulva if not examined.

#### Other areas of the skin

Sometimes small patches of lichen sclerosus occur on other parts of the body. These areas also look like small pearly white areas on the skin. They can occur in people with or without genital lichen sclerosus. Away from the genital area, patches of lichen sclerosus usually do not cause itch or other symptoms.

#### What causes Lichen Sclerosus?

The cause is not known. There is a type of inflammation within affected skin which causes changes to the structure of the affected area.

It is thought that the cause is probably an autoimmune disease and around 1 in 4 people with Lichen Sclerosus have another autoimmune disease such as thyroid disease, vitiligo or pernicious anaemia.

It is not known what triggers Lichen sclerosus to develop. A positive family history is reported in 12% of patients, but there's no evidence of it being hereditary.

# Are there any complications from Lichen Sclerosus?

The itch and discomfort may cause more distress. The changes to the genital skin may cause sexual difficulties or problems in passing urine.

There's a small risk of developing skin cancer in the affected Lichen sclerosus areas (less than 5%). This often appears as a hard craggy lump, a non-healing ulcerative sore or crusted area.

## How is Lichen Sclerosus diagnosed?

The appearance is often typical and is often diagnosed just with examination of the area, but occasionally a small skin biopsy will be taken under local anaesthetic to confirm the diagnosis.

#### What is the treatment for Lichen Sclerosus?

**Topical Steroid** 

A strong steroid ointment or cream (topical steroid) is the main treatment as this will reduce inflammation. It is usual to use the ointment or cream regularly for three months. A common plan is to use a single application at night for 4 weeks, followed by alternate nights for 4 weeks and then twice a week for 4 weeks. Use the steroid as directed by your doctor and keep on with the steroids for as long as advised. Irritation tends to ease off after two weeks or so, but the skin may take 3 months of treatment to look and feel better.

The skin may return to normal if lichen sclerosus is diagnosed and treated with a topical steroid at an early stage. However, if the appearance of the skin has already changed, these changes may not always be reversed, although symptoms of itch and soreness are often relieved. After the initial regular treatment for about three months, you may then only need to use the ointment or cream once or twice weekly every 1-2 weeks to keep symptoms under control.

#### Some general measure

Use an emollient (moisturiser) cream or ointment instead of soap, to clean the genital area. Examples of these are epaderm, diprobase or oilatum. Avoid bubble baths, scented soaps, detergents, perfumes, Coloured underwear etc, to the vulva. These may irritate the skin and make some symptoms worse. Lubricants are useful during sex if having sex is painful. Try to avoid tight clothing, rubbing or scratching. Some activities such as riding a bicycle or horse may aggravate symptoms.

CAUTION: This leaflet mentions 'emollients' (moisturisers). Emollients, creams, lotions and ointments contain oils which can catch fire. To reduce the risk of fire, patients using skincare or haircare products are advised to be very careful being near naked flames (candles inclusive) and near people who are smoking cigarette, especially in bed. It is advisable to wash clothing daily which is in contact with emollients and bed linen regularly

## Will it go away?

There is no permanent cure for Lichen Sclerosus. However, treatment with a topical steroid usually controls the symptoms of itch and soreness, and often prevents the condition from getting worse. Occasionally, the condition clears away for good for no apparent reason. This is often more common in young girls when the condition often goes during puberty.

# **Check your vulva**

As mentioned above, cancer of the vulva is an uncommon complication. Therefore, it is best to get into the habit of checking your vulva about once a month to look out for any signs of early vulva cancer. As a rule, the earlier any cancer is detected, the easier to treat. To check the area, use a handheld mirror to see your vulva, use your finger to feel your vulva, and see a doctor if any changes occur. For example, if you detect thickening, warts, lump, ulcers, blisters or sores.

Further help and information

National Lichen Sclerosus support group

Helpline: 07858 402473 Web: www.lichensclerosus.org

Sites with pictures of skin conditions: www.patient.co.uk, DermNet NZ

#### References

British Association of Dermatologists guidelines for the management of lichen sclerosus, 2018 (bad.org.uk)

Lichen Sclerosus | Doctor | Patient Patient.co.uk

#### Consent

Although you consent for this treatment, you may at any time after that withdraw such consent. Please discuss this with your medical team.

## **Important information**

The information in this leaflet is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

#### Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: 0300 131 4784 or by email at: esh-tr.patientexperience@nhs.net

# **Hand hygiene**

We are committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

#### Other formats

If you require any of our leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department on 0300 131 4434 or <a href="mailto:esh-tr.AccessibleInformation@nhs.net">esh-tr.AccessibleInformation@nhs.net</a>

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.	W

#### Reference

The following clinicians have been consulted and agreed this patient information: Kerry Sargant, Oluwatolafunmi AWE

The directorate group that have agreed this patient information leaflet: Guideline Implementation Group & Governance and Accountability.

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