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 sclerosus. 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 (LS) is a long-term inflammatory skin condition which can affect any part of the skin, but it most often affects:

- genital skin (vulva)
- skin around the anus

It can start in childhood or adulthood, most commonly after menopause (the time when periods stop because of changes in hormones).

There is a small risk (less than 5 out of 100) of developing a skin cancer in the 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.

WHAT CAUSES LICHEN SCLEROSUS?

The cause of LS is not fully understood. It can be linked to other conditions where the immune system attacks healthy cells in the body by mistake. These are called autoimmune conditions. Examples include vitiligo and overactive or underactive thyroid gland. However, it is not yet clear whether LS itself is an autoimmune condition. LS does not make your immune system weaker and does not affect any organs inside your body.

LS is not due to an infection. It is not contagious and so it cannot be spread by touching, including sexual intercourse. It is not related to allergy or hormonal abnormalities.

Friction or damage to the skin can make LS worse. 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 LS is hereditary, but it occasionally occurs in relatives.

WHAT DOES LICHEN SCLEROSUS FEEL AND LOOK LIKE?

It is common for LS to feel itchy. Scratching may break the skin, which can be painful. Without treatment there can be a change in how the vulva (the skin around the vagina) looks with some loss of tissue. If the damage to the skin causes narrowing of the entrance of the vagina, sexual intercourse can be painful. The skin can also be more easily torn, particularly during sex. If there is severe scarring, this can interfere with passing urine although this is very rare. It can also affect the skin around the anus.

In children, constipation (unable to have a bowel movement) is a common symptom when the skin around the anus is affected.

In some people, patches may appear on non-genital skin. This can be itchy but often does not cause other symptoms.

The skin affected by LS can become paler, white and shiny. Typically, the affected skin is thinner than usual but can sometimes become raised and thickened.

When the skin around the anus is also affected, it is described as 'a figure of eight pattern'. Fragile skin and scratching may lead to some small blood vessels in the skin breaking, and this appears as tiny blood blisters. Sometimes, blisters and small cracks called fissures can be seen. If not treated, the vulva may look different from how it looked before.

In non-genital skin, lichen sclerosus appears as small white, slightly raised areas, which can join up to form white patches. After a

while the surface of these areas can look like white wrinkled tissue paper. This is most common in areas where there is frequent pressure or rubbing (for example, the waist, shoulders and around the breasts).

HOW WILL LICHEN SCLEROSUS BE DIAGNOSED?

The diagnosis can usually be made from how the condition looks. This is done by a healthcare professional who is experienced in diagnosing and managing the condition. All children should be seen by a specialist for diagnosis. If there is any doubt, a skin biopsy may be needed. Skin biopsy includes taking a small skin sample and examined under a microscope to confirm the diagnosis, especially if there is an open sore or a thickened area of skin. This is called a skin biopsy. Skin biopsy requires a local anaesthetic injection and possibly stitches to close the wound. This is usually not done in children.

CAN LICHEN SCLEROSUS BE CURED?

There is no cure for lichen sclerosus, but the symptoms and signs of the disease can be well controlled by using ointments on the affected skin. If LS starts in childhood, and is properly treated, it often settles by puberty in most girls. But, it may come back later in life.

HOW CAN LICHEN SCLEROSUS BE TREATED?

Treating lichen sclerosus is really important as it reduces the risk of developing cancer of the affected areas. The most effective treatment for LS is a strong steroid ointment (clobetasol propionate 0.05% is most often used). This stops the inflammation and also softens the affected skin.

Please do not worry about the warning inside the packaging, where it might say 'not to use these ointments on genital skin' as clobetasol propionate 0.05% is safe for treating this condition. Less strong steroid ointments are not effective in controlling the disease or preventing the skin changes.

After diagnosis, this treatment will be prescribed to use for three months. In the first month, you should use it once every day. In the second month, once every two days. In the third month, only twice a week. After this, your dermatologist will advise you how and when to apply the steroid ointments.

It is best to use an ointment-based emollient instead of soap, to protect and moisturise your skin. It is most effective when applied frequently, for example morning and evening and after every visit to the toilet.

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. Products which avoid these are usually called 'fragrance free'.
- Avoid the use of wet wipes.
- 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.
- Use a bland emollient ointment or soft white paraffin (such as Vaseline®) as a barrier cream to protect your skin from exposure to urine.
- If sexual intercourse is painful because of tightening of the skin at the entrance to the vagina, it may help to use lubricants and, if required, vaginal dilators. 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 the 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 important for all females who have had genital lichen sclerosus. If any skin changes develop which do not go away after using steroid ointment, in particular any skin thickening, soreness or ulceration lasting more than two weeks, you need to see your GP who may refer you to a specialist for further assessment.

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

WHERE CAN I GET MORE INFORMATION ABOUT LICHEN SCLEROSUS?

Weblinks to other relevant sources:

LS Guide:
www.lichensclerosusguide.org.uk/
Vulval skincare:
www.bad.org.uk/pils/vulval-skincare
DermnNetNZ:
dermnetnz.org/topics/lichen-sclerosus
Patient Info:
patient.info/womens-health/vulval-problems-leaflet/lichen-sclerosus
British Association of Dermatologists guidelines for the management of lichen sclerosus, 2018
https://onlinelibrary.wiley.com/doi/full/10.1111/bjd.16241
Jargon Buster:
www.skinhealthinfo.org.uk/support-resources/jargon-buster

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

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. There is still a risk if the emollient products have dried. People using skincare or haircare products should be very careful near naked flames or lit cigarettes. Wash clothing daily and bedlinen frequently, if they are in contact with emollients. This may not remove the risk completely, even at high temperatures. 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

BRITISH ASSOCIATION OF DERMATOLOGISTS

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PRODUCED | AUGUST 2004
UPDATED | MARCH 2010, JANUARY 2014, FEBRUARY 2017, FEBRUARY 2018, SEPTEMBER 2022, SEPTEMBER 2026
NEXT REVIEW DATE | SEPTEMBER 2029