

# LICHEN SCLEROSUS in female children

## 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 children and young people 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. The information will also be helpful to parents.

#### What is lichen sclerosus?

Lichen sclerosus is an inflammatory skin condition. It mainly tends to affect the genital areas (vulva and penis). The cause is not known, but it may be a form of autoimmune disease (when the immune system attacks healthy cells in the body by mistake) and can run in families.

#### What is the vulva?

In girls LS most commonly affects the vulva. The vulva is the outer part of your genitals. A lot of people (even grown-ups) call this the vagina. In fact the vagina is the tube bit (which connects to the womb and where babies come through when they are born). The vulva gets called lots of things for example pussy, fanny, privates. You and your family may have your own names for it. The vulva is quite tucked inside when you are young. Around puberty when a lot of changes happen to your body the vulva also changes quite a bit, in particular the inside flaps (called labia minora) grow and it is quite normal for them to be visible. The skin of the vulva has lots of nerves in it which means it is very sensitive to touch.

#### Why have I got this condition?

Usually there is no obvious reason why you have got lichen sclerosus. It can be associated with other autoimmune conditions such as diabetes and those affecting

the thyroid gland. Friction, when the skin rubs against something, such as panty liners or tight clothing can trigger the condition.

## What are the symptoms?

The common symptoms are of itchy, sore skin around the genital area and bottom. This can cause the area to be uncomfortable when passing stools (pooing) and lead to constipation. Activities like riding a bike or a horse can be uncomfortable. In the genital area, there are likely to be pale areas of skin and also red areas which may sometimes bleed. If not treated, the skin can split and bruise and scarring can occur. The symptoms can be mistaken for other conditions like thrush and eczema, particularly in the early stages.

#### 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 vulva. It may feel a bit embarrassing to have someone look at your vulva but, in the clinic, this is a normal thing to do. 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 bleeding and scarring.

#### How is lichen sclerosus treated?

Treatment is usually an ointment containing strong topical corticosteroids such as clobetasol propionate (Dermovate or Clobaderm). Your GP will refer you to a dermatologist who will recommend which treatments to use and ask your GP to give them to you on prescription

Although a strong corticosteroid ointment is being used, this is a tried and tested treatment which is safe. Always use the amount of ointment as advised by your doctor to ensure the treatment works. Weaker corticosteroids do not work as well.

### When is the treatment applied?

The ointment is applied to the affected area the vulva and around the bottom once a day. Initially, you will need to use the ointment every day for 4-12 weeks even if the symptoms improve quite quickly. Your dermatologist will discuss how many days a week to use the ointment after the first 4-6 weeks (for example you may reduce to alternate days.)

Lichen sclerosus can flare up again, even after treatment. If this happens you can use the same ointment for a few days to control the symptoms.

Using the ointment regularly (for example 2 days a week) for at least the next 12 months may help to prevent future flare-ups.

Your dermatologist will give you information about how to treat any flare-ups and how to use the ointments

### When should the treatment not be applied?

After the initial 12 weeks, treatment 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 but not putting on a strong corticosteroid when this 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 that swabs can be taken to check for infection, and they will give advice on how to treat any infection that is present.

### What can you expect?

This condition can sometimes cause no symptoms or may get better without treatment. However, treatment will improve things more quickly and may reduce the risk of long-term problems.

Lichen sclerosus in children tends to improve with treatments and symptoms can improve as you get older but it may not completely disappear. Flare-ups may still be experienced which will need to be treated with the strong corticosteroid ointment. Ongoing review may be required.

Girls are not likely to have any problems with their periods, sexual intercourse, pregnancy or delivery of babies, if the skin condition has been treated.

There is a very small risk of developing certain types of genital skin cancer, if the condition continues into adulthood. Your dermatologist will tell you if there is a need to be seen regularly. If your symptoms are under control, unless you have a flare, like many other children you will not need to be seen again by the dermatologist.

### Other treatments

A different anti-inflammatory ointment (tacrolimus, a <u>calcineurin inhibitor</u>) can be used in some cases. A strong corticosteroid ointment is usually used as there is better evidence that they work.

It is important not to irritate the skin. Using non-fragranced moisturising emollient cream instead of soap can help to reduce irritation (see information on vulvitis). You can get this on prescription from the GP.

There is some evidence that silk or cotton underwear can be better for symptoms compared to synthetic underwear.

### Where can I get further information?

The Association for Lichen Sclerosus and Vulval Health is a useful resource

The Association for Lichen Sclerosus and Vulval Health

NHS Patient information:

https://www.nhs.uk/conditions/lichen-sclerosus/

National treatment guidelines:

<u>British Association of Dermatologists guidelines for the management of lichen</u> sclerosus (2018)

For details of source materials used 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 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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