



Lichen sclerosus

Information for patients from Women's Health

You have been diagnosed with a skin condition called lichen sclerosus. This leaflet will explain:

- · what lichen sclerosus is
- · what the symptoms and causes are; and
- how the condition is diagnosed and treated.

We hope the leaflet will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of your healthcare team.

What is lichen sclerosus?

Lichen sclerosus is a skin condition which commonly affects the vulva (genital skin) of women. Less commonly it affects other areas of the skin.

It can happen at any age but most commonly develops in middle-aged women. It is estimated that lichen sclerosus effects about one in 1000 women. However, it may be more common than this, as some mild cases may go undiagnosed.

Lichen sclerosus is a skin condition only and does not extend into the vagina and inside the anus.

What are the symptoms of lichen sclerosus?

In a typical case, small pearly white patches develop on the vulva which are usually itchy. However, in some people, there is no itch or other discomfort. Lichen sclerosus is sometimes diagnosed by chance when a doctor examines the genitals for another reason.

In about 3 in 10 cases, the skin around the anus is also affected (sometimes it is only the skin around the anus that is affected). Typically, the itch and irritation become persistent and distressing. The itch tends to be worse at night, which can disturb sleep. Sometimes soreness, rather than itching, is the main symptom.

Small patches of lichen sclerosus can appear on other parts of the body. These look like small pearly white areas on the skin. They can appear in people who also have genital lichen sclerosus, and sometimes they

happen without genital problems. Away from the genital area patches of lichen sclerosus may not cause itching or other symptoms.

What if lichen sclerosus is left untreated?

Overtime the white patches may become larger and join together. The whole vulva and / or anal skin may become white and be more fragile than normal. The fragile skin may become damaged, inflamed, raw, and more likely to cause painful splitting and cracking. If the anal skin is affected, passing stools may cause pain and splitting of the skin.

If left untreated over months or years, the vulva may atrophy (shrink). In some cases, the changes to the vulval skin may make the entrance to the vagina narrower, which can make it difficult or painful to have sex. Thrush and other infections also tend to be more common if the vulva is sore and / or cracked.

Symptoms may slowly get worse but you may not get all of the above symptoms. It can take months or years for the first skin patches to progress to more severe symptoms. At first the symptoms may be mistaken for thrush or other problems, if the vulva is not examined.

What causes lichen sclerosus?

The cause is not known. There is a type of inflammation within affected skin, which causes changes to the structure of the affected skin but it is not clear why this happens. It is not due to infection.

The cause is possibly an autoimmune disease. This is when the body's immune system attacks a part of the body. This causes inflammation and damage to the affected part of the body. In people with lichen sclerosus the genital area of skin may be attacked by some parts of the immune system, which then causes inflammation.

Can complications develop from lichen sclerosus?

- The itch and discomfort may cause distress.
- The changes to the genital skin may cause problems when having sex or passing urine.
- There is also a small increased risk of developing cancer of the vulva. The exact risk is not known, but about 4 in 100 women with lichen sclerosus develop this form of cancer.

How is lichen sclerosus diagnosed?

The appearance is often fairly typical, so no further tests are needed. If the diagnosis is in doubt, a small sample (biopsy) of affected skin may be taken under local anaesthetic (you are awake but the area is numbed). The sample of skin is put under the microscope to look at the structure of the skin cells and tissues. This can confirm the diagnosis and rule out other disorders, which can sometimes mimic this condition.

For more information on what to do following your biopsy, please read the **Discharge advice following a vulval biopsy** leaflet. (/discharge-advice-following-a-vulval-biopsy)

What is the treatment for lichen sclerosus?

A strong steroid ointment or cream (topical steroid) is the main treatment, as steroids reduce inflammation. The ointment or cream is usually applied regularly, as recommended by your doctor.

How long does it usually take for the treatment to work?

Irritation tends to ease after 2 weeks, but the skin may take about 3 months of treatment to look and feel better.

If diagnosed and treated with a topical steroid at an early age, the skin may return to normal. However, if the appearance of the skin has already changed a lot, the changes may not reverse much with topical steroid treatment. Although symptoms of itch and soreness are often relieved.

Will it go away permanently?

There is no permanent cure for lichen sclerosus. However, treatment with a topical steroid usually controls the symptoms of itch and soreness. It often prevents the condition from getting worse as well.

How do I check for vulval cancer?

Cancer of the vulva is an uncommon complication of lichen sclerosus. However, it is best to get into the habit of checking your vulva about once a month, to look out for any signs of early vulval cancer. As a rule, the earlier any cancer is detected the easier it is to treat.

To check your vulva, use a hand-held mirror to see your vulva and use your fingers to feel your vulva. Get to know what your vulva looks and feels like, and see a doctor if any changes occur. Changes can include thickening, warts, lumps, ulcers, blisters, or sores.

Further information

 Lichen sclerosus in females: British Association of Dermatologists (BAD) (https://www.bad.org.uk/pils/lichen-sclerosus-in-females/)

Note

We have used the term 'women' throughout this leaflet. When we use this term we also mean people with female reproductive organs who do not identify as a woman. East Kent Hospitals is committed to supporting people of all gender **identities**. Please tell your nurse or doctor how you would like them to address you, so we can be sure to get this right.

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- · If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (https://www.ekhuft.nhs.uk/ais).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (https://pp.ekhuft.nhs.uk/login).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekhtr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

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