



LICHEN SCLEROSUS PATIENT INFORMATION LEAFLET

What are the aims of this leaflet?

This leaflet has been written to help you understand more about lichen sclerosis. 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 sclerosis?

Lichen sclerosis is a relatively uncommon condition in which thin white crinkly patches appear on the skin. They can come up anywhere, but cause most trouble in the genital areas.

What causes lichen sclerosis?

The cause of lichen sclerosis is not known. Sometimes it is associated with diseases in which the body's immune system attacks normal tissues such as the thyroid gland (causing an over or under active thyroid gland) or the insulin-producing cells in the pancreas (causing diabetes). However, there is no evidence this is happening in lichen sclerosis itself.

Lichen sclerosis can occur in either sex and at any site, but is more common in women, in whom the vulva is the most common site. Lichen sclerosis can affect women of any age and may occasionally develop in girls prior to puberty. A similar process affects men and boys. Despite the tendency to affect genital skin, lichen sclerosis is not an infection - it is quite certain that the disease is not contagious, so sexual partners cannot pick it up.

Is lichen sclerosis hereditary?

Rarely lichen sclerosis can occur in relatives.

What are the symptoms of lichen sclerosis?

Many patients have none, but the most common symptom of lichen sclerosis is itch. As a rule the spots on the general skin surface seldom itch much, but those in the genital area do, and can be sore if the skin breaks down or cracks. In the genital area, the scar-like process can tighten the skin, and this can interfere with sexual intercourse in affected men or women. In men, lichen sclerosis can make the foreskin tight and difficult to retract, and can even partly block the flow of urine.

What does lichen sclerosis look like?

On the main areas of the skin, the spots of lichen sclerosus look like small ivory-coloured slightly raised areas, which can join up to form white patches. Some have tiny yellowish horny plugs within the pale areas. After a while the surface of the spots can look like wrinkled tissue paper. The most common sites are the bends of the wrists, the upper trunk, around the breasts, the neck and armpits.

Women with lichen sclerosus in other areas of the body often have it on the vulva as well. Sometimes this causes no symptoms and they may not even know it is there. The white thin fragile areas, surrounding the vulva and the anus in a figure of eight pattern, have a crinkly surface, and their fragility may lead to easy bruising and erosions. Later on, the inner lips of the vulva and its opening can shrink, leading to pain on intercourse, but this is unusual in most cases. Less often lichen sclerosus can develop in young girls - in which case, about two thirds get better at puberty. A similar process in men affects the penis (balanitis xerotica obliterans): it can make retraction of the foreskin difficult and interfere with passing water.

How will lichen sclerosus be diagnosed?

The diagnosis of lichen sclerosus can usually be made from the typical appearance of the spots. However lichen sclerosus can look a bit like vitiligo (though this has a normal skin texture) and lichen planus (which is more purple). If there is any doubt, the examination of a small specimen of skin (a biopsy) under the microscope will help.

Can lichen sclerosus be cured?

No treatment is sure to reverse the changes of lichen sclerosus completely, but the symptoms and signs of the disease can usually be well controlled with a steroid application.

How can lichen sclerosus be treated?

A variety of treatments is available for lichen sclerosus:

- Your symptoms can be relieved by the use of steroid creams or ointments. It is usual to treat symptomatic skin with quite strong steroids regularly for two to three months, and then to keep things under control with only occasional applications. This may be more effective than continuing with milder creams, and is safe for this period of time.
- Bland moisturisers help to soften and protect the skin.
- In men, tightening of the foreskin will often respond to steroid ointments. If not, a circumcision may be worth considering.
- The fragile skin of lichen sclerosus may be more susceptible than normal skin to infection with candida yeasts (thrush) or bacteria; and may split or even bleed. Your doctor will treat all of these problems on their merits.

What can I do?

- Cancer of the vulva may be a little more likely to occur in lichen sclerosus that has been present for many years than in normal skin. If you have any lumps or non-healing sores in that area, you should ask your doctor to look at them.

- If sexual intercourse is painful because of tightening at the entrance to the vagina, the use of lubricants, and on occasions of vaginal dilators, will help.

Where can I get more information about lichen sclerosis?

The patient support group is:

Lichen Sclerosis Support Group (NLSSG), PO Box 7600, Hungerford, RG17 7XD.

www.lichensclerosis.org

Web links to detailed leaflets:

www.niams.nih.gov/hi/topics/lichen/lichen/htm

www.emedicine.com/derm/topic234.htm

www.dermnetnz.org/dna.ls/ls.html

Published guidelines for the management of lichen sclerosis: British Journal of Dermatology (2002), volume 147, pages 640-649.

(While every effort has been made to ensure that the information given in this leaflet is accurate, not every treatment will be suitable or effective for every person. Your own doctor will be able to advise in greater detail)

**BAD PATIENT INFORMATION LEAFLET
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