

LICHEN SCLEROSUS – BOYS

Written for parents and young people (key stage 2 and above)

What are the aims of this leaflet?

This leaflet has been written to help boys, teenagers and their parents 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 the condition.

What is lichen sclerosus?

Lichen sclerosus is an uncommon skin condition which mainly affects the genitals (private parts). It is more common in girls and in older men and women. In boys, it usually affects the foreskin and tip of the penis (willy).

Why have I got this condition?

The cause is not known, but it may be due to the immune system attacking healthy cells in the body by mistake (a form of autoimmune disease). Patients with LS are more likely to have other autoimmune conditions (such as vitiligo and thyroid problems).

Injury or friction, when the skin rubs against something, can worsen the condition. There is a potential link to urine causing irritation of the foreskin – in boys and in men who are circumcised in childhood, the condition is extremely rare.

What are the symptoms?

LS can be itchy, or cause inflammation (<u>redness</u>, pain, splitting) of the foreskin. This can be followed by paleness and tightening of the foreskin, which is called phimosis. Boys can have worsening tightness of their foreskin with no other symptoms. Tightening of the foreskin can cause difficulty when passing urine (going for a wee or peeing) and if LS affects the tip of the penis it can cause spraying of urine.

LS can affect other parts of the body, where it causes pale patches on skin which can be wrinkly or thickened, but this is very rare.

What tests do I need?

You should be referred to a dermatologist who will be able to diagnose and treat this condition by looking at the area and so usually no tests are needed. They will need to examine all of your skin as well as your penis. It may feel a bit embarrassing to have someone look at your penis but, in the clinic, this is a normal thing to do and you always have someone with you, either a relative/carer or a member of nursing staff, as well as the doctor. The examination should not hurt and it is important that they can check this so that they can give you the right treatment to help.

Why treat lichen sclerosus?

The aim of treatment is to reduce inflammation, stop the itch and soreness and to prevent scarring if the condition was left untreated.

How is lichen sclerosus treated?

We usually treat LS with a strong steroid ointment (a corticosteroid ointment called clobetasol propionate, for example Dermovate[®] or ClobaDerm[®]) to reduce the inflammation. Your dermatologist will explain how much ointment is needed and where to apply the ointment. Parents of younger children should help with their treatment to ensure it is used in the correct way.

If the foreskin is very tight, boys may need help to apply the steroid ointment under the foreskin; sometimes using a cotton bud can help. If the tip of the penis is affected, the steroid ointment should be applied there also.

Please do not worry if there is a warning inside the box, where it says not to use these ointments on genital skin. These are very safe to use in this condition when you follow your dermatologist's instructions properly. Weaker treatments do not work as well.

When is the treatment applied?

In the beginning, you will usually treat LS with the steroid ointment for 4 to 12 weeks, even if the symptoms start to improve quickly. Initially, you will need to use the ointment every day. Your dermatologist will discuss how many days a week to use the ointment after the first 4 to 6 weeks (for example, you may reduce to every second day). Most people find it easiest to apply the ointment at night. LS might flare up again in the future, even if the treatment has worked well. If this happens you can use the same ointment for a few days (or weeks) to control the symptoms. Your dermatologist will give you information about how to treat any flare-ups and how to use the ointments.

Alternative treatments

Strong steroid ointments are usually used first as there is better evidence that they work. In some circumstances, your doctor may prescribe an alternative ointment, such as tacrolimus, a <u>calcineurin inhibitor</u> (Protopic[®]).

It is important not to irritate the skin. Using non-fragranced moisturising cream instead of soap can help to reduce irritation. Washing your penis after going to the toilet may prevent irritation from urine – some boys may also find applying a moisturiser to the penis and foreskin helpful. Patients with LS can get moisturisers on prescription from their GP.

In boys, if treatment with the steroid ointment does not help LS to clear up, your doctor may recommend circumcision (removal of the foreskin) as a cure. This would be done by a surgeon when you are asleep under general anaesthetic and normally you go into hospital for the day only. It is important that any circumcision skin is sent to the laboratory so that the diagnosis can be confirmed. If your urine does not have a good flow, your doctor may refer you to another specialist (urologist) to advise on treatment.

When should the treatment not be applied?

After the initial treatment period, the steroid ointment does not need to be applied if the skin is not sore or itchy. It is important to get the balance between treating symptoms effectively and not using strong steroids when it is not needed.

If symptoms get worse despite treatment, this may mean there is another problem, such as an infection. You will need to see your GP or dermatologist so they can review your skin.

What can you expect?

LS in children tends to improve at puberty but it may not completely disappear. Flare-ups may still be experienced which will need to be treated with the steroid ointment. Cure is possible in early LS. Circumcision can also be a cure.

In adults with LS, there is a small risk of developing certain types of genital skin cancer. The risk of developing genital skin cancer for children whose LS continues into adulthood is very small. Your dermatologist will tell you if there is a need to be seen regularly, but most children can be discharged when their condition is stable and only need to be seen if they have any problems or concerns.

Where can I get further information?

Patient association for lichen sclerosus (both male and females): <u>Association for Lichen Sclerosus</u>

NHS patient information: https://www.nhs.uk/conditions/lichen-sclerosus/

National treatment guidelines: British Association of Dermatologists guidelines for the management of lichen sclerosus 2018

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Society for Paediatric Dermatology which is a part of the British Association of Dermatologists. Individual patient circumstances may differ, which may alter both the advice and treatment given 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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