

LICHEN SCLEROSUS in Females

What are the aims of this leaflet?

This leaflet has been written to help you understand more about lichen sclerosus (LS). It tells you what it is, what causes it, what can be done about it, and where you can find out more about it.

What is lichen sclerosus?

Lichen sclerosus is a chronic inflammatory skin condition which can affect any part of the skin, but it most often affects the genital skin (vulva) and the skin around the anus. It can start in childhood - or adulthood (usually after the menopause) and affect girls or women of any age.

What causes lichen sclerosus?

The cause of lichen sclerosus is not fully understood. It can be associated with other diseases in which the body's immune system attacks normal tissues such as the thyroid gland (causing an overactive - or underactive thyroid gland) or the insulin-producing cells in the pancreas (causing diabetes), but it has not been proven that it is an auto-immune condition in itself.

Lichen sclerosus is not due to an infection – the disease is not contagious and cannot be spread through contact, including sexual intercourse.

Friction or damage to the skin triggers lichen sclerosus and make it worse. This reaction is called a 'Koebner response'. Irritation from urine leakage or wearing incontinence pads or panty liners can make the problem worse.

Is lichen sclerosus hereditary?

It is not known if lichen sclerosus is hereditary, but it rarely occurs in relatives.

What are the symptoms of lichen sclerosus?

The most common symptom of vulval lichen sclerosus is itching, which may be severe and be very sore if the skin breaks down or cracks. In the genital area, the scar-like process can tighten the skin which can interfere with urination and sexual intercourse. Tightening of the skin around the anus may cause discomfort when passing bowel motions and aggravate any tendency to constipation, especially in children.

The patches on the non-genital skin rarely cause any symptoms at all.

What does lichen sclerosus look like?

The skin has a white shiny appearance which is usually thinned but can sometimes become raised and thickened. When the anus is affected it is described as 'a figure of eight pattern'. Skin fragility may lead to breaking of some small blood vessels in the skin which appear as tiny blood blisters. Occasionally, blisters and small cracks called fissures can be seen. If not treated, there may be a change in the normal appearance of the vulva. There is a small risk (less than 5%) of developing a skin cancer in affected areas on the vulva. This can look like lumps, ulcers or crusted areas.

In areas away from the genital skin, lichen sclerosus looks like small ivory-coloured slightly raised areas, which can join up to form white patches. After a while the surface of the spots can look like white wrinkled tissue paper. The most common sites are the bends of the wrists, the upper trunk, around the breasts, the neck and armpits.

How will lichen sclerosus be diagnosed?

The diagnosis can usually be made from the typical appearance of the condition. If there is any doubt, a small skin sample may be taken and examined under a microscope to confirm the diagnosis, especially if there is an open sore or a thickened area of skin. This is known as a skin biopsy and requires a local anaesthetic injection and possibly stitches to close the wound, leading to a small scar.

Can lichen sclerosus be cured?

There is no permanent cure for lichen sclerosus, but the symptoms and signs of the disease can be well controlled with the application of creams to the affected skin. If it starts in childhood, it usually goes away around the time of puberty.

How can lichen sclerosus be treated?

A variety of treatments are available for lichen sclerosus:

- Strong steroid ointments (most commonly clobetasol propionate 0.05%) are
 used to stop the inflammation and also soften the affected skin. Please do not
 worry about the warning inside the pack, where it might say 'not to use these
 ointments on genital skin' as these are very safe for this condition and your
 dermatologist will advise you how and when to apply the steroid ointments
 safely.
- Moisturisers help to soften and protect the skin.
- It is possible to develop thrush or other infection is the skin cracks and your doctor will treat these problems if they arise.
- Rarely, a small operation may be needed to divide adhesions if the skin sticks together.

Self Care (What can I do?)

- Avoid washing with soap and instead use an emollient soap substitute/cream.
- Carefully dry yourself after passing urine to reduce the contact of urine with your skin.
- Using a moisturiser or yellow soft paraffin (such as Vaseline) as a barrier cream can protect your skin from exposure to urine.
- If sexual intercourse is painful because of tightening of the skin at the entrance to the vagina, the use of lubricants and, on occasions, vaginal dilators, will help.
- Keep an eye on your skin. There is a small risk of developing vulval cancer in lichen sclerosus, but with good control of the symptoms and signs this risk is reduced further. Lifelong regular self-examination is very important for all females who have had genital lichen sclerosus. If any skin changes develop which do not respond to steroid creams, in particular any skin thickening, soreness or ulceration lasting more than two weeks, you need to tell your doctor without delay. You may need a biopsy to test for skin cancer.
- If you are a smoker, stop smoking to reduce the risk of cancer.

CAUTION: This leaflet mentions 'emollients' (moisturisers). Emollients, creams, lotions and ointments contain oils which can catch fire. When emollient products get in contact with dressings, clothing, bed linen or hair, there is a danger that a naked flame or cigarette smoking could cause these to catch fire. To reduce the fire risk, patients using skincare or haircare products are advised to be very careful near naked flames to reduce the risk of clothing, hair or bedding catching fire. In particular smoking cigarettes should be avoided and being near people who are smoking or using naked flames, especially in bed. Candles may also risk fire. It is advisable to wash clothing daily which is in contact with emollients and bed linen regularly.

Where can I get more information about lichen sclerosus?

References:

British Association of Dermatologists guidelines on the management of lichen sclerosus 2018 (in development)

European Dermatology Forum guideline on lichen sclerosus

Web links to detailed leaflets:

www.niams.nih.gov/Health Info/Lichen Sclerosus/default.asp http://dermnetnz.org/immune/lichen-sclerosus.html

Link to patient support group:

National Lichen Sclerosus Support Group (NLSSG)
Web: http://lichensclerosus.org/

Published guidelines for the management of lichen sclerosus:

British Journal of Dermatology 2010; 163:672-82

http://www.sggg.ch/fileadmin/user_upload/Dokumente/3_Fachinformationen/2_Guidelines/De/Guideline on Lichen sclerosus.pdf

For details of source materials use please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

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