

# Lichen sclerosis

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## Information for patients from Women's Health

This leaflet is not meant to replace the information discussed between you and your doctor, but can act as a starting point for such a discussion or as a useful reminder of the key points.

### What is lichen sclerosis?

Lichen sclerosis 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 sclerosis affects about one in 1000 women. However, it may be more common than this as some mild cases may go undiagnosed.

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

### What are the symptoms of lichen sclerosis?

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, and lichen sclerosis is sometimes diagnosed by chance when the genitals are examined by a doctor for another reason.

In about three 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 becomes persistent and distressing. The itch tends to be worse at night which can disturb sleep. Sometimes soreness rather than itching is the main symptom.

Sometimes small patches of lichen sclerosis 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 sclerosis, and sometimes they happen without genital problems. Away from the genital area patches of lichen sclerosis may not cause itching or other symptoms.



### What if lichen sclerosis is left untreated?

Overtime the white patches may become larger and join together. The whole vulval and/or anal skin may then become white and be more fragile than normal. The fragile skin may become damaged, inflamed, raw, and more likely to painful splitting and cracking. If the anal skin is affected, passing faeces (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 sclerosis?

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.

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 sclerosis the genital area of skin may be attacked by some parts of the immune system which then causes inflammation.

### Can complications develop from lichen sclerosis?

- 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 it is thought that about four in 100 women with lichen sclerosis develop this form of cancer.

### How is lichen sclerosis 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 ask a member of staff for a copy of the Trust's **Discharge advice following a vulval biopsy** leaflet or download a copy from the Trust web site [www.ekhuft.nhs.uk/gynaecology-patient-leaflets/](http://www.ekhuft.nhs.uk/gynaecology-patient-leaflets/)

### What is the treatment for lichen sclerosis?

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 two weeks or so, but the skin may take about three months of treatment to look and feel better.

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

### Will it go away permanently?

There is no permanent cure for lichen sclerosis. However, treatment with a topical steroid usually controls the symptoms of itch and soreness, and often prevents the condition from getting worse. Occasionally the condition clears away for good for no apparent reason.

### How do I check for vulval cancer?

As mentioned on page two, cancer of the vulva is an uncommon complication of lichen sclerosis. 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 (for example, if you find any thickening, warts, lumps, ulcers, blisters, or sores).

### Further information

- **Association for Lichen Sclerosus** (a UK based organisation offering information and support to people with lichen sclerosis)  
**Telephone:** 07858 40 24 73 (mobile)  
**Web:** [www.lichensclerosus.org](http://www.lichensclerosus.org)

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

**Any complaints, comments, concerns, or compliments** please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email [ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)

**Patients should not bring in 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 had been handed in to Trust staff for safe-keeping.

**Further patient leaflets** are available via the East Kent Hospitals web site [www.ekhuft.nhs.uk/patientinformation](http://www.ekhuft.nhs.uk/patientinformation)