

Patient Information Leaflet.

Lichen Sclerosus.

What is Lichen Sclerosus?

Lichen sclerosus is an uncommon skin condition that most commonly affects the vulva (genital skin) of women, although other areas of skin may also be affected. Though Lichen Sclerosus may occur at any age it most commonly occurs in middle-aged women with an incidence of approximately 1 in 1,000 women.

What causes Lichen Sclerosus?

The cause of Lichen Sclerosus is not known although it 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. However, this has not been proved and it is not known what triggers lichen sclerosus to develop.

About 1 in 4 people with lichen sclerosus have another autoimmune disease such as thyroid disease, vitiligo, or pernicious anaemia. This is why it is thought that lichen sclerosus is also an autoimmune disease.

What are the symptoms of Lichen Sclerosus?

The most common symptom of Lichen Sclerosus is itching. The itch tends to be worse at night, which can disturb sleep. Sometimes soreness rather than itch is the main symptom.

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

The skin may become pale or white and become more fragile than normal. The fragile skin may become damaged, inflamed, raw, and prone to painful splitting and cracking. It may become painful to have sex. If the anal skin is affected, passing faeces (stools) may cause pain or splitting of the skin.

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

Symptoms may slowly get worse but not all the above symptoms may occur. It can take months or years from the first small spots to progress to more severe symptoms. At first the symptoms may be mistaken for thrush or other problems if the vulva is not examined.

Can there be any complications from Lichen Sclerosus?

The itch and discomfort may cause much distress and the changes to the genital skin may cause sexual difficulties or problems in 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 4 in 100 women with lichen sclerosus develop this cancer.

How is Lichen Sclerosus diagnosed?

The appearance of Lichen Sclerosus is often fairly typical so can often be diagnosed simply by the appearance of the skin. Sometimes to confirm the diagnosis a small sample (biopsy) of affected skin may be taken under local anaesthetic and examined under the microscope. This can confirm the diagnosis and rule out other disorders, which can sometimes mimic this condition.

What is the treatment for Lichen Sclerosus?

A strong steroid ointment or cream (topical steroid) is the main treatment often used in conjunction with a bland moisturizer.

It is important to maintain treatment for as long as advised. Irritation tends to ease after two weeks or so, but the skin may take about three months of treatment to look and feel better.

Can my Lichen Sclerosus be cured ?

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

Where can I get further information about Lichen Sclerosus ?

We recommend that you use dedicated websites or helplines to gain further information on lichen sclerosus as generic internet searches can lead to you reading information that is not accurate or out of date.

National Lichen Sclerosus Support Group -

Helpline: 07765 947599

Web: www.lichensclerosus.org

Vulval Health Awareness Campaign (VHAC) –

Web: www.vhac.org