

PATIENT INFORMATION LEAFLET

LICHEN SCLEROSUS IN FEMALES

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about lichen sclerosis (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 sclerosis 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, most commonly after menopause.

WHAT CAUSES LICHEN SCLEROSUS?

The cause of lichen sclerosis 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 sclerosis does not lower your immunity and does not affect any internal organs.

Lichen sclerosis is not due to an infection – the disease is not contagious and cannot be spread through contact, including sexual intercourse. It is not related to allergy or hormonal abnormalities.

Friction or damage to the skin triggers lichen sclerosis 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 symptoms worse.

IS LICHEN SCLEROSUS HEREDITARY?

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

WHAT ARE THE SYMPTOMS OF LICHEN SCLEROSUS?

The most common symptom of vulval lichen sclerosis is itching, which may be severe. If the skin breaks from scratching, it can be sore. Until the condition is treated, there can be a change in the appearance of the vulva with some loss of tissue. If there is narrowing of the entrance of the vagina, sexual intercourse can be painful. The skin can also be prone to tearing, particularly after sex. If there is severe scarring, this can interfere with urination although this is very rare. It can also affect the skin around the anus.

In children, constipation is a very common symptom.

In a minority of people, patches may occur on non-genital skin, but these 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 skin around the anus is affected, it is described as 'a figure of eight pattern'. Skin fragility and scratching 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.

In non-genital skin, lichen sclerosis appears as small white, 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. They most commonly occur at sites of pressure such as the waist, shoulders and around the breasts.

HOW WILL LICHEN SCLEROSUS BE DIAGNOSED?

The diagnosis can usually be made from the typical appearance of the condition, by a health care professional who is experienced in the diagnosis and management of the condition. All children should be seen by a specialist for diagnosis. 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. This is not generally done in children.

CAN LICHEN SCLEROSUS BE CURED?

There is no permanent cure for lichen sclerosis, but the symptoms and signs of the disease can be well controlled with the application of ointments to the affected skin. If it starts in childhood, and is properly treated, then it goes away by the time of puberty in the majority of girls.

HOW CAN LICHEN SCLEROSUS BE TREATED?

The most effective treatment for LS is a strong steroid ointment (most commonly clobetasol propionate 0.05%). This stops the inflammation and softens 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. Less strong steroid ointments are not effective in controlling the disease or preventing the skin changes.

At the time of diagnosis, the treatment is used intensively for a 3-month period. This only needs to be applied once on the day when it is used. The recommended regimen is every day for 1 month, then alternate days for 1 month and then twice weekly for a month. After this, your dermatologist will advise you how and when to apply the steroid ointments.

An ointment-based emollient is used as a soap substitute to protect and moisturise the skin.

SELF-CARE (WHAT CAN I DO?)

- Avoid washing with soap and instead use an emollient soap substitute/cream.
- Avoid scented products such as bubble baths and shower gels.
- Avoid wearing panty liners if possible and if they are essential use fragrance free ones.
- Carefully dry yourself after passing urine to reduce the contact of urine with your skin.
- Using an emollient ointment 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. If this continues to be a problem, then you should be seen by a specialist as there are some surgical procedures that may be helpful.
- Keep an eye on your skin. 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. This particularly tends to occur on some



special types of LS where the skin is thickened. 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 ointment, in particular any skin thickening, soreness or ulceration lasting more than two weeks, you need to see your GP who will refer you to a specialist for further assessment. You may need a biopsy.

- If you are a smoker, stop smoking to reduce the risk of cancer.

WHERE CAN I GET MORE INFORMATION ABOUT MALE GENITAL LICHEN SCLEROSUS?

Plain language summary of British Association of Dermatologists guidelines on the management of lichen sclerosus

British Association of Dermatologists guidelines on the management of lichen sclerosus 2018

Web links to detailed leaflets:

<http://dermnetnz.org/immune/lichen-sclerosus.html>

<http://www.patient.co.uk/health/Lichen-Sclerosus.htm>

Please note: The BAD provides links to external pages to help people access a range of information about their skin disease. The views expressed in these pages may not be those of the BAD or its members.

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

CAUTION:

This leaflet mentions 'emollients' (moisturisers). Emollients, creams, lotions, and ointments contain oils. When emollient products get in contact with dressings, clothing, bed linen or hair, there is a danger that they could catch fire more easily, even if the emollient products have dried. To reduce the fire risk, patients using skincare or haircare products are advised to be very careful near naked flames or lit cigarettes to reduce the risk of clothing, hair or bedding catching fire. It is advisable to wash clothing daily and bedlinen frequently, if they are in contact with emollients; however, this may not remove the risk completely, even if washed at high temperatures, so caution is still needed. More information may be obtained at

<https://www.gov.uk/guidance/safe-use-of-emollient-skin-creams-to-treat-dry-skin-conditions>.

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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