



ANZ Vulvovaginal Society

Lichen sclerosus

What is lichen sclerosus?

Lichen sclerosus (LS) is a chronic inflammatory skin condition. It can occur anywhere on the body but is most often found on the vulva. This information sheet focuses on vulval LS.

LS can occur at any age, including in childhood. Some people used to believe that it 'went away' in teenagers, but we now know this is not true. Over the years it has better and worse phases, but it is always there. Since it is a chronic disease, it needs to be managed with ongoing treatment. To prevent complications from LS, it is important to be diagnosed promptly, started on appropriate treatment, and have return visits to make sure the condition is controlled. Almost all people with LS need a treatment regimen that continues throughout their life, and a doctor or women's health nurse who does vulval skin checks at least once a year. People with severe LS need daily treatment and review with their doctor several times per year.

What are the symptoms of lichen sclerosus?

For most people, LS is itchy. Some people report discomfort, pain, stinging with urination, skin splits, and uncomfortable sex. About 10% of people have no symptoms. Some people notice their skin is pale and looks whiter than in the past. They may notice a different texture to the skin and describe it as thin, crinkled, dry, or fragile. Other people find their skin has become thick and rough. Another possible change is the labia minora are 'stuck' or seem to be smaller than before.

What does lichen sclerosus look like?

LS is different from person to person. In some people there is an oval or figure-of-8 shape of pale or pink-white skin, with an obvious border between normal and affected skin. In others there are white dots and splotches scattered around. It can affect just one place, like the perianal area or periclitoral region (see *Vulval anatomy*). When it has been scratched or rubbed, there might be purple areas of bleeding under the skin, thick white areas, splits, and red shiny areas where the skin has come away. When infected with yeast or bacteria, the skin may look pink or red



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with flakes or tiny pimples. If doctors are not familiar with the way LS looks in children, changes like bruising and skin splits make them worry about sexual abuse.

Changes to the vulval anatomy are also different from person to person. In some people, everything stays the same. In others, there are minor changes to the skin folds, especially around the clitoris. In others, the labia might completely disappear, and the clitoral hood might flatten or close over the clitoris. The posterior part of the labia may become scarred, making the opening to the vagina less flexible.

How do we make the diagnosis of lichen sclerosus?

Doctors and women's health nurses with experience in vulval skin conditions can make the diagnosis based on the way the vulva looks. In adults, it is often useful to take a skin biopsy to confirm the diagnosis and provide proof for future doctors that ongoing treatment is required (see *Biopsy*). Most of the time, the biopsy report describes typical features LS and provides a clear diagnosis. However, sometimes the biopsy report is non-specific, and just mentions inflammation or changes due to chronic scratching. When the diagnosis was made by someone who knows a lot about vulval skin conditions, a negative or non-specific biopsy report does not 'overturn' that diagnosis. Sometimes the biopsy cannot tell the difference between LS and lichen planus (see *Lichen planus*). In this situation, it is important to continue treatment and base the decision about the diagnosis on how the skin looks.

What are the complications of lichen sclerosus if it is not treated?

Lichen sclerosus causes major problems to quality of life and sexual function. Any uncomfortable condition in the vulval area may increase the chances of having chronic pain in that area. The changes to vulval anatomy that occur due to LS are permanent and irreversible. These can be prevented if adequate steroid ointment treatment is provided promptly and continued indefinitely. The goal of treatment is to make the skin look and function as normally as possible. This means that the inflammation settles down, so the skin does not stick and scar together anymore.

Before we knew how to effectively treat LS, there was a 5% (1 in 20 people) rate of vulval cancer and pre-cancer in patients with LS. Any vulval cancer or pre-cancer



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should be removed surgically, and this can result in scarring and loss of important structures. Treatment for vulval cancer often involves removal of groin lymph nodes. It seems that early and high-quality treatment of LS reduces the risk of vulval cancer to less than 1%.

Some people are tempted to stop their steroid ointments once they feel better – this is not a good idea. People may seek out miracle cures on the internet – these range from laser to platelet-rich plasma to fat transplants to supplements or ‘natural’ lotions. At this time, there is no such thing as a cure for LS – so any person or product that claims to cure LS is making a promise they/it cannot keep. There are many products that improve symptoms, and this makes people think the disease is gone. Making matters worse, some doctors will tell people they don’t have to use treatment if they feel OK. Unfortunately, the degree of symptoms does not match up with the level of disease activity. Likewise, symptoms are not a good predictor of the risks of scarring and vulval cancer. For these reasons, consult with an expert in LS before stopping steroid ointments or signing up for surgery, laser, or injections.

What is standard treatment of LS, and how do I know it is working?

Corticosteroid ointment is the tried-and-true treatment for LS. There are excellent long-term studies on its safety and effectiveness. There are no other options that come close to how well steroid ointments work for this condition.

The strength and frequency of steroid ointment can be individualised. Each person’s LS is different, so it makes sense that each person needs to find the right steroid regimen for their situation. Some people like to get into a pattern using ointment every day. Other people find it easier to use something 2 or 3 times a week. So, if someone has mild LS, they might be able to use a low-strength steroid daily or a medium-strength steroid 2-3 times per week. A person with moderate LS might use a medium-strength steroid every day, or a strong steroid 2-3 times per week. If someone has severe LS, they will need a strong steroid every day. Your GP should continue to prescribe the steroid ointment, since you will use it long-term.



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The steroid ointment may be applied right after a shower or bath. Pat the skin dry and then apply it to all affected areas. Your specialist often will point out all the places you need to put it. Many people forget to put it on the area just under the clitoris or the area around the anus. Another common mistake is to spread it out too far sideways. Often the hairy skin of the labia majora does NOT have LS – if that is the case, then steroid does not need to go there.

It is best to wait at least 30min after applying the steroid before putting anything else on the vulval skin. To maintain the skin's moisture and health, people with LS should find a soothing barrier ointment or oil and apply this at least 1 other time per day (see *Vulval care advice*).

People with LS on steroid ointment may experience yeast infections or herpes outbreaks (see *Vulvovaginal candidiasis*). While this is annoying, it is not dangerous. If this is a recurrent problem, a preventative regimen of tablets for yeast or HSV may be helpful. Warts also can occur and usually are not treated unless they are causing symptoms (see *HPV and the vulva*). If you notice new lumps or bumps, make sure your doctor or nurse takes a look. Sometimes a biopsy is needed to make sure the bump is not something more serious.

You know the treatment is working if the skin looks, feels, and functions normally. It is NOT good enough to have the symptoms under control if the skin still has an abnormal colour and texture. Most people have a hard time examining their own vulva – using a mirror or taking your own photos can be helpful. A regular review with your doctor or women's health nurse is important to see if the disease is being controlled and guide you to areas that might need more attention.

I'm not sure about using steroid ointments – what should I do?

Lots of people are afraid of using steroids and there are many myths about them. Even chemists will sometimes cause fear by telling people things like 'use only a tiny amount' or 'only use this for a short period of time'. The things you hear and read about steroid ointments do NOT apply to chronic vulval skin conditions like LS and LP. The people who are giving you this advice have no idea what your condition is,



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how it behaves, and the risks of not treating it. If you have concerns, it is best to speak to an expert in LS who can examine you and provide individualised advice.

Experts in LS find that the biggest problems result from UNDER-treatment. In the rare case that people use more steroid than they need, this shows up as red skin with a normal texture. This is a reversible change once the strength or frequency of the steroid is reduced.

Is it OK to have sex if I have LS?

Yes, so long as the condition is well controlled. If people try to have sex when the skin is inflamed, it might cause skin splits, bruising, and pain. If people keep having sex when it is painful, the pain nerves may become overactive and pelvic floor muscles may become tight and tender.

After menopause, many people find that oestrogen cream or pessaries help sex be more comfortable. Some people benefit from patches or tablets that provide oestrogen and/or progesterone to the whole body. The *Australian Menopause Society* has excellent information sheets about this.

If there has been scarring around the vaginal opening, treatment options include pelvic floor physiotherapy and vaginal trainers. Steroid ointments help to soften scar tissue, so treatment may improve things over time. Rarely, people need a small surgical procedure to release scar tissue that interferes with sex or urination. This only works if strong steroid ointments are used daily to twice daily before and after surgery until the skin is healed, and then in a long-term regimen.

Does lichen sclerosus cause problems for pregnancy and childbirth?

Since LS is so common, many people with LS fall pregnant and give birth. It is important to continue steroid ointments throughout this time. The strength and frequency of steroid should NOT be decreased just because of pregnancy. Well controlled LS does NOT cause problems with pregnancy or birth. Women with LS can have a vaginal birth and it is fine for them to have episiotomy, forceps, or ventouse-assisted birth if needed. There is no reason to request a caesarean just



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because of LS – this decision should be based on any other issues going on with baby and mother. It is common for LS to flare after childbirth. Check with your vulval specialist about your treatment plan after birth – you may need to increase the steroid and have more frequent visits until everything settles down.

Why did this happen to me?

Lichen sclerosus is a common skin condition, affecting at least 5% (1 in 20) of people who have gone through menopause. No one knows why it happens. It is NOT contagious, and it is NOT transmitted sexually. People with LS often have a family member with LS. People with LS are more likely to have autoimmune thyroid disease or other autoimmune conditions. The most severe forms of LS seem to occur in people who are overweight, have diabetes, and have chronic urine leakage. However, many people with LS do not have any other medical problems.

We know what is happening to the skin in people with LS. T-cells are a type of white blood cell. These are the cells in our bodies that fight infection and cause inflammation. In LS, the T-cells attack the bottom layer of the skin. This 'attack' damages the skin, so the skin tries to repair itself. While the LS is not treated, there is a cycle of damage and repair and a fine layer of scar tissue is set down just underneath the skin. When we treat with steroid ointments, this makes the T-cells go away. That way the skin can repair itself and then stay normal. However, if treatment stops the T-cells gradually find their way back to the skin to attack it and re-start the cycle of damage and repair.

What does the future hold?

People with vulval LS can expect to have an excellent outcome with normal function, so long as they commit to using steroid ointment regularly and periodic review with their doctor or women's health nurse. Lichen sclerosus is an active area of research, so people may consider taking part in a study to contribute to medical knowledge about this common condition. In the future, it is possible researchers will identify the reason for T-cell attack on the skin and find a way to prevent this from happening.