

Lichen sclerosis

You have been advised that you have a condition called lichen sclerosis. This leaflet outlines the symptoms and explains the treatment options. If there is anything you do not understand or if you have any questions, please ask the clinic nurse or telephone us on 0118 322 7181.

What is lichen sclerosis?

Lichen sclerosis is a skin condition. It most commonly affects the vulva and skin area surrounding the anus. The vulva is the skin covered area of the female genitalia, outside the vaginal opening. Lichen sclerosis does not affect the inside of the vagina. Parts of the affected skin become thickened (lichenified) while other parts become thin, crinkly and pale-looking (atrophic). There can also be shrinkage of the skin.

It is mostly seen in women of menopausal age (3%), although it is known to occur rarely in young girls aged 3-5 years old (0.1%).

This leaflet is aimed mainly at mature women with the condition.

Is it contagious?

The condition is not contagious and cannot be transmitted between partners. It is not a result of poor personal care but careful hygiene measures can help control it.

What are the symptoms?

- **Itching:** the commonest symptom is itching, soreness and even pain around the vagina and the anus.
- **Skin splitting:** the skin may become fragile and split, especially if it is scratched a lot.
- **Difficulty with sex:** Soreness around the vaginal opening may make sexual intercourse painful. This is due to shrinking of the skin surrounding the vagina, making the entrance to the vagina narrow. This problem is seen in only a few women suffering from lichen sclerosis.
- **Difficulty passing stools:** if the skin around the anus is affected it may be uncomfortable passing a bowel motion.
- **Problems with passing urine:** if lichen sclerosis affects the skin around the urethra (the hole you pee out of), passing urine may be uncomfortable and you may feel the need to pass urine more often. The skin edges may become 'stuck' together (adhesions). This may partially block off the urethra and so cause 'spraying' on passing urine.

What causes lichen sclerosis?

The cause of this condition is unknown. In 30% of cases it is associated with the kind of diseases that involve the production of antibodies against the body's own tissue, e.g. thyroid disease or diabetes. These diseases are called 'auto-immune' diseases. It is possible that lichen sclerosis is also an auto-immune disease although there is no real proof of this.

We do know that the disease is not contagious. You have not 'caught' it from a sexual partner, nor can you pass it on to anyone else.

What treatments are available?

- **Steroid creams:** the main treatment of lichen sclerosis is with steroid creams. The other treatments mentioned in this leaflet are soothing and will help your symptoms, but only steroid creams will improve the skin condition. There are a number of different preparations available and your doctor will instruct you on how often and how long to use the cream.
- **Stop using soap:** avoid all soaps, gels, bubble baths and scented products in the bath or shower. These are likely to contain chemicals, which will irritate sensitive areas of skin and make your symptoms worse. Aqueous cream should be used instead of soap to clean the skin around the vagina and anus. It is inexpensive and readily available from high street chemists.
- **Aqueous cream** can also be very soothing for cleaning the anal area after bowel motions, put some aqueous cream on the toilet tissues. It eases the 'scratchy' feeling that toilet paper has on sensitive skin. Remember to wash your hands after applying the cream.
- Keep some aqueous cream in the fridge. You can use it to dab (don't rub it in) onto sensitive areas at any time of day. It is very soothing.
- **Vaginal lubricants:** if sexual intercourse is painful, the use of lubricants (e.g. KY Jelly or aqueous cream) and, on occasions, vaginal dilators may help. Don't be shy about discussing this with your doctor or nurse.
- **General measures:** avoid wearing tight trousers and tights. Women with lichen sclerosis often find loose cotton underwear is more comfortable.
After washing 'down below', pat the area dry rather than rubbing. Some people find that using a hair dryer on a cool setting and held well away from the skin is more soothing.

Can surgery help?

Occasionally, it may be necessary to take a small sample of skin (biopsy) from the affected area to make the diagnosis of lichen sclerosis. This can usually be done using an injection of local anaesthetic to numb the area. If the area is very sore, a general anaesthetic (i.e. you are asleep) may be better.

Surgical removal of the affected area will not cure the condition and unfortunately the lichen sclerosis will return. In exceptional circumstances, if the tissues are stuck to each other causing problems peeing or difficulty in sexual intercourse, corrective surgery to release the stuck tissues might help. This is done only in specialised centres.

What happens in the long term?

Some women have no more symptoms after the first treatment for the condition. Others will have flare-ups and remissions. Using the cream for a couple of weeks every time you think the condition is starting to flare up usually settles things down again.

How often should I see my doctor?

You will be reviewed by a doctor 3-6 months after the initiation of treatment to see whether treatment is effective.

If you are responding to steroid cream, visit your GP every year to have a look at the affected area. You should visit your doctor earlier, if you have non healing ulcers or lumps. Your doctor will refer you to a specialist for further assessment.

Why do I need to see my doctor every year?

There is less than 5% risk of developing skin cancer in those women who have Lichen Sclerosus, so it is important for you to have the annual examination done by your GP.

Further information

More information can be found through the National Lichen Sclerosus Support Group

www.lichensclerosus.org

<http://lichensclerosus.org/contact-us/>

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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