



# Lichen Sclerosus Guide

## The LS Guide

Empowering everyone with vulval lichen sclerosus (LS) to learn about the condition, access the right treatment and live more comfortably.

If you've got vulval LS, or you're supporting someone who has, we've created this guide to help you. Written by our team of doctors, researchers and, most importantly, people with LS, it's full of information, practical advice and easy-to-use resources to help you learn more, and live better.



### What is vulval LS?

Learn about LS, what causes it and the signs and symptoms to look out for. Get to know the anatomy of the vulva and how to do your own regular vulva checks at home.



### Medical support

Find out how to get an LS diagnosis, what to expect and who can help. Learn about the specialists you might see and the appointments you should have.



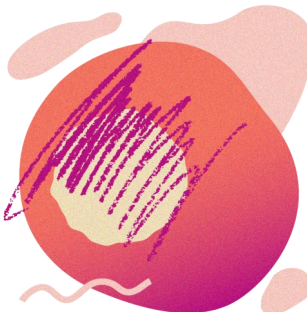
### Treatment for vulval LS

Get to know about LS treatment, find out how it works and how to calm and control your symptoms at home.



### Everyday life with LS

Get to know how to look after your vulva and prevent and relieve your LS symptoms. Find practical advice on sex, periods, clothing, exercise and emotional wellbeing.



### LS in the long term

Learn how LS can progress over time, how treatment might change, and how this relates to other conditions, including vulval cancer, the menopause and incontinence.



### Families, carers, and health professionals

Find out about supporting someone with LS, including the role you can play, the help they might need, how to do vulva checks and what support is available, for them and you.





# Lichen Sclerosis Guide

## What is the guide for?

The guide is here to give you the information you need to get a diagnosis, treatment and support for your LS, as well as to manage your symptoms and make everyday life easier.

## Who is the guide for?

The LS guide focuses on adult vulval lichen sclerosis (LS), which can affect anyone who has a vulva. We recognise that not everyone who has vulval LS will identify as a woman. It's a condition that can affect anyone assigned female at birth, including those who are non-binary, gender non-conforming, or trans.

We've included information for partners and carers, so they can provide the emotional and physical support their loved ones or clients with vulval LS need. We also hope that health professionals will find the guide a useful resource for growing, consolidating, or refreshing their understanding of LS.

While LS can affect different parts of the body, our focus in this guide is on supporting adults with vulval LS, so we don't currently provide specific information about children's LS (also known as juvenile or paediatric LS), or penile LS. Find links to information about these conditions on our website.

## Who created the LS guide?

**Dr Sophie Rees**, Research Fellow, University of Bristol; **Dr Caroline Owen**, Consultant Dermatologist, East Lancashire Hospitals NHS Trust; **Clare Baumhauer**, Patient Advocate, creator of LS & Vulval Cancer Awareness UK; **Zoe Breem**, Patient Advocate; **Dr Lisa Kirby**, Consultant Dermatologist, Nottingham University Hospitals NHS Trust; **Jaclyn Lanthier**, Patient Advocate and creator of The Lost Labia Chronicles; **Dr Rosalind Simpson**, Associate Professor and Consultant Dermatologist, University of Nottingham and Nottingham University Hospitals NHS Trust

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# Vulval lichen sclerosis (LS)

- Causes, symptoms, and signs
- Anatomy of the vulva
- Checking your vulva

## Causes, symptoms, and signs

### What is vulval LS and who can get it?

Lichen sclerosis (LS) is a long-term skin condition that mainly affects the genital area, although it can actually appear anywhere on your skin. It's believed to affect at least 1 in 100 women, or people assigned female at birth. Men or people assigned male at birth can have penile LS, but this happens much less often.



It was previously thought that vulval LS mainly affected young children and postmenopausal women, but recent research is changing that. Today, we believe people of all ages can have LS, but it can often take several years before they're successfully diagnosed.

That's one of the reasons we created this guide. It's here to help you understand the symptoms of LS, get support and treatment, and learn to live more comfortably with the condition. It's aimed at any adult with vulval LS, as well as carers and healthcare professionals.

### What causes LS?

The cause of LS isn't yet fully understood. Some people seem more prone to it than others, and we know it can run in families, so it's likely some people's genes make them more at risk of developing it.

Autoimmune conditions, where the body's immune system targets normal tissues, tend to happen more often in people with LS. These include morphea, lichen planus, alopecia, vitiligo, thyroid autoimmune disease, diabetes, Crohn's disease and coeliac disease. However, LS itself hasn't been proven to be simply an autoimmune condition.

In people with vulval LS, urinary incontinence (leaking pee) also tends to be more common, but we don't yet know whether LS causes incontinence, or if LS is caused by incontinence. What we do know is that friction or damage to the skin for any reason can trigger LS and make it worse.

It's important to know that LS isn't caused by an infection. It's **not** contagious and can't be spread through contact, including sex. It's not related to allergies, and it doesn't lower your immunity or affect your internal organs.



## What are the symptoms and signs of vulval LS?

The most common symptoms reported by people with vulval LS are itching or discomfort around the vulva, but there's a range of other symptoms you might notice too. Sometimes people experience bleeding around their genitals or bottom because of cracks (known as fissures) in their skin. Some people find sex painful, less pleasurable, or even impossible. For others, going to the toilet (either to pee or poo), can also be painful. LS symptoms can make all sorts of ordinary, everyday activities, like sitting, walking and exercising, feel uncomfortable or difficult.

### Common symptoms you might feel:

- Itching
- Painful sex
- Pain or soreness
- Burning
- Irritation
- Feeling of dryness
- Change in sensation
- Pain when you pee or poo
- Disturbed stream when you pee

If you think you might have LS, or want some advice about getting help from a health professional for your vulval symptoms, read our information on diagnosis and support.

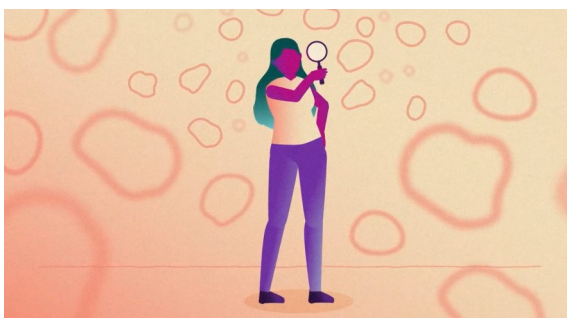
LS can also be asymptomatic, which means some people can have the condition without experiencing those uncomfortable or painful symptoms. Even if that's the case, they might still notice some visible signs of LS.

### Visible signs you might notice:

- White or pale patches of skin
- Crinkly or thickened skin
- Swelling
- Small cracks (fissures) in the skin
- Bleeding or bruising
- Areas of your vulva fusing together

LS can often cause white or pale patches of skin on your vulva and around your bottom. You might also notice these patches merging into areas of crinkly or thickened skin. It's common to experience swelling, particularly around your clitoris, or to notice small cracks (fissures) appearing in your skin. You might also see blood under the skin or bruising.

Over time, if it isn't treated, LS can also cause what's known as scarring or fusion, which is where parts of your vulval skin start to stick together. It means your inner lips (labia minora) might shrink and become stuck down, while your outer lips (labia majora) might start to stick (or fuse) together. Sometimes this can make the entrance to your vagina narrower, and the skin surrounding your clitoris stiffer and less flexible.



For more about scarring and fusion, [read our information on LS in the long-term](#).



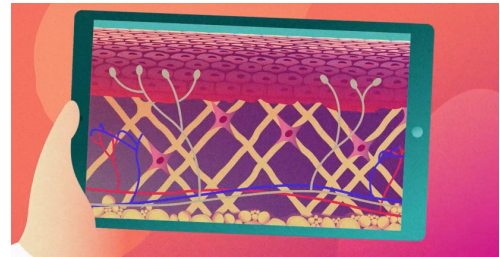
## Why does the skin change?

Your skin is divided into two main layers, the epidermis on the surface and the dermis underneath. The dermis is a complex structure, and contains blood vessels, nerves and collagen.

When you first get LS, it increases inflammatory cells (called T cells) which collect where your epidermis and dermis meet. These cells release tiny proteins called cytokines which upset the normal balance of your skin, affecting the way it works and renews itself. As LS develops, your epidermis (the top layer of your skin) becomes thinner. This is called epidermal atrophy, and it can make your skin look thin and wrinkled.

Watch our video on what LS is, and why the skin changes

<https://vimeo.com/1044752540>



## Are there any complications with vulval LS?

The most serious potential complication with LS is an increased risk of cancer. But it's important to remember that vulval cancer is very rare, so your risk will still be very low. If your LS is properly treated, it's thought this risk is even lower. We have lots more information on vulval cancer and pre-cancer in our LS in the long-term section.

## How can steroid treatment help?

At the moment, topical steroids (also known as topical corticosteroids) are the best treatment we have for LS. By 'topical' we mean a treatment that's applied to your skin, usually as an ointment or cream.

In LS, topical steroids reduce the inflammation caused by your body's T cells. This helps to stop damage to your skin and ease discomfort. To do this, they need to be very strong (you might hear this described as potent or very potent) so they can work deep down in your skin where the inflammation and damage is happening.

To find out more about topical steroids, and other options, [explore our treatment section](#).

## Is there a cure for LS?

LS is a long-term skin condition and, right now, there isn't a cure. But while many people have it for many years, it's really important to remember that you don't have to live with constant symptoms or discomfort. Help is out there, and we've put together this guide to help you find it.

Created by healthcare professionals, expert researchers and, most importantly, people with LS, it's your guide to understanding your treatment options, managing everyday life and feeling better, more of the time.



# Anatomy of the vulva

## Understanding your body

To really understand vulval lichen sclerosus (LS), it's important to understand your body, your vulva and what's normal for you. We know lots of people feel uncertain about the anatomy of that area, or uncomfortable asking questions in person. So in this section, we're going to explain the different parts of the vulva, and how they change over time.

## What exactly is the vulva?

Lots of people use the word 'vagina' when what they're actually talking about is the vulva.

If you're a woman, or were assigned female at birth, your vagina is the internal part of your genitals, and your vulva is the part that's on the outside of your body. It's the area of skin between your legs, going from the top of the area where pubic hair grows to just behind the entrance to your vagina.

## Does your vulva change as you get older?

Yes. Just like the rest of your body, your vulva changes over time. Hormonal changes during puberty, the menstrual cycle, pregnancy and menopause can all leave it looking a little different than before.

At puberty, the inner and outer lips become gradually larger and thicker. After puberty, your labia, particularly the labia minora (inner lips), become more prominent and more easily visible. The thickness and length of your labia can also increase after pregnancy and childbirth. You might also notice that your labial skin becomes darker in colour as you get older, or during pregnancy.

After menopause, your body produces less of the hormone oestrogen, and that can leave your vulva and vagina feeling thinner and less hydrated. As a result, you might notice your vulva feels drier and less plump.

## Do all vulvas look the same?

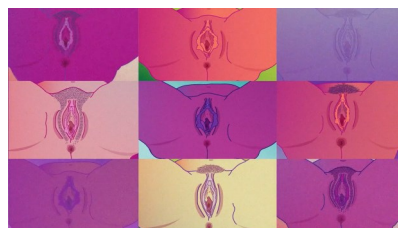
**No.** As well as all the changes that happen to your vulva as you go through life, it's important to remember that everyone's vulva is different. Yours won't necessarily look like the next person's, and that's ok.

Sometimes the pictures we see in the media, or in pornography, can make us feel self-conscious about how our bodies look. But vulvas and labia come in different shapes, sizes, and shades of pink, red, and brown. There isn't one right way to be. One side of your labia might look bigger than the other, or the skin tone there might be different to the rest of your body. **All of this is completely normal.**

We have a whole range of [resources](#) showing the variety of sizes and shapes of normal labia and vulvas.

Watch our video explaining  
vulval anatomy

<https://vimeo.com/1045687799>



## Your vulva is made up of the following parts:

### Mons pubis

This is the soft area where pubic hair grows. It's there to protect the pubic bone underneath, and acts like a cushion. As you go through puberty, this area becomes more rounded.

### Inner lips (labia minora)

The inner lips run from your clitoris down to the area of skin between your vagina and bottom (called the perineum). They're also very sensitive and swell when aroused. Labia minora are extremely variable in size and shape, so they can look very different in different people.

### Urethral opening

Your urethra is a tube which carries pee from your bladder down to the urethral opening, where it leaves your body. The urethral opening is a tiny hole between your labia minora, sitting below your clitoris but above your vaginal opening.

### Vaginal opening

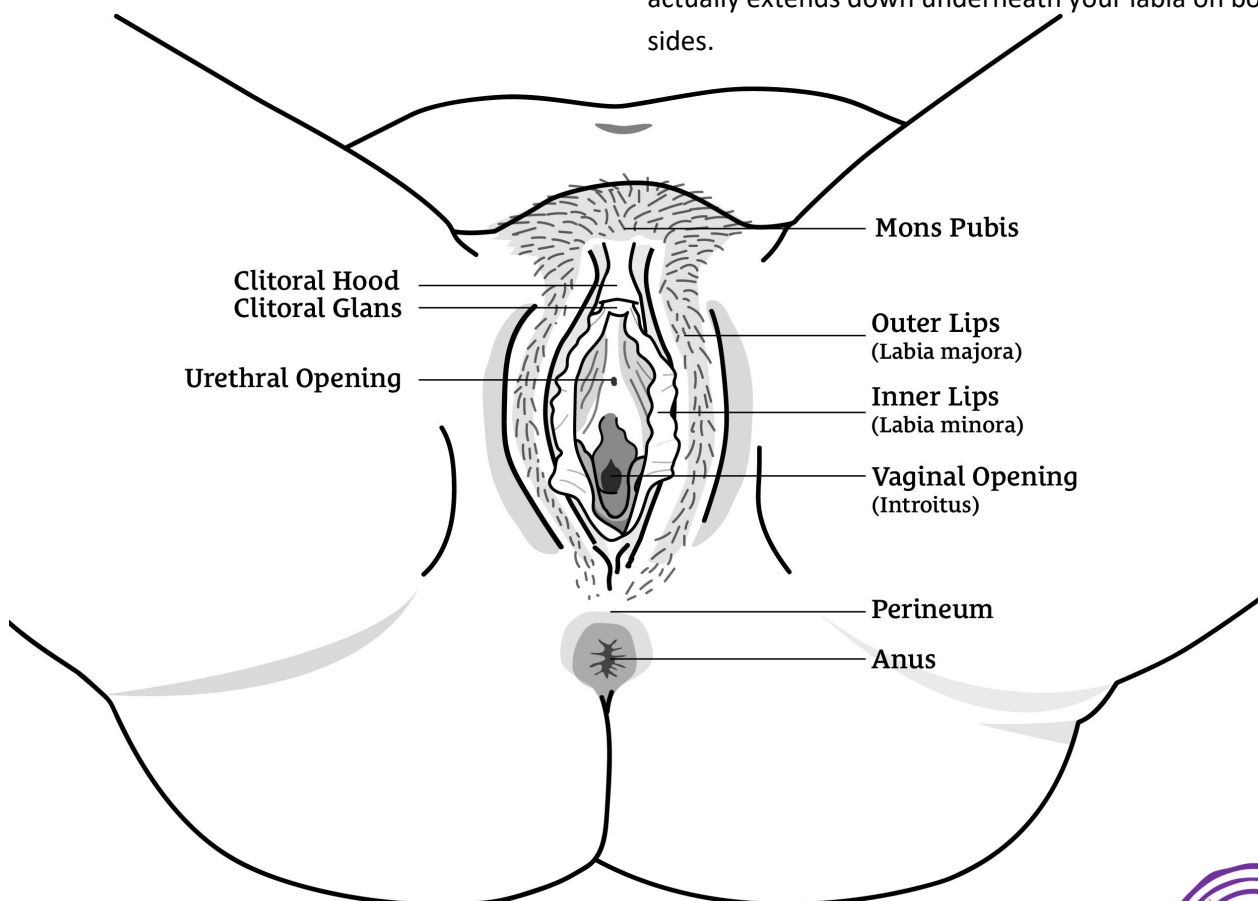
Also called the introitus, your vaginal opening is the entrance to your vagina – the stretchy, muscular tube inside your body which leads to your cervix and womb.

### Outer lips (labia majora)

These are the soft, plump skin folds on the outer part of your vulva. They come in different shapes and sizes, and usually grow pubic hair. The labia majora are sensitive and swell when aroused. Because they're soft and plump, they provide cushioning during sex.

### Clitoris

Your clitoris is highly sensitive and contains tens of thousands of nerve endings, largely responsible for pleasurable sensations during sexual activity. The head (glans) is the visible part, and sits at the top of your labia minora, or inner lips. It's about the size of a pea, but the size varies in different people. The body of the clitoris actually extends down underneath your labia on both sides.



# Checking your vulva

## Why you should check your vulva

If you've never looked at your own vulva, you're not alone. A lot of people feel too shy or intimidated to take a look, or find it too physically difficult to do, especially if mobility is a challenge. But your vulva really is just like any other body part. To look after it, you need to get to know it and build up the confidence to recognise what's normal for you.

Just like we need to check our breasts regularly, we need to check our vulvas too, keeping a look out for any potentially worrying changes. If you have vulval lichen sclerosus (LS), that's even more important. Getting familiar with how your vulva looks will help you notice changes sooner, and apply your treatment better – both of which will help you manage your LS and live more comfortably with it.

## How to examine your vulva

If you've never checked your vulva before, and you'd like some guidance, we've put together a set of instructions to help you get started.

### Before you start

Checking your vulva can be daunting, especially if you haven't done it before. But the more you do it, the more confident you'll feel and the more familiar you'll become with your vulva. Remember, they come in all shapes, sizes and shades of pink, brown and red. Checking yours is about knowing what's normal **for you**.

### So, what's the best way to look at your vulva?

Choose a brightly lit, private place – like your bathroom. Find a position that feels comfortable for you. You could try standing with one foot on the toilet, bath or a chair. Hold a mirror in one hand, or balance it somewhere that gives you a good view of your vulva.

Alternatively, you could try sitting on the floor in front of a mirror. Use your fingers to part your outer and inner lips, then look at and feel all the parts of your vulva. Look at and under all the folds of skin, including around your clitoris, between the entrance to your vagina and bottom (or anus), and around your bottom.

### What are you looking and feeling for?

Vulva checks are about knowing what's normal for you, and looking for signs things might be changing, or not quite right. It's important to check for signs of vulval cancer and precancer.

These can include:

- Lumps
- Colour changes, like white patches, darker spots or red, inflamed areas
- Patches of thickened or raised skin
- Ulcers or sores

If you've got vulval lichen sclerosus (LS), it's important to know which parts of your vulva are affected and what that looks like, so you can use your medication in the right places and check it's working. Look for new patches of white or crinkly skin or bleeding under your skin. Check for cracks, paper cuts, or folds of skin fusing together.





## How often should you check your vulva?

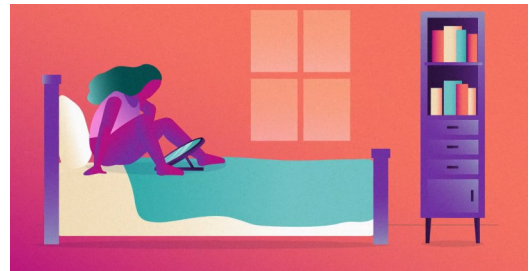
It's a good idea to get into a routine. Some people find it helps to pick a certain date each month, or do it just after their period. If you haven't got LS, or your LS is stable, you might not need to do it so often. But if you do see something you're worried about, or you're treating an LS flare-up, you might want to check more often to see whether things are settling.

## What if you notice any changes?

If you're worried about anything, or your LS isn't settling with treatment, book in with your GP. Make sure they know they'll need time to examine you, so they can check your symptoms or changes.

Watch our video on  
vulva self-checks.

<https://vimeo.com/1044751895>



## Extra resources

The University of Manchester has also produced an online leaflet and video resource with more information and a demonstration by a real vulval cancer patient, which you might find helpful.

**Warning:** please be aware that this leaflet was designed for patients with a whole range of vulval conditions, including vulval cancer. It includes detailed photographs of real vulvas with these skin conditions.

**Find it on our website or through this link:** <https://bssvd.org/wp-content/uploads/2021/05/VSE-Brochure-.pdf>





# Diagnosis, referrals, check-ups and support

- Getting a diagnosis
- Referrals to specialists
- Check-ups
- Vulval biopsies

## Getting a diagnosis

### Who should I go to if I have LS symptoms?

If something's not right, don't ignore it. Make an appointment with a healthcare professional and talk it through. Most people with LS symptoms go to their local GP or practice nurse, but a sexual health clinic may be able to help too.

You could also make an appointment with a private health professional. If you do, check their details beforehand to make sure you're confident they specialise in this area. The British Society for the Study of Vulval Disease (BSSVD) has a [list of experts in vulval skin disorders](#) you can check (*opens in new tab*).

The most important thing is that the person you go to listens and tries to help, whether that's by making a diagnosis themselves, or referring you on to a specialist.

### Can I see a pharmacist?

You can, but there's only so much they can do to help. While they should be able to recommend products to wash and moisturise with, or advise on vulval care, they won't be able to examine or diagnose you. They also won't be able to give you the topical corticosteroid ointment you need, because it's only available on prescription. So, if you think you might have LS, it's always best to make an appointment with your GP, who should be able to give you a proper diagnosis, recommend the right treatment or, if need be, refer you to a specialist.

### What if I'm struggling to talk about my symptoms?

We know it might feel uncomfortable talking about your symptoms, or using the correct anatomical words for the vulva, but it's really important to be as specific as you can when you talk to your doctor.

You could write down the affected areas and show the list to your doctor if you're struggling to say them out loud. Or you could take along our printable vulva diagram and point them out. If you've self-treated for thrush but your symptoms haven't improved, make sure you let your doctor know.

We've also put together a checklist of vulval LS signs and symptoms to help you explain what you're concerned about. If you like, you can print it out and take it along to your appointment.

**Find the checklist on the 'Resources' page of our website or by following this link:**

[https://www.lichensclerosusguide.org.uk/files/2025/01/LSGuide-Symptoms-Checklist\\_v1.0.pdf](https://www.lichensclerosusguide.org.uk/files/2025/01/LSGuide-Symptoms-Checklist_v1.0.pdf)



## How will the doctor diagnose me?

To diagnose LS, your doctor will need to examine you. It's the only way to be certain about a diagnosis, and to make sure you get the treatment you need. So, go to the appointment prepared for this to happen and make sure your doctor knows that's what you expect. Sometimes health professionals are hesitant because they're worried their patients will be uncomfortable, so you might need to ask them to examine you.

If it helps you feel more comfortable, you can bring a chaperone: someone to be there with you during the examination. You may request a chaperone at the surgery or when you book your appointment and a female colleague will stay in the room with you while they examine you. Sometimes people need a biopsy to confirm their LS diagnosis. If your doctor says you need one, you can find out what to expect in our biopsy information.

## What can I do if I think I've been misdiagnosed?

We know that LS is often misdiagnosed, most commonly as thrush (a yeast infection) or as a symptom of menopause. That's why it's so important to have an examination.

There are some **key signs of LS which you wouldn't get with thrush or the menopause**, so if you notice them, tell your doctor and, if necessary, ask them to examine you again. These signs often (but not always) include changes to the colour of your skin and persistent itching. But you might also experience:

- Extremely intense itching
- Itching in your bottom or the area between your vagina and bottom
- Taking thrush treatment and finding it hasn't helped
- Bleeding and tearing of fragile skin when you have sex or exercise
- Changes to the shape of your vulva, for example if the skin has started to fuse together or you can't clearly make out the distinct [parts of the vulva](#)
- No signs of thrush-like discharge (or discharge that's unusual for you)

If you think you've been misdiagnosed, book another appointment and make sure you mention these signs. You could share our [information for healthcare professionals](#) with them.

## What can I do if my GP doesn't give me the care I need?

If you've seen a GP but you haven't been given treatment that helps, ask reception for a face-to-face appointment with a GP who is confident in women's healthcare. If this isn't available at your surgery, you could try your local sexual health or genitourinary medicine clinic. Take our checklist with you and explain why you think you might have LS.

## If I've got an LS diagnosis but I'm struggling, who can help?

If you've been diagnosed with LS and you're struggling with flare-ups, treatment or any other aspect of the condition, the first person to talk to is your GP. Let them know what's happening, how you're feeling and whether anything's changed or become worse. They should be able to give you advice, change your treatment or refer you to a specialist clinic.

If you feel unclear about your LS treatment, we've created a LS treatment plan template. You could take this along with you to an appointment and ask your doctor to complete it with you.

Find the template on the 'Resources' page of our website, or by following this link: [https://www.lichensclerosusguide.org.uk/files/2025/01/de\\_Treatment\\_Plan\\_v1.0.pdf](https://www.lichensclerosusguide.org.uk/files/2025/01/de_Treatment_Plan_v1.0.pdf)



# Referrals to specialists

## Will I be referred to a specialist for a diagnosis?

Vulval lichen sclerosus (LS) can often be diagnosed and managed by your GP or practice nurse, but sometimes they might decide to refer you to a specialist. In this section we'll look at why that might happen, and what to expect from your specialist appointments.

Many GPs, practice nurses and sexual health practitioners have the knowledge and experience to diagnose and look after LS themselves. But in some cases they might feel it's best to refer you to a specialist (often a dermatologist or gynaecologist). This might be because they're unsure about making a firm diagnosis of LS, or for other reasons, for example your skin not responding well to treatment.

Specialists often have long waiting lists, but while you're waiting for your appointment, you can start or continue with your treatment.

Try to take photos of your vulva before and after starting treatment, so you've got a record of how your skin has changed. This is important because if your skin responds really well, there might be no active signs or symptoms of LS by the time you see the specialist, which could make it difficult to be sure of the diagnosis.

The doctor can use the 'before' photos to help them make a diagnosis and give you more accurate advice about your treatment going forward.

There are ways of storing photos privately and securely on your phone but if you don't want to take photos, you or the doctor referring you can take information down on a detailed diagram.

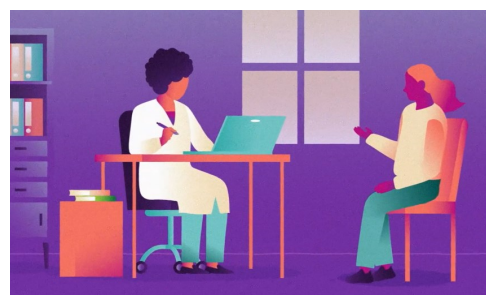
## What should I expect when I see a specialist?

At your appointment, the specialist will ask you questions about your symptoms and experiences so far. They'll want to examine you, so they can confirm your diagnosis and prescribe the [most suitable treatment](#). They should explain clearly how and how often to use the treatment, including where and how much to use. They may also explain how to wash and moisturise with emollients.

## Will I need a biopsy?

It's not always easy to diagnose LS, so sometimes doctors ask for a biopsy to make sure. This isn't the case for everyone, but there's a chance it could happen to you.

[Find out more about biopsies](#) later in this section.



## How many specialist appointments will I have?

Current NHS guidelines suggest that you should have a second appointment with your specialist around three months after you first see them. At this appointment, they'll assess you again to see if your skin has responded to the treatment. They should also talk to you about sexual function.

If your treatment doesn't seem to be working at this point, the specialist will check whether you've had any problems using it. If your treatment still isn't helping, they might talk to you about further investigations (like a biopsy, swab, blood tests or checking for incontinence) or other types of treatment.

On the other hand, if at three months you've had a good response to the treatment, the specialist might discharge you, offer you a follow-up appointment in a few months, or give you an open appointment so you can come back if you feel you need to.

If you're discharged, your specialist should explain how to manage your LS long term, including [how to do regular vulva checks at home](#).

## What happens after I see a specialist?

When you're discharged by your specialist, you'll be taken off their clinic list and looked after by your GP instead. So if you need to see your specialist again, you'll need a new referral from your GP.

This approach is recommended under the latest guidelines, because it's not possible for everyone with LS to stay under a specialist's care on the NHS. It's thought that once you've got an accurate diagnosis and a treatment plan that works for you, you can be looked after by your own GP, without regular specialist appointments.

If you've been discharged, make sure to read our information on [check-up appointments](#) and [monthly vulva checks at home](#).

## Who else can help?

### Physiotherapists

If you have problems with [incontinence \(leaking pee or poo\)](#), you might find that irritates your vulva, making your LS symptoms worse. Physiotherapists who specialise in pelvic health can assess how well the muscles in your pelvic floor are working and recommend treatment, including muscle-strengthening exercises. In many cases, that can help improve bladder and bowel control, in turn easing LS symptoms.

If you're experiencing [pain during sex](#), a pelvic health physiotherapist can also examine you to check whether your pelvic floor muscles are overly tight. This often happens with LS as your body's way of protecting itself, but your physio can give you treatment and exercises to help.

Access to local pelvic health physios varies depending on where you live, but you'll usually be referred by your GP or gynaecology or dermatology consultant.



## Psychosexual counsellors

Research shows that psychosexual counselling (sometimes called sex therapy), can significantly improve the sex lives, happiness and overall quality of life of people with vulval LS. It uses several different psychological and physical approaches to help you explore and cope with the physical or relationship issues you're experiencing. You can see your therapist on your own or, if you prefer, with your partner.

In some parts of the UK, you can access psychosexual therapy on the NHS, usually with a referral from your GP or consultant.

If psychosexual therapy isn't available in your area, or there's a long waiting list, you could also consider a private therapist. [The College of Sex and Relationship Therapists](#) keeps a list of registered, qualified and accredited therapists who can work with you face to face or online. It's a good idea to contact a few therapists initially, so you can check how much they charge and find someone you feel comfortable with.

## Check-ups

### Overview

Vulval lichen sclerosus (LS) is a long-term condition, and the latest guidelines from the British Association of Dermatologists recommend having a check-up with a healthcare professional once a year. In this section we'll look at why that's so important, what to expect, and what you can do to make the most of your check-ups.

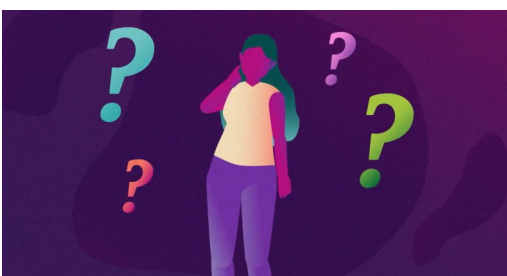
### Do I need check-ups?

Yes. Even if your symptoms are under control and your LS feels calm, it's recommended that you have a yearly check-up so a healthcare professional can examine you and make sure nothing is missed.

It might not always be possible, but ideally you'll see the same person each time, and they'll be knowledgeable about conditions affecting the vulva. This will usually be your GP, but it could also be your practice nurse.

There isn't a formal check-up process for LS, so you probably won't be automatically contacted to arrange a check-up. Instead, you'll need to get in touch with your GP practice to arrange it yourself.

This doesn't mean your check-up is any less important. It's a crucial way to make sure you're managing your symptoms, happy with your treatment and feeling as comfortable as possible. Research also shows that check-ups give people with LS valuable peace of mind. Try to keep a note of when you've seen your doctor or nurse, and keep a reminder in your diary so you know when to book in again.



But remember, if you've got any worries, you don't have to wait for a yearly check-up. If you're struggling with flare-ups or your symptoms are changing or getting worse, it's always ok to ask for help sooner.



## What will my doctor or nurse be checking for?

It's vital that your doctor or nurse examines you at your yearly check-up, so when you book your appointment, mention this to the reception team and they'll make sure you have enough time.

Your doctor or nurse will check to make sure you're using your treatment properly and it's working well for you. Because LS is a long-term condition, changes can happen over time, so they'll also look for any new areas showing signs of LS, which might now need treatment. Importantly, they'll also check for any signs of potential [vulval cancer or pre-cancer](#).

Your check-ups are also an important opportunity for you to ask questions, so if you have any worries about your LS, let your doctor or nurse know.

## How should I keep track of my treatment and symptoms?

Keeping track of your treatment and symptoms can help you give your doctor or nurse an update at each check-up. Some people keep a diary of their flare-ups to try to track what triggers them, as well as what helps or prevents them.

Taking regular photos when you do your own [monthly vulva check](#) can help you recognise any changes if they occur, or see your skin improving over time. Some health professionals might take photos at each check-up, if you're happy for them to do so.

# Vulval biopsies

## Overview

In a lot of cases, vulval lichen sclerosis (LS) can be diagnosed by your doctor, based on an examination and a conversation about your symptoms. However, for a small number of people, the signs can be less clear, and a biopsy might be recommended to make sure LS is the right diagnosis.

This means taking a small sample of skin, which is tested to confirm whether you have LS, and what treatment is right for you. As well as checking for LS, biopsies are sometimes used to rule out other conditions, including vulval cancer. In this section, we'll explain what a vulval biopsy involves, and how to prepare if you're told you need one.

## What is a vulval biopsy?

A vulval biopsy involves taking a small sample of skin from your vulva, after numbing the area with a local anaesthetic. You'll be awake while this happens, and the whole appointment usually only takes 20 to 30 minutes.

The sample is sent to a laboratory, where it's examined under a microscope to check for signs of LS or other conditions. The results are sent to your doctor. Your doctor should let you know how long this is likely to take. This can vary a lot, because of pressure on services, but it can be several weeks.



## How to prepare

- You don't need to do anything special before your biopsy.
- If you can, have a bath or shower on the day, washing your skin gently but thoroughly.
- You can eat, drink and take your usual medicines as normal, unless you're told otherwise.
- If you take any medication that thins your blood, like aspirin or warfarin, let the doctor or nurse know.
- It's helpful to wear close-fitting underwear so you can use a light period pad if you need one afterwards.
- There's no need to stop using your topical steroid (or any other kind of treatment) before your biopsy unless your doctor asks you to.

## What to expect

- Your doctor or nurse will explain what your biopsy involves – either at your previous appointment, or when you arrive on the day. They'll also ask you to sign a consent form before they begin.
- The appointment usually takes 20-30 minutes and the procedure might take place in a clinic room or a minor surgery room – you can ask in advance where it's going to be.
- You'll be asked to undress below the waist and lie on the examination couch.
- As well as the doctor or nurse who's taking your biopsy, there will usually be another nurse with you, who'll talk to you and reassure you while it's happening. If you'd like, they can hold your hand.
- Vulval biopsies are usually done under local anaesthetic, so you'll have a small injection to numb the skin, and you'll stay awake the whole time. The needle will feel sharp and local anaesthetic can sting when it's first injected, but after that, the area will go completely numb and although you might feel some pressure, you shouldn't feel any pain. You can ask your doctor or nurse to check that the area is numb before they begin.
- Numbing cream isn't usually used because it can affect how the skin cells appear under the microscope, making it more difficult to diagnose some conditions.
- A small instrument called a punch biopsy is used to take a small sample of skin (usually less than half a centimetre in size).
- After your biopsy, you might have one or two stitches, which are usually dissolvable so they won't need to be removed. They take 7-10 days to dissolve. If you have stitches that do need to be removed, the doctor or nurse will let you know when and how to arrange this.
- You may have some mild discomfort for a few days after your biopsy.
- It's a good idea to bring a pad or period underwear to the appointment, as you might have some light bleeding afterwards (usually only a small amount of spotting).

## What to ask for

- Make sure you understand the procedure and why it's been recommended.
- If you don't have a pad, don't be afraid to ask the team for one.
- You shouldn't feel any pain once you've been given the local anaesthetic, so if you do feel pain during the biopsy, let the doctor or nurse know immediately.
- Before you go home, you should be given written information about how to look after the biopsy area and any stitches you might have.





## What should I do after the biopsy?

- The local anaesthetic will wear off after an hour or two and you may find the area feels uncomfortable. If you like, you can take over-the-counter pain relief, and if you need any advice, your local pharmacist can help.
- You might find that loose clothes are more comfortable for a couple of days.
- When you go to the toilet, you can just wipe the skin gently with paper as normal. After a poo, make sure you wipe away from your vulva, to keep the biopsy area as clean as possible.
- It's ok to gently wash your vulva the day after the procedure, using plain water and patting the area gently dry with a soft cloth. Avoid soaking in the bath for the first 2 or 3 days. Your doctor or nurse should let you know when to restart your topical corticosteroids. This will usually be 3 to 7 days after your biopsy.
- Avoid vigorous exercise like running or cycling for a few days after your biopsy because your vulva is likely to be uncomfortable and the biopsy area will be fragile.
- You can start swimming again after your stitches have dissolved or been removed, or once the biopsy area has healed fully.
- It's ok to have sex a few days after your biopsy, as long as the area is fully comfortable.





# Treatment of vulval LS

- Topical steroids
- Other treatments

## Topical steroids

### What are topical steroids?

Topical steroids are a type of medicine that's applied directly to your skin as a cream or ointment, to reduce inflammation. They are also sometimes called topical corticosteroids.

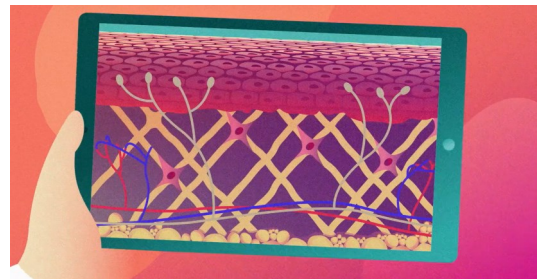
Topical steroids are the main treatment for vulval lichen sclerosus (LS), and they play the most important part in reducing flare-ups and soothing symptoms. The word 'topical' just means they're used directly on your skin, rather than taken as a tablet or medicine.

### How do topical steroids help with LS?

LS causes inflammation within your skin and this inflammation can lead to itching, cracking, fusion and scarring. Topical steroids work by switching off this inflammation, but it takes a strong or very strong steroid to get through the top layers of skin, as the inflammation associated with LS can be quite deep.

To find out more about this, watch our video on what LS is, and why the skin changes

<https://vimeo.com/1044752540>



### Do topical steroids come in different strengths?

Yes. In the UK there are four different strengths or 'potencies' of topical steroid:

- Very strong (also known as very potent or super potent)
- Strong (also known as potent)
- Moderate
- Mild (also known as weak)

Unfortunately, it can be difficult to work out how strong a topical steroid is just by looking at the box, because there's often a number or percentage next to the name of the steroid which doesn't actually have anything to do with its strength.

Read on for information about [different steroids used to treat LS](#). If you're not sure how strong your treatment is, check with your doctor, nurse or pharmacist.



## What strength of steroid is best for LS?

When you have LS, it's important to use a very strong or strong topical steroid to keep your symptoms calm and under control.

More research is needed to prove that a very strong topical steroid is better for LS than just a strong one, but most vulval specialists recommend starting treatment with a very strong steroid (usually clobetasol propionate ointment 0.05%). Some doctors then recommend reducing to a strong one when your LS is under control.

## What's the difference between ointments and creams?

Topical steroids for vulval LS are available as ointments or creams. Ointments are generally seen as the most effective and soothing topical steroid option for the vulva. They're greasier and more moisturising than creams, and because they contain less water and fewer preservatives, they're less likely to sting or cause allergic reactions.

## How much topical steroid should I be using?

This will vary from person to person and it depends on a number of things. For example, how much of the skin on your vulva and around your bottom is affected by LS and how active (or irritated) it is.

Generally, the advice tends to be to use one to two pea-sized blobs each time you put it on, but ask your doctor to show you the right amount for your body – and your LS. You might also sometimes hear doctors and nurses talk about using 'fingertip units' to measure creams and ointments. Usually around half a fingertip unit would be similar to one to two pea-sized blobs.

Usually when you first start treatment, you'll be advised to use your topical steroid once a day. You can put it on at any time, but it can be helpful to do so at night, so it's less likely to be rubbed off by clothes or toilet paper.

People also tend to notice itching more at night, so using it before bed can be soothing.

For more tips, watch our video about applying topical steroids:

<https://vimeo.com/1045686487>



## How often should I apply my topical steroid?

It's always best to talk through your treatment routine with your doctor and follow their advice. In the UK, it's generally recommended that you use your topical steroid once a day until your LS is under control, then gradually reduce it. We've put together a treatment template for you to fill in with your doctor so that you are clear about your individual plan.



### My LS Treatment Plan

We've put together this easy-to-use plan to help you keep track of your LS treatment. Take it along to your next appointment and ask your doctor or nurse to help you fill it in.

My topical steroid is called: \_\_\_\_\_

It might also be known as: \_\_\_\_\_

Its strength is:

Potent  Very potent

This is how much I need to use each time.

Generally, the advice tends to be to use one to two pea-sized blobs each time you put it on, but ask your doctor to show you the right amount for your body and your LS.



Ask your doctor to shade in how many pea-sized blobs or what proportion of a fingertip unit to use each application.

[www.lichensclerosisguide.org.uk](http://www.lichensclerosisguide.org.uk)

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Download our treatment plan from the 'Resources' page of our website, or by following this link:

[https://www.lichensclerosisguide.org.uk/files/2025/01/LSGuide\\_Treatment\\_Plan\\_v1.0.pdf](https://www.lichensclerosisguide.org.uk/files/2025/01/LSGuide_Treatment_Plan_v1.0.pdf)



## Are there any alternatives to topical steroids?

It's not unusual for people to worry about using topical steroids. Sometimes pharmacists or health professionals mistakenly think they should only be used short term, or avoided entirely for the genital area.

But research shows that topical steroids are safe and effective if you have vulval LS, and they're also safely used to treat a range of other vulval skin conditions. Studies have shown that side effects (like skin thinning) are very rare if people use their steroids properly.

It might take a bit of time to adjust to the idea of using topical steroids on a long-term basis, but they're the best treatment we have for LS. It's also really important to remember that active LS has the potential to cause much more damage to your vulva than topical steroids.

Topical steroids are safe to apply to the vulval skin, including the perineum and anus, if you have LS in those areas.

Topical calcineurin inhibitors like tacrolimus (also known by its brand name Protopic) and pimecrolimus (also known by its brand name Elidel) are topical immunosuppressants. They have been used to treat LS, but it's been shown that they are not as effective as topical steroids.

## What can I expect when I use a topical steroid?

Once you start using your topical steroid, you should see signs of active LS improving. For example, cracking and bleeding under your skin should happen less often, your skin texture should start to normalise, and itching should stop or reduce. If your skin has turned a white colour, this might improve but it won't necessarily disappear completely. This return to your more normal skin texture and colour is the goal of topical steroid treatment.

If your LS has already caused scarring on your vulva, for example loss of the labia minora or scarring over the hood of the clitoris, it might not be possible to reverse this, but your treatment should prevent more scarring from happening, or at least minimise it.

## Is it normal to feel a burning sensation when I first use my steroid?

Yes, this is quite common, especially at the beginning of your treatment when your LS is most active, or during flare-ups. Generally this sensation settles as your LS settles. If you're struggling with this burning feeling, you might find it helps to use your steroid in the day, when you're going to be busy with other things, instead of at night, when you have less to distract you.

If you start to get a burning sensation after you've been using your steroid for a while, let your doctor know. Occasionally people can develop an allergy to topical treatments, so you might need to have this checked out (for example with allergy patch testing) or switch to a different topical steroid.

## Can I get my topical steroid on repeat prescription?

Yes. It's very important to get your steroid on repeat prescription and make sure you don't run out.

It's also important to check that your GP knows exactly which topical steroid you're using. Mistakes can sometimes happen because the same steroid can have more than one name, or have a similar name to a weaker option. If you're prescribed something you think might be different to your usual treatment, it's always ok to ask your doctor or pharmacist about it.



## Topical steroids used most often for vulval LS:

### **Dermovate Clobaderm**

Medical name: Clobetasol Propionate 0.05%  
Strength: very strong (very potent/super potent)  
Notes: The most commonly prescribed first treatment for vulval LS. Despite the low percentage in the name, this is a very strong topical steroid.

### **Betnovate Audavate**

Medical name: Betamethasone valerate 0.1%  
Strength: strong (potent)  
Notes: Sometimes used as a first treatment or maintenance treatment.

### **Synalar**

Medical name: Fluocinolone acetonide 0.025%  
Strength: Strong (potent)  
Notes: Sometimes used as a first treatment or maintenance treatment. Often used if people have a suspected contact allergy to topical steroids.

### **Elocon**

Medical name: Mometasone furoate 0.1%  
Strength: strong (potent)  
Notes: Sometimes used as a first treatment or maintenance treatment.

### **Locoid**

Medical name: Hydrocortisone butyrate 0.1%  
Strength: strong (potent)  
Notes: Sometimes used as a first treatment or maintenance treatment. Not to be confused with plain hydrocortisone which is a weak (mild) topical steroid.

### **Diprosone**

Medical name: Betamethasone dipropionate 0.05%  
Strength: strong (potent)  
Notes: Sometimes used as a first line or maintenance treatment.

### **Cutivate**

Medical name: Fluticasone propionate 0.005%  
Strength: strong (potent)  
Notes: Sometimes used as a first line or maintenance treatment.

## Topical steroids that are **not** thought to be strong enough to treat vulval LS:

### **Eumovate Clobavate**

Medical name: Clobetasone butyrate 0.05%  
Strength: moderate  
Notes: This isn't usually strong enough to treat vulval LS and is sometimes prescribed by mistake because the generic name is very similar to Dermovate.

### **Hydrocortisone**

Medical name: Hydrocortisone  
Strength: mild  
Notes: This comes in several percentages (0.5%, 1% and 2.5%) but they're all mild and not strong enough to treat vulval LS.

## Should I use a moisturiser with my topical steroid?

Yes, absolutely. It's a good idea to use a moisturiser (also called an emollient) if you have LS. Just like with your topical steroids, choosing a greasy ointment-type emollient will tend to protect your skin better than a lighter lotion, gel or cream. Emollient ointments can also provide a barrier to urine, yeasts and bacteria.

Emollients can be really soothing when your skin feels sore and irritated, so it's good to know there's no limit to how often you can use them, or how much you can put on.

Read more about emollients in our section on [looking after your vulva](#).



# Other treatments

## Overview

Sometimes when people are first diagnosed with vulval lichen sclerosus (LS), topical steroids don't work as well as their doctors expect. In this section we'll look at why that might be, and alternative treatment options. Some of these alternative options are already available, while others are still being tested in studies. If they're proven to be effective, they may be available in the future.

## What if topical steroids don't work?

If your prescribed topical steroid treatment doesn't work, the first thing your doctor will do is assess why that might be. They'll explore whether:

- You're using your topical steroid on the wrong area
- You've got an infection that's making your LS worse
- There's another reason for your symptoms, like a lack of oestrogen, thrush or an allergic reaction or sensitivity to the steroid
- Something else is irritating your skin, like other over-the-counter products or incontinence

Your doctor might also do extra checks to make sure your LS diagnosis is actually correct. That might include taking swabs or a biopsy to rule out any other conditions that could be causing your ongoing symptoms.

If they're sure your symptoms are caused by LS and the topical steroids still aren't working, there is a range of other options they might consider to get things under control.

## Other topical treatments for LS

Two different anti-inflammatory topical treatments, called topical tacrolimus (brand name Protopic) or pimecrolimus (brand name Elidel), are sometimes used to treat LS.

There are some studies showing the effectiveness of these treatments, but their side effects can be uncomfortable. They can create a burning feeling on the skin for the first few applications. This usually goes after 1-2 weeks, but some people can't tolerate the sensation. Some doctors also aren't happy to use this treatment due to a theoretical chance of it increasing the risk of cancer development.

## Tablets for LS

There are lots of tablets (also known as oral medications or 'systemic' treatment) used to reduce inflammation in skin conditions. Many of them have been available for decades and are commonly prescribed. These are sometimes used to treat LS, but none have been tested in clinical studies, so we don't have solid evidence on how well they work. They can only be prescribed by a specialist and you'll need blood tests to monitor for side effects.

These tablets include:

- **Oral steroids:** these are sometimes given as a short course, starting at a higher dose and gradually reducing over a period of time (for example 4-6 weeks).
- **Acitretin:** this can be useful if your skin has thickened (a process called hyperkeratosis).
- **Methotrexate:** this can be particularly useful if you also have LS on other parts of your body.
- **Tetracycline antibiotics:** these are sometimes used for their anti-inflammatory effects (rather than for antibacterial properties) but very few studies have been carried out on their use in LS treatment.



## What other treatments are being researched?

### Topical Janus kinase (JAK) inhibitors

These new topical treatments are currently being tested in clinical trials for LS. If it's proven that they can successfully reduce inflammation, JAK inhibitors could offer a new treatment for LS that doesn't rely on steroids.

### Laser treatment

Laser therapy is also being researched as a treatment option for LS. There are several different types, but the CO2 laser is the most commonly used with LS. Skin is usually prepared with numbing cream before laser therapy is used on the affected area. Unfortunately, studies so far haven't been able to prove that lasers reduce inflammation, so there's limited evidence to support using them as a main treatment option for LS, although some patients do report an improvement in their symptoms. So far this isn't available on the NHS because more research is needed.

### Platelet-rich plasma (PRP)

This is a form of regenerative medicine. Regenerative medicine focuses on repairing or replacing damaged tissues or organs. To do this, it uses stem cells (unspecialised cells able to become any type of cell your body needs), growth factors (proteins that stimulate healing) and biomaterials (materials that support or replace your own tissues).

PRP involves using your own plasma and platelets (taken from a sample of your own blood) and injecting them into the affected skin on your vulva to help your tissue heal. While PRP has had positive results in treating injuries, there hasn't been enough good quality research on its effectiveness for LS, and results so far have been mixed. It isn't available on the NHS.

### Lipofilling (also known as fat grafting)

Another form of regenerative medicine, lipofilling involves transferring a small amount of fat from one part of the body to another. One study has shown promising results in reducing scarring and fibrosis (hardening and thickening of the skin), and researchers have also found that it may help to improve LS symptoms. However, more research is needed to confirm these findings and explore the long-term benefits, so it's not currently approved as an LS treatment.





# Everyday live with vulval LS

- Caring for your vulva
- Relieving pain
- Sex and LS
- Your periods and LS
- Clothing and LS
- Exercise and LS
- Emotional wellbeing



## Caring for your vulva



### Overview

Vulvas can be delicate, with more sensitive skin than other areas of the body. If you have vulval lichen sclerosus (LS), you're likely to notice that sensitivity even more. Ordinary, everyday products can often cause irritation, including things like soaps, shower gels, cleansing wipes, feminine hygiene washes, panty liners, talcum powder, perfumes and deodorants. So to reduce the risk of flare ups, it's a good idea to avoid them if you can.

In this section we'll be sharing advice and ideas on everyday things you can do to protect your skin, ease your symptoms and live more comfortably with LS.

### Moisturising

Using an emollient moisturiser regularly is a good way to help protect your vulva's delicate skin, forming a barrier against irritants like sweat, friction and pee.

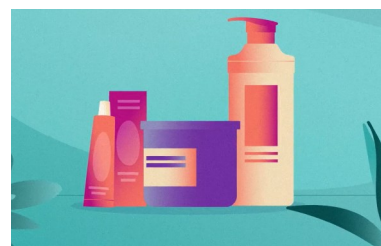
Unlike ordinary moisturisers, emollients are specifically designed to soften and soothe dry skin conditions. They're also unperfumed, so they're less likely to add extra irritation. They come in different forms, including lotions, gels, creams and ointments:

- **Lotions and gels:** very light, providing the least moisture
- **Creams:** thicker and more moisturising
- **Ointments:** thicker and greasier, even more moisturising, for maximum protection

It's completely up to you which emollient you use, and you might need to try a few before you find one that suits your skin. It's worth remembering that lighter gels and lotions often contain more preservatives than thicker creams and ointments, so they can be more irritating. Your GP, specialist, or local pharmacist will be able to suggest emollients for you to try.

Watch our video about topical steroids and emollients:

<https://vimeo.com/1045686487>





## How do I use my moisturiser?

If your emollient comes in a tub (without a pump), make sure you scoop it out with a clean teaspoon or spatula instead of your fingers, to avoid contaminating the rest of the tub. Smooth the emollient over your skin with your fingers and gently rub it in. If your skin is very sore, you might find a spray moisturiser works better for you instead.

You can use your emollient as often as you need to. Twice a day is a good place to start, but settle on a routine that suits your own schedule and skin. Some people find it helpful to apply emollient before exercising to reduce friction, or before going to the toilet to avoid stinging if the skin is broken or irritated.

## How do I use my moisturiser with my topical steroid?

While emollients help to soothe and protect your skin, if you have LS, your doctor will also prescribe a topical steroid ointment to treat your symptoms. You can find out lots more about them in our [steroid treatment section](#).

Ideally, apply your steroid ointment, then leave a 20 minute gap before using your emollient. That gives the steroid enough time to be absorbed into your skin and start working. If you find it's not practical to wait that long, you might prefer to just apply the steroid ointment, then use the emollient at a different time of day.

## Do emollients have side effects?

It's very unusual for emollients to cause side effects, unless you're allergic to a specific ingredient, which doesn't happen often. If you're worried about allergies, you could try applying your emollient to a small patch of skin elsewhere on your body (such as the inside of your arm) and waiting for three days to check it still feels comfortable. If your emollient irritates your skin, either when you're trying it out or later on, it's a good idea to switch to a different one. There are lots of options available, and your local pharmacist will be able to recommend something.

It's important to remember that emollients contain oils which are flammable, even when they're dry, and this can make your clothing or bedding flammable too. So, while you're using emollient treatments, be very careful near naked flames or lit cigarettes. For more information see [Government information about flammable emollients \(PDF, 1.5MB\)](#).

## Washing

Lots of shower gels labelled gentle, sensitive, or dermatologically tested still contain soap, so they can be irritating on your sensitive skin. Washing your vulva with an emollient instead can be a good way to avoid extra discomfort and gently moisturise while you wash.

Try mixing some of your emollient moisturiser with warm water in your hands, as if you were lathering soap, then use it to wash your vulva. It's best to use your hands rather than a cloth or flannel, because they can cause friction and irritate delicate skin.

Some people find that even the runoff from their shampoo or a shower gel they're using on other parts of their body can irritate their vulva in the shower. If this happens, you could try applying some emollient to your vulva before you get in the shower to act as a barrier, or washing your hair separately over the bath or sink.



## How often should I wash my vulva?

Washing your vulva once a day is usually enough. In fact, washing too much can cause dryness and irritation. If you feel you need to wash more often, for religious or other reasons, try to use an emollient moisturiser instead of soap or shower gel, or apply your emollient after washing to soothe your skin.

Remember, when you're drying, be gentle. Use a soft towel and lightly pat your skin dry.

## Going to the toilet

If it stings when you pee or poo, the tips below may help you.

It might help to apply your emollient before you go to the toilet. Try unbleached, chemical-free toilet paper made from recycled or bamboo fibres. If you'd like to clean your skin afterwards, try a gentle cotton pad moistened with tap water.

Peri bottles can also be helpful if this is a problem for you. If you've never used one before, they're small, handheld plastic bottles with a long neck and nozzle, and they're sometimes used after childbirth or surgery to clean the vulva and around your bottom with a gentle squirt of warm water instead of toilet paper. The word 'peri' comes from perineum, which is the area between your vagina and bottom.

As well as using your peri bottle to clean your vulva and around your bottom, you can try using it while you're actually peeing too. By squirting warm water towards your urethral opening, you'll dilute the pee, making it less likely to sting your skin. If you're not sure where that is, there's lots of help in our section on the [anatomy of the vulva](#).

Once you're done, use a clean, soft cotton cloth to pat your skin dry.

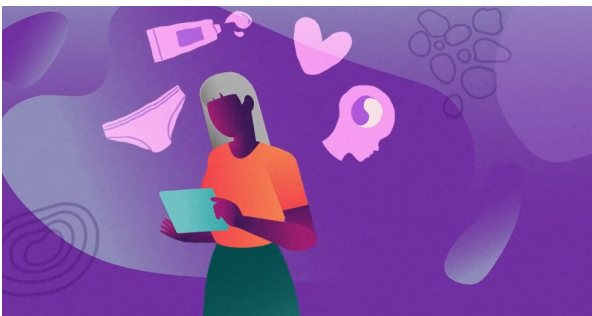
It's important to note that using a peri bottle on your vulva is different from vaginal douching, which squirts water right inside the vagina. Douching isn't recommended because it can increase the risk of infections.

## Pubic hair

Pubic hair helps to protect your vulva, but hair removal is a personal decision. Some people have cultural or religious reasons for doing it, while for others it's about feeling comfortable with the way their bodies look and feel.

If you do remove any, or all, of your pubic hair, you might notice that some removal techniques make your LS symptoms worse. That's often because of the friction or chemicals involved. Trimming, laser hair removal and sugar waxing tend to cause less irritation than other techniques.

If you do opt for waxing or laser hair removal, it's best to wait until your symptoms are calm and you don't have any cracked skin or sore patches.





# Relieving pain and discomfort



## Overview

Keeping up a regular routine of [topical steroids](#) and emollients is really important for keeping your vulval lichen sclerosis (LS) calm, under control and as comfortable as possible. But flare-ups can still happen and even with a well-established routine, some people still experience discomfort or pain.

We know it's not always possible to avoid triggers, so we've put together some suggestions to help you manage those symptoms, based on the experience of patients and health professionals.

Remember, everyone's different, and what works for some people might not work for others. It's all about trying different techniques to find the things that make **you** feel better.

## Dealing with itching

If your LS leaves your skin feeling itchy, antihistamine tablets can often help, and taking them before you go to bed can be a good way to get a more restful night. Some people also find that putting a pillow between their knees in bed improves airflow and relieves itching. Bedding made from natural fibres can be gentler on your skin, and if you think you're scratching in your sleep, wearing cotton gloves can help too.

Cold compresses (like a soft flannel or cotton wool pad soaked in cold water) can also help to relieve the itching sensation. Some people find that soaking in the bath soothes their skin, but others find this dries it out, so see what works for you.

## Relieving pain

Pain can often be caused by sitting for too long or moving too much (causing friction). Finding the right balance isn't always easy and it's different for everyone. Listen to your body and get to know what makes you feel more, or less, comfortable.

If it's painful during or after peeing, a [peri bottle](#) can be helpful, gently rinsing your skin with warm water and diluting the pee to make it less irritating. When you're away from home, you could try using a travel spray bottle instead. If you take the tube out, you should find it still sprays, even when it's upside down. Read more about this in our section on [going to the toilet](#).

If you know you're going to be sitting for long periods of time, or you need some relief in especially sore areas, you could try using lidocaine. It's a numbing cream that you rub onto your skin, and it's available over the counter from pharmacists, or as a stronger prescription version. We don't recommend it before sex (especially penetrative sex) because it could mean you don't realise your skin is tearing, which can have a long-term impact.

If you have a pain syndrome (like vulvodynia) your doctor might also prescribe specific pain medication for you, so talk to them about how you're feeling. You can find out more about vulvodynia from the [Vulval Pain Society](#).





# Sex and vulval LS



## How you feel about sex

Unsurprisingly, vulval lichen sclerosus (LS) can often affect the way you experience or feel about sex. That can happen in a number of different ways. You might notice changes in the way your clitoris feels, or you might experience pain or tearing when your vulva is touched or penetrated. All of this can, understandably, have an impact on your libido and your relationships.

Try to remember that there are things you can do to manage these symptoms and feelings, so you can have a positive, healthy relationship with sex. In this section, we'll look at different techniques and treatments.

## Psychosexual counselling and how it can help

Research shows that when people are given therapy focusing on both their mental and sexual health (known as psychosexual counselling) they experience much better improvements in their sex lives, overall happiness, and the way they feel about themselves.

That's why we recommend asking your GP or consultant about psychosexual counselling options. Unfortunately, this kind of counselling isn't always available or accessible on the NHS, so if your GP's unable to help, you may need to look for a private practitioner.

## Low libido

Libido refers to your spontaneous desire for sexual activity. It can be affected by all sorts of things, including the way you're feeling physically and mentally. While some people with LS experience changes to their libido which mean they don't want to have sex anymore, others feel differently and find ways to continue being intimate.

If you're experiencing low libido and it's impacting your quality of life, talk through your options with your GP. Ideally, they'll explore both the physical and mental reasons why this might be happening. If they uncover a biological reason for your low libido, they might prescribe treatment such as hormones. If they think there's a psychological cause, they might also recommend counselling.

If you have counselling, your counsellor might talk about techniques like sensate focus, where partners explore each other's bodies through touch, focusing on pleasure without any pressure to perform, stick to old patterns, or do what they feel they 'should' be doing. They might also encourage you to try mindfulness practice, which has been shown to be helpful for people with sexual pain and low libido.

## Clitoral fusion and lack of sensation

Even if there's fusion over the hood of your [clitoris](#), it's important to know that you can still have an orgasm (climax).

Fusion can happen when the hood of your clitoris partially or completely scars over and sticks to the head (that's the roughly pea-sized visible part, also known as the glans). But if you feel this fusion is causing a loss of sensation and problems with sex, there are treatment options you can explore. This might include removing scar tissue and separating the hood from the head to help restore sensation. To find out more about different treatments, take a look at our section on [LS in the long term](#).



## Pain when you have penetrative sex

We know that some people with vulval LS experience pain when their vagina is penetrated, whether that's by their partner's penis, or by fingers or sex toys.

Even though LS pain tends to be felt in the vulva, which is on the outside of your body, sometimes you might feel pain in your vagina (the internal part) too.

Sometimes this is caused by tight pelvic floor muscles, because the persistent pain of LS can mean these muscles tighten up as a protective response. Unfortunately, this tightening makes the pain worse, causing discomfort during and after some sexual activity.

If you're experiencing this, it can help to see a [pelvic floor physiotherapist](#). They should be able to give you an assessment and a treatment plan, which might include muscle release work, using a dilator to very gently stretch your vagina, or breathing exercises.

It's completely understandable to feel concerned about the impact of LS on your sex life or relationship, but try to remember that sex doesn't have to be about penetration. You can have a pleasurable sex life in other ways, so try to keep an open mind and explore what's possible.

## Tearing during sexual activity

When you have LS, your skin can be delicate and easily damaged, so the friction that often happens with sex can lead to tearing.

If this happens to you, it's really important to follow your treatment routine so your skin can repair and recover as quickly as possible. You can find more advice in our [section on how LS can progress](#).

To reduce the chances of tearing, you might want to experiment with different positions, or touching each other in different ways. Some people find certain things more comfortable than others, and less likely to cause tearing. Using lots of lubrication can be helpful too. Everyone's different, so see what works for you.

## Why doesn't my doctor ask about the impact of LS on my sex life?

People often feel that their doctors neglect the impact of LS on their sex lives, and there could be a few different reasons for this.

We know that, in general, doctors don't like to ask about something which they're not sure how to help with. For example, if they know that the waiting list for psychosexual counselling is very long, they might not want to raise it with you. On top of this, they might not want to embarrass you, they might feel embarrassed themselves or they might be worried about cultural inappropriateness.

Even so, you have the right to raise the topic yourself and ask for help. It's up to your doctor to try to provide whatever support, advice and referrals they can.

## Forming new relationships

Just because you've got vulval LS, it doesn't mean you can't form new, meaningful relationships or be intimate with people. But it's understandable to feel worried about how potential new partners might react, or how you'll deal with sexual activity. Remember, LS absolutely isn't contagious, so whatever happens, there's no risk you'll pass it on.

It's completely up to you how and when you tell a new partner. We've created a section of this site specifically for [carers and partners of people with LS](#), so if they want to find out more, and you feel comfortable, you could start by sharing it with them.



If you're worried about sex and LS, take a look at our tips on managing pain during sex, and remember that sex is about so much more than penetration. The right partner should be understanding and allow you to set the pace of the physical side of your relationship. Above all, nobody should feel pressured into any kind of sexual activity, whether it's painful or not.



## Your periods and LS



### Overview

Periods (also known as menstruation) are a normal, regular part of the lives of many women and people assigned female at birth.

Each month (or thereabouts), the lining of the uterus sheds and menstrual blood leaves the body through the vagina. It's a natural process experienced by around 800 million people on any given day. But if you have vulval LS, your periods could bring extra challenges, including symptom flare-ups.

In this section, we'll look at how your vulval lichen sclerosus (LS) might be affected, the symptoms you might have, how your period might affect your treatment and which period products can help.

### How do periods affect LS symptoms?

Everyone's different, and your periods might affect your LS in a different way to other people. Some people say they feel better during their period, while others say it increases their symptoms.

If you find that your symptoms get worse when you're on your period, you could try:

- Using a peri bottle filled with warm water to gently rinse the blood from your vulva a few times a day
- Soaking in a warm water bath a couple of times a day
- Using an ice pack wrapped in a soft towel (or through your clothes) to ease soreness, pain and itching
- Wearing loose, breathable clothing
- Prioritising rest and relaxation

If you're having very heavy periods or they regularly trigger a flare-up of your LS, talk it through with your GP, practice nurse or consultant. They might suggest treatment options to lighten or shorten your periods.

### How does my period affect my LS treatment?

During your period, it's completely fine to carry on with your treatment as normal. We know some people worry that their menstrual blood will dilute their [topical steroid](#), but if you smooth in the ointment for about 60 to 90 seconds, most of it will have absorbed, and it will be able to work properly.

### Which period products work best for LS?

We don't recommend pads or panty liners because they're known to easily irritate the delicate skin around your vulva.

There are lots of good, more comfortable options available, including:

- Period underwear
- Period discs or cups
- Unbleached, unscented tampons





# Clothing and LS



## Overview

When you have vulval lichen sclerosus (LS), finding something comfortable to wear can be tricky, especially during a flare-up. So, in this section, we look at what kind of clothing might irritate your LS, and what might work better. There hasn't been a lot of research about clothing and LS, so we've based our suggestions on the expertise and experience of patients and health professionals.

Everyone's different, and what works for some people might not work for you. The most important things to remember are to choose natural materials as much as possible, and avoid bulky seams around your vulva.

## Underwear

Try to choose underwear made from 100% cotton, bamboo, silk or other natural materials as often as possible. Think about what shape feels comfy for you too; thongs and other tight-fitting styles are much more likely to irritate sensitive skin.

Sometimes the best underwear is no underwear. When you have a flare-up, wearing no underwear (for example under a long skirt, dress or loose trousers) can be helpful. It might take a bit of getting used to, but it's a good way to ease your symptoms, so try it around the house or wherever you feel comfortable.

## Trousers and tights

Sometimes jeans or trousers with a stiff or chunky seam can rub against your vulva and cause soreness or irritation. Trousers made with synthetic materials can also make the area feel generally hot and irritated. You might find loose trousers, leggings or very soft jeggings without a bulky inside seam are more comfortable, helping to keep your LS calm.

Tights are often made from synthetic materials, so they can be irritating too. Look for options made from natural materials like bamboo or cotton instead. They're less likely to upset your skin and you can usually find them in the same sections of the shop as standard tights.

When you're [exercising](#), you might want to consider a pair of loose shorts or yoga pants instead of tight leggings.

## Staining from treatment

Sometimes people find their ointment stains their clothes. If this is happening to you, we know it can be an unwelcome reminder of your LS, as well as an annoying ongoing expense.

So, to protect your clothes, we recommend putting on absorbent period underwear (also called period pants) after you've applied your ointment. If your treatment routine means you only use ointment on certain days, you could also pick one or two items of clothing to wear on those days, helping to keep the rest of your clothes stain-free.

## Washing your clothes

If your skin is sensitive to fragrance, try to avoid highly fragranced laundry detergents and fabric softeners. These days there are lots of fragrance-free options, and they'll usually be gentler on your skin. You might also find that sometimes a very hot wash with no detergent is enough to get your clothes clean. Just make sure you check the labels first to avoid shrinking.





# Exercise and LS



## Overview

We all know exercise is good for us. It helps us keep fit, relieve stress and boost our wellbeing. So it's good to know you don't need to stop being active just because you've got vulval lichen sclerosus (LS). Whether you already exercise a lot, there's a particular activity you enjoy, or you'd like to start exercising for the first time, there's lots you can do to exercise more comfortably with LS. In fact, most exercises can be adjusted slightly to make them more suitable. In this section we'll take a closer look.

## General tips

- Every body is different so listen to yours; don't do anything that doesn't feel right.
- Don't overdo it; build up gently.
- During flare-ups you might want to do less exercise, or stick to upper body work.
- Find [exercise clothes](#) that work for you and don't rub or irritate.
- Change out of sweaty clothes as soon as you can.
- After exercise, have a brief shower (or cleanse your vulva with moist cotton wool and emollient) to wash off any sweat, then reapply your emollient.

## Walking

- Use an emollient as a barrier to reduce friction and protect your vulva
- Build up slowly; take shorter walks at first

## Swimming or other water sports

- Use an emollient before swimming to protect your vulva
- Have a shower afterwards to wash off any irritants, then reapply your emollient
- Change out of your wet swimwear as soon as you can
- Avoid wearing wetsuits for long periods of time

## Cycling or horse riding

- If you feel uncomfortable on your saddle, try switching to a wider padded one
- Try cycling underwear, shorts or leggings with added padding
- Try to avoid clothing with seams in the middle

## Yoga

- Yoga's about listening to your body, so it's a great option if you've got LS
- Your teacher will usually give options for every pose, so you can do what feels right for you
- If you're not happy with a pose, lie back and focus on your breathing or try a different one instead
- If it's uncomfortable, avoid or modify poses that open up your vulval area, for example hip openers like warrior or happy baby

## Weights or gym work

- Don't overdo it; build up slowly
- To begin with, try focusing on your upper body and core
- If they're uncomfortable, avoid lower body exercises that open up the vulval area, like squats







# Emotional wellbeing and talking to others



## Overview

Everyday life with vulval lichen sclerosus (LS) isn't always comfortable or easy, and over time that can have an impact on the way you feel, and the way you relate to others. But if you're feeling anxious, depressed or isolated, you don't have to settle for feeling that way. Help is out there, and in this section we explore different things you can do to start feeling more like yourself again.

## Talking to other people

We know that for lots of people with vulval lichen sclerosus (LS), it's not easy to talk to others about their condition, especially when it affects such a personal part of their body.

Awareness about LS (and other vulval conditions) in the general public is thought to be quite low. That means people who have it often feel they'll have to explain it in detail, which can be an embarrassing prospect. And even if they do explain, other people might not really understand.

We know this can leave some people with LS feeling isolated or lonely, especially if they need to say no to social invitations and stay at home during flare-ups.

But there are people you can talk to. There are LS support groups online (including on Facebook), or there might be a group in your area that meets up in person or online. A lot of people find that talking to others with similar experiences can be really empowering, and research suggests that fostering connectedness online could be helpful for people with long-term conditions.

However, keep in mind that through support groups you might encounter difficult and sad stories, as well as uplifting and useful ones. Remember that everyone's different, and just because someone else has a difficult experience, it doesn't necessarily mean you will too.

## Looking after your emotional wellbeing

We know that having a vulval condition can affect your emotional wellbeing. Long-term conditions can often make people feel their sense of self and identity has changed. And when the condition is poorly understood, feels so personal and causes a sense of loneliness, that can be even worse.

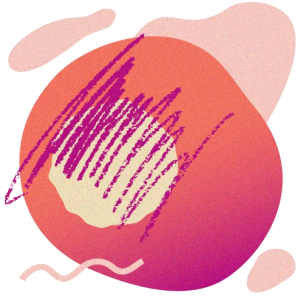
There's good evidence that [psychosexual counselling](#) can help, but this doesn't address every difficult aspect of living with LS, and it's not accessible to everyone.

We also know that physical activity can help improve the wellbeing of people with depression and anxiety. It's completely understandable that not everyone wants to exercise, or is able to, but even very small changes can make a big difference to the way you feel.

If you'd like to get started or get back to physical activity with LS, our [exercise](#) section has lots of suggestions to help you feel more comfortable and confident.

There hasn't yet been a lot of research into what improves the mental health of people with vulval LS, but getting your condition under control might be the first step to feeling more like yourself again. Talk to your GP, practice nurse, or consultant about how it's affecting you, and ask for support if you need it.





# Looking after LS in the long term

- How LS can progress
- Treatment options
- Vulval cancer and VIN
- Menopause and LS
- Incontinence and LS
- Pregnancy and birth
- Other vulval conditions

## How LS can progress

### Overview

Whether you're going through a flare-up or a more comfortable time, if you have vulval lichen sclerosus (LS), it's really important to stay on top of your treatment. Without that ongoing treatment, LS can progress and start to cause structural changes to your vulva, which are often irreversible. These are also sometimes called 'architectural' or 'anatomical' changes, and in this section we'll explore the signs to look out for.

### Checking for structural changes

We know that lots of people with vulval LS worry about structural changes, and that's understandable. Not everyone will experience these changes, but it's important to be aware of what can happen, carry out [monthly vulva checks at home](#) and make sure you're [examined every year by a health professional](#).

Unfortunately, sometimes people already have structural changes by the time they get the right diagnosis. While these often can't be reversed without surgery, it should be possible to stop them getting worse.

### Skin fusion

Skin fusion (also known as adhesion) is when parts of the [skin on your vulva](#) start to stick together, changing its structure. This can affect your labia or your clitoris.

### What is labial fusion?

Labial fusion is when your labia minora and labia majora stick together. This can give your vulva a flat appearance, or mean that the individual labia are hard to see or even invisible. Sometimes it also means that your left and right labia minora stick to each other, also known as 'bridging'.

This fusion can make it difficult to insert a tampon, or make certain sexual activity painful or (for some people) impossible. You might also notice your skin tears or splits more easily.

Labial fusion can also cause changes when you go to the toilet. You might notice spraying or dribbling when you pee, because the liquid can't leave your body in the normal way. LS doesn't typically affect your urethra (the tube carrying pee out of your body), but the fused labia can get in the way of your normal flow, making peeing look and feel different.

In very severe cases, pee, vaginal discharge and menstrual (period) blood can build up under the fused skin. This is rare, but if it happens to you, get medical help immediately.



## What is clitoral fusion?

Clitoral fusion is when the hood of your clitoris sticks to and scars over the head of your clitoris.

This fusion can be mild, moderate or severe. It might make it difficult to pull back the clitoral hood to reveal the head, and that can lead to complications. For instance, occasionally, dead skin cells and body oils can build up and become trapped under the hood, forming a swelling known as a 'clitoral pseudocyst', which can be uncomfortable.

In some people, fusion can also lead to reduced sensation in the clitoris which, in turn, can make it more difficult to have an orgasm (climax). If this happens to you, it's important to understand that your clitoris is still there, underneath the fusion, and it isn't damaged in any way.

To find out how your doctor can help, [read about treatment options if LS progresses](#).

## Scar tissue

Some people with LS notice that their skin tears during sexual activity. When your skin tears, scar tissue can form as your vulva heals. Unfortunately, scar tissue tends to be thick and rigid, so it doesn't easily expand and stretch when you put things into your vagina. This loss of flexibility can lead to more tearing, scarring and pain, with some people finding that a band of scar tissue builds up at the entrance of their vagina, causing the opening itself to become narrower.

To find out how your doctor can help, [read about treatment options if LS progresses](#).

# Treatment options as LS progresses

## Overview

The best treatments we have right now for vulval lichen sclerosus (LS) are topical steroids. These are usually ointments, or sometimes creams that you rub gently onto your skin to reduce inflammation. Our main treatment pages have lots more information on [how steroids work and how to use them](#).

Steroid treatment can help you get symptoms under control and reduce your risk of developing vulval cancer. But if you've already got skin fusion or scarring, steroids may not be able to reverse it.

This fusion or scarring can change the way your vulva looks, feels and works, so if it's causing pain, making sex difficult or stopping you peeing properly, surgery might be an option to consider.

In this section we'll look at what surgery involves, and what options might be available, so you can talk to your doctor about whether it's right for you. It's important to remember though: **most people with LS won't need surgery**.

## Treating clitoral or labial fusion

If your LS is causing [skin fusion](#), your doctor might first recommend that you try to gently separate the parts of your vulva that are sticking together and then apply a topical steroid to these areas (for example under the hood of your clitoris or between your labia).

If you can't do this, your doctor might recommend a surgical technique called division of adhesions, which is done under local or general anaesthetic. It involves your doctor separating out the layers that are stuck together. Sometimes this can be done by gently pulling apart the layers, sometimes a small cut (also called an incision) may be needed to release the scarring. Some of the scar tissue might also be removed.



## Treating clitoral or labial fusion (*continued*)

There hasn't been a lot of research into surgery for LS so it's important to talk through your options with your doctor before making a decision.

If you do have surgery, to help your vulva heal afterwards, you'll use topical steroids each day on the affected area. These will also help to reduce the chances of your skin fusing again. Your doctor might also prescribe a moisturiser (also called an emollient).

Sometimes doctors also recommend injecting steroids into the area. Later on in the healing process, they might also refer you to a pelvic floor physiotherapist who might use dilator therapy to gently stretch the vaginal opening.

## How long do the benefits of surgery last?

At the moment, very few studies have looked at the outcomes of surgery for LS, and more research is needed to understand how long the benefits last.

## Think carefully about why you want surgery

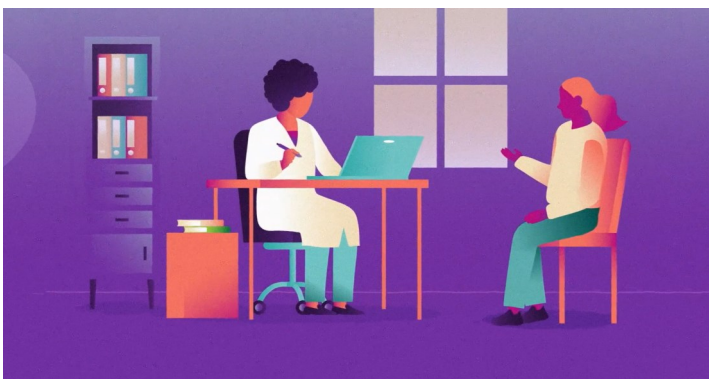
Research suggests that one of the main reasons people want this kind of surgery is so that they can have penetrative sex. Of course, sex is an important part of many relationships, providing a source of pleasure and enjoyment. But it's important to recognise that a focus on penetration can also be caused by society's expectations about what makes a 'real' woman, or what is 'real' sex.

In reality, sex doesn't have to be about penetration. Sexual pleasure, enjoyment, closeness and connection can absolutely be found without it. Whether or not you decide to have surgery, consider trying to access psychosexual counselling (sex therapy), or exploring other ways to enjoy intimacy with your partner.

## Why surgical aftercare is so important

Whenever you have surgery, your aftercare (also known as post-operative care) makes a huge difference to the results you'll see and feel. So before you go ahead, talk to your doctor about what you'll need to do afterwards. There might be things you need to buy or get ahead of time, like a [peri bottle](#) to help you wash or go to the toilet more comfortably, or ointments to look after your wound.

Remember that following your aftercare instructions carefully is critical for success, so ask your doctor for a printout you can take home. If a carer, family member or friend will be helping you after your surgery, show them the instructions too.



# Vulval cancer and VIN

## Overview

Vulval lichen sclerosus (LS) isn't a cancerous condition, but over a long period of time, it's thought that the inflammation associated with LS increases the risk of developing precancerous changes (known as VIN) and vulval cancer.

This is especially the case if LS isn't diagnosed and treated appropriately, which is why getting a [diagnosis](#), and [using steroid treatment](#) to address the inflammation is so important.

In this section we'll look at the risks associated with LS, the different types of precancerous cells, and the signs, symptoms, diagnosis and treatment associated with vulval cancer and VIN.

## What's the risk of LS turning into skin cancer?

It's different for everyone and depends on your age, how long you've had LS, how well controlled it is and whether you have any precancerous changes. Overall, the risk is thought to be less than 5%. This means that out of every 100 people with vulval LS, more than 95 will **not** develop vulval cancer. If your LS is properly diagnosed and well controlled, it's thought this risk is even lower.

Even though the risk is small, it's important for everyone with vulval LS to be aware of the warning signs and symptoms, and do regular [monthly vulva checks](#). That's because the sooner cancerous or precancerous cells are found, the easier they are to treat, which can lead to a better prognosis and reduced side effects from treatment.

## What are precancerous cells?

Precancerous cells are cells that have grown abnormally, so their size, shape or appearance is different to normal, healthy cells. They haven't yet developed into cancerous cells, but there's a greater risk that they might. So, depending on their type, your doctor might recommend monitoring or treating them.

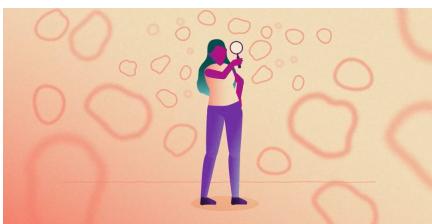
In the vulva, precancerous cells are known as VIN, which stands for vulval intraepithelial neoplasia. There are two main types, 'usual' or 'classical' (shortened to VIN), and 'differentiated' (shortened to dVIN).

## What is VIN and what happens if I have it?

Usual or classical vulval intraepithelial neoplasia (VIN) isn't usually associated with LS. Instead, it's linked to wart viruses like human papillomavirus (also known as HPV).

It's also sometimes called HPV-dependent VIN and is divided into:

- LSIL (low-grade squamous intraepithelial lesion), also known as VIN1
- HSIL (high-grade squamous intraepithelial lesion), also known as VIN2/3 or HPV-dependent high-grade VIN



If you have LSIL, you won't need any treatment but you may be monitored. If you have HSIL, which is caused by high-risk types of HPV, you'll need treatment to stop the abnormal cells developing into cancer. This might involve topical treatments (used on your skin) like imiquimod or cidofovir, or alternatively laser or surgical removal.



## What is dVIN and what happens if I have it?

Differentiated VIN (known as dVIN) is the type that's often associated with LS. It has a higher risk of developing into cancer than usual or classical VIN, so it's very important that it's treated with surgery.

## Signs and symptoms of dVIN

The symptoms of dVIN can be the same as those of many other vulval conditions (including LS) and include itching, soreness, painful sex and changes to your vulval skin.

Not everyone has these symptoms, but you might notice visual signs of dVIN instead. These might include a patch of skin on your vulva that looks or feels different in texture and doesn't go away when you treat it with steroid ointments or creams. It may be pink, brown, red or white.

## How is dVIN diagnosed and treated?

If you're worried you might have dVIN, ask your doctor to refer you to a gynaecologist or vulval specialist. To make a diagnosis, they'll take a sample of skin ([a vulval biopsy](#)) which is looked at under a microscope.

If you do have dVIN, it should be treated with surgery. That's because there's a high risk of cancer already being present, or the cells progressing to become cancerous.

## What is vulval cancer?

There are several types of cancer that can affect the skin on your vulva, but the type that's associated with LS is squamous cell carcinoma (SCC). Vulval SCC develops when precancerous dVIN cells penetrate into deeper tissue below the top layer of your skin. You might hear this described as 'invasive' (moving from the top layer of skin into the deeper layers).

## Signs and symptoms of vulval cancer

The symptoms of vulval cancer can be the same as those of many other vulval conditions (including LS) and include itching, soreness, painful sex and bleeding (or a blood-stained discharge).

You might also notice visual signs, including:

- A lump, wart-like growth or raised rough area.
- A patch of skin that looks or feels different in texture. It might be pink, brown, red or white.
- Bleeding from your vulva.
- An open sore area.

## How is vulval cancer diagnosed and treated?

If your doctor is concerned that you might have vulval cancer, they should refer you to a gynaecologist or vulval specialist urgently. In England, this means they should follow the cancer pathway, which makes sure you're seen by a specialist and are diagnosed and receive treatment as quickly as possible. The specialist will take a biopsy, looking at some of your skin cells under a microscope to make a diagnosis.

If you do have vulval cancer, your treatment will depend on a number of factors, like the size and site of the cancer and your general health. However, surgery and/or chemotherapy and radiotherapy are the main treatments you can expect.

If you're given a cancer or VIN diagnosis, it's important to keep using your topical steroid because there's evidence that keeping LS under control reduces the risk of cancer coming back.



# The menopause and LS

## Overview

The menopause is a natural process that can affect people physically and mentally in a whole range of different ways. In this section we'll look at what exactly we mean by the menopause and perimenopause, how they can affect your vulva, and what they might mean for your vulval lichen sclerosus (LS).

## What exactly is the menopause?

If you're a woman or you were assigned female at birth, you'll usually reach the menopause between the ages of 45 and 55, but for some people it can happen sooner. It's the point at which you haven't had a period for 12 months because of changes in your body's hormone balance.

Menopause is usually a natural part of the ageing process, but it can also be triggered when people have their ovaries removed during surgery, or take medication that stops their ovaries producing hormones (for example, during cancer treatment).

## What is perimenopause?

Perimenopause is the period of time leading up to the menopause, when your ovaries have fewer eggs and stop producing the same amount of hormones. It can last anything from a few months to ten years and the hormonal changes can cause irregular periods and a whole range of other symptoms. These often include hot flushes, night sweats, difficulty sleeping and changes in mood.

## How the menopause affects your vulva

Your vulval skin contains hormone receptors that respond to oestrogen. So, when your oestrogen levels start to drop during perimenopause and menopause, the skin can become thinner and less able to make its own natural lubrication. This can cause symptoms like vaginal dryness, vulval dryness, itching and pain. Medically known as urogenital atrophy, these symptoms can make sex painful.

Your bladder and pelvic floor muscles also respond to oestrogen. So, during perimenopause and menopause, you might notice that it's harder to control your bladder, which means you're more likely to leak a little pee when you're not expecting it.

When the skin around the opening to your bladder ([known as the urethral opening](#)) is thinner, it's easier for bacteria to enter your bladder, and this can also make bladder infections (also called urinary tract infections or UTIs) more common.

Together, these symptoms are called genitourinary syndrome of menopause (or GSM) and they can be treated with a topical oestrogen (usually a cream or tablet that you put inside your vagina). Because of its low absorption to the rest of the body, this approach is suitable for a lot of women. It's very effective at treating GSM symptoms, but you need to use it regularly or your symptoms will usually come back.

Alternatively, depending on your menopause symptoms and medical history, your doctor might prescribe systemic hormone replacement therapy, commonly called HRT, which comes in tablets, patches and gels.

[Read NHS information about vaginal oestrogen.](#)



## How the menopause affects your LS

The symptoms of GSM can be the same as the symptoms of LS (itching, soreness, dryness and painful sex). It's not unusual to have both conditions, and some people with well-controlled LS notice their symptoms get worse during perimenopause and menopause. This might be because they've also developed GSM, or it might be because they've developed some incontinence (leaking pee) that's causing flare-ups in their LS.

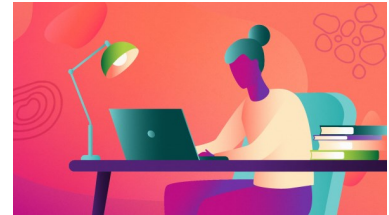
The perimenopause or menopause might also be the first time someone's vulval LS gets diagnosed. This could be because GSM makes their LS symptoms more noticeable, or it could be because they're struggling with a whole range of symptoms, so they get examined and diagnosed.

It's always important to discuss any new symptoms with your doctor and to be examined to make sure you're on the right combination of treatments for you.

## Where can I find out more?

[The NHS](#)

[Menopause Support](#)



# Incontinence and LS

## Overview

Urinary incontinence is when pee (urine) leaks from your bladder when you don't mean it to. It's very common, especially after childbirth and after the menopause, but it's not just a part of ageing that you have to put up with. In fact, in most cases it's very treatable.

There are two main kinds of urinary incontinence – stress incontinence and urge incontinence. In this section we'll look at what each one means, how they might affect your vulval lichen sclerosus (LS), and what treatment and lifestyle changes might help.

## What's the link between vulval LS and incontinence?

We know that people who have vulval LS are more likely to have urinary incontinence than people who don't have LS. We're not yet sure of the reasons for this, but it might be that the leaks of pee, however small, cause inflammation in the vulval skin which then triggers the development of LS in people who are susceptible.

It can also be harder to treat vulval LS if you have urinary incontinence because topical treatments can be washed off, soaked up by pads, or wiped away because you're going to the toilet more often. Even so, nobody should have to accept incontinence without knowing what's causing it. In most cases it's very treatable, and resolving the problem will make a huge difference to keeping your LS under control.





## When should I talk to my doctor?

If you think you might have stress or urge incontinence, please talk it through with your doctor. There are lots of treatments available, so it's not something you just have to live with.

If you think you might have a [urinary tract infection \(UTI\)](#) (*opens in new tab*) or you notice any blood in your pee, it's even more important to get help quickly, as this could make you unwell, or be a sign of something serious.

If incontinence is one of the genitourinary symptoms you're having during [menopause](#) or perimenopause, you might find that vaginal oestrogen or HRT can help, so talk to your doctor about your options.

## Simple changes that can help with incontinence

As well as talking to your doctor, there are a few changes you could try at home which might help to improve your continence and reduce leaks.

Some people notice that they're sensitive to caffeine and that they have fewer leaks when they cut it out of their diet. Cutting down on alcohol and maintaining a healthy weight can also help.

If you have stress incontinence, pelvic floor exercises can help to strengthen the muscles that support your pelvis and control leaks.

## Resources

The NHS has [advice on how to do pelvic floor exercises](#), and other simple lifestyle changes. You could also ask your doctor about referring you to a [pelvic floor physiotherapist](#).

# Pregnancy and birth

## Overview

If you're pregnant, or planning to have a baby, you might be wondering how your vulval lichen sclerosus (LS) will affect your pregnancy and birth – and how they'll affect your LS.

In this section we'll be looking at LS treatment during pregnancy, how LS might affect your birth choices, what you can do to get ready, and the kind of conversations it's important to have with your midwife.

## How does LS affect pregnancy and birth?

At the moment, there hasn't been a lot of research into how vulval LS affects pregnancy and birth, and it's an area we'd love to see studied more. But the good news is, the studies that have been done so far don't suggest that LS causes any particular problems during pregnancy.

When it comes to birth, the studies show that only a small number of people with LS needed a caesarean section instead of a vaginal birth, and we'll look at this more in our birth information later in this section.



## Is my LS likely to get worse... or better?

Again, there have only been a small number of studies into how LS is affected by pregnancy and birth, but the evidence so far is relatively positive. In one study which included 85 people, 65 had stable LS throughout pregnancy, 12 saw an improvement in their LS and only 7 said their LS became worse.

One of the real positives about pregnancy and LS is that, for people who've been living with undiagnosed LS, it can be an opportunity to finally get a diagnosis. Regular pregnancy examinations by doctors, nurses and midwives provide opportunities for you to talk about any symptoms you've been struggling with and, if necessary, get a referral to a specialist.

## Is it safe to carry on using topical steroids?

Yes. Even if you're using a very potent [topical steroid](#) to treat your vulval LS, it's safe for you to carry on throughout your pregnancy. In fact, it's really important that you do, so you can keep your LS symptoms as calm as possible, get your body ready for the birth, feel well before and after your baby arrives, and look after the long-term health of your vulva.

## Can I have a vaginal birth if I've got LS?

Yes. Lots of people with LS have vaginal deliveries and, in the studies so far, only a small number needed a caesarean section instead. This might be because their LS symptoms were more severe, or their LS had progressed into more complex structural changes. If your LS is relatively calm, you're likely to be able to have a vaginal birth, if you want one.

Of course, even in people who don't have LS, tearing during a vaginal delivery is very common. In fact it happens in around 90% of first births. If you've got LS, there's a possibility it might reduce the elasticity and stretchiness of your vulva and vaginal opening, making your skin more fragile and more likely to tear. Your LS might also mean it takes you longer to recover, but your doctors, nurses and midwives should be able to support you through this.

Over a third of vaginal births in the UK also involve an episiotomy, where a doctor or midwife needs to make a small cut in your [perineum](#) (the area between your vaginal opening and your bottom) to help the baby come out more easily if this is proving difficult. You'll be stitched with dissolvable stitches but again, you might find your LS makes your recovery a little slower.

If you have an episiotomy or a tear, it's really important to keep using your topical steroid, helping your skin stay as calm as possible while your body heals and repairs.

## How do I decide what type of birth I want?

It's your choice to make, and the best way to make it is to have all the facts. Talk to your midwife and, if you have one, your LS consultant. They'll be able to give you advice based on your specific circumstances, how under control your LS is, and any scarring or structural changes you have.

If you've had a baby before, talk to them about your experience, what went well and less well, and how your LS reacted to the birth.

If you think you'd prefer one type of birth over the other, let your midwife and doctor know and talk it through with them. They'll be able to support you in your decision, help you get ready for the birth and make sure your preferences are written down in your medical records.



## What if my midwife doesn't know about LS?

Unfortunately, some midwives don't know about vulval LS, or don't know a huge amount about the condition. We're working hard to raise awareness, so pregnant people with LS can get better, more tailored support from their whole healthcare team.

In the meantime, ask your midwife how much they know about LS and talk to them about how it affects you day to day. You can point them towards this website too, giving them an easy way to find out more about the condition and the care you need.

## What can I do to get ready for the birth?

The most important thing you can do is look after yourself, and as well as eating healthily and staying active, that means keeping on top of your LS treatment by using your [topical steroid](#).

Perineal massage is also a simple, effective way to help your body get ready for the birth, and it can be especially helpful if you have LS. It involves massaging and gently stretching your [perineum](#) to improve elasticity and reduce the risk of tearing. If you'd like to try it, [read a step-by-step NHS guide](#) (*opens in new tab*).

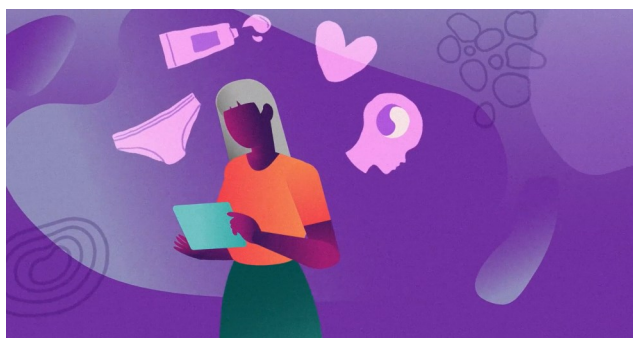
It's also a good idea to say that you have LS in your birth plan, and make a note that you might be more prone to tearing. Your LS will be in your medical records already, but adding it to your birth plan will be an extra reminder to the people looking after you on the day. Talk to your partner, or whoever's going to be with you at the birth, and make sure they know about your LS so they can advocate for you and express any concerns you might have.

Finally, try to remember that all births are different, and they don't always go to plan. Your baby might arrive much more quickly, or slowly, than you expect. Or, for all sorts of reasons, the type of birth you have might need to change at short notice. Try to keep that in mind and remember, however your baby is born, the most important thing is that you're both safe and well.

## Will my LS get worse after the birth?

It might and it might not. Sometimes people report having more flare-ups while their body's recovering from a vaginal birth, and if you've had tearing or an episiotomy, you're likely to experience some pain and discomfort in the first few weeks. But this doesn't happen to everybody, and it won't necessarily be the case for you.

Whatever happens, keep up your topical steroid treatment and remember that your midwife, local health visitors and GP are there to support you. It's completely normal to have plenty of check-ups and check-ins after you've had a baby. These might include home visits, appointments at your local GP surgery or health centre, or drop-in sessions for new parents where you can talk things through and get advice.



# Other vulval conditions

## Overview

There are lots of conditions that can affect your vulva, and they often have the same symptoms as vulval lichen sclerosus (LS); things like itching, soreness and painful sex. That's why it's so important to be examined by a healthcare professional who knows how to properly check your vulva, or who can refer you on to someone else if they're not sure. In this section, we'll look at some of the conditions most commonly confused with LS, so you can have more confident conversations with your doctor.

## Thrush

Thrush (also known as candidiasis) is a common condition caused by the overgrowth of a yeast called candida. There are a few things that can increase your risk of getting thrush, including having recently taken antibiotics, or going through hormonal changes. One of the most common signs of thrush is a white curdy discharge, but not everybody gets this. Sometimes the skin looks dry and fragile or feels swollen, itchy or irritated. You can buy over-the-counter treatments for thrush, but if it doesn't settle quickly, or you keep getting it, don't keep repeating the treatment. Instead, see a health professional and have your vulva swabbed, so they can check whether you actually have thrush, or another condition like LS.

## Vulval eczema

Eczema (also known as dermatitis) can affect the skin on any part of your body, including your vulva. The skin becomes dry, itchy and sore, and struggles to maintain its natural barrier function. This can make it more susceptible to irritation or infections like thrush. Often people already have eczema elsewhere, but sometimes it only affects the vulva, which makes it harder to diagnose. Eczema flare-ups can be triggered by an allergy to something you're using on your skin (like wet wipes or shower gels) or something irritating your skin (like hair removing creams or pee). Sometimes the itch is so severe that the skin thickens to protect itself from repeated scratching, and this can cause a change in its texture and colour.

## Lichen planus

Lichen planus is a skin condition that, like LS, can cause scarring and changes in the structure of your vulva. However, there are some key differences between the two conditions. Lichen planus often affects the mouth (this is called oral lichen planus) and can cause raw areas to develop (this is called erosive lichen planus). It can be harder to treat than LS and doesn't always respond to even very strong topical steroids. It can also cause a rash on the rest of your body which looks completely different to when it affects the mouth or vulva. Sometimes people have features of both conditions (this is called a lichen sclerosus / lichen planus overlap).

## Where can I find out more?

Thrush:

[NHS advice on thrush](#)

[A dermatologist's explanation of thrush](#)

[A resource on people's experiences of recurrent thrush and ways to access support](#)

Eczema:

[NHS information on eczema](#)

[Helpful information from Eczema Care Online](#)

Lichen planus:

[Lichen planus](#)

[Erosive lichen planus](#)





# Information for partners, carers, and health professionals

- Information for carers
- Information for partners
- Information for health professionals

## Information for carers

### Overview

Whether you're caring for a parent, partner, family member or friend, or you work professionally as a carer, looking after someone with vulval lichen sclerosus (LS) isn't always easy. In this section, we take you through some practical tips and suggestions you can use when you're helping them.

If the person you're caring for is visually impaired, has mobility issues or is elderly, you might need extra support to give them the best care for their condition, so we've also included recommendations for taking those next steps.

### Understanding vulval LS and vulval care

If you're caring for someone with vulval LS, it's really important to have a good understanding of what the condition actually is. If you'd like to find out more about it, we've put together an [easy-to-understand guide](#).

It's also really important to make sure someone with LS avoids potential triggers for their condition. Vulval skin can be delicate and it may need a different hygiene routine than skin on other parts of the body. For example, if someone has problems with incontinence, this needs to be properly managed, otherwise it may cause painful and distressing flare-ups.

Read about the best way to [look after vulval skin](#), and [manage incontinence](#).

### Treatment

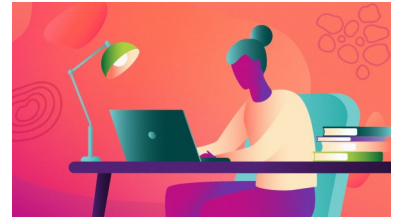
Getting the right treatment is one of the most important parts of managing LS and minimising discomfort. For most people, it involves using [topical corticosteroid ointments](#), which are gently smoothed onto the skin.

If they're elderly, have difficulties with mobility or can't see well enough to apply the ointments themselves, you might need to do it for them. If so, you'll want a good understanding of how much to use, where exactly to apply it and how often. Their doctor, nurse or consultant should be able to explain this, so you feel clear and confident about what you're doing.



The person you're caring for might need help sticking to their treatment plan, which might mean reminding them when and how to apply their ointment. We've created a treatment plan template, which might be a useful way to document their routine, with the help of their doctor.

Download the treatment template plan from the 'Resources' page of our website, or by following this link: [https://www.lichensclerosusguide.org.uk/files/2025/01/LSGuide\\_Treatment\\_Plan\\_v1.0.pdf](https://www.lichensclerosusguide.org.uk/files/2025/01/LSGuide_Treatment_Plan_v1.0.pdf)



You might find our information on [steroid treatments](#) and the [anatomy of the vulva](#) helpful, but if you're not sure, check with your loved one's doctor, nurse or consultant so you feel clear and confident about what you're doing.

If the person you're caring for wants or needs to take a shower or bath before using their ointment, you might find they need your help to do that too.

## Managing symptoms

As well as helping them follow their treatment plan, you might also need to support the person you're caring for with managing their symptoms, especially if they're newly diagnosed, starting a new treatment or experiencing a flare-up.

If they have active cuts or fissures, it might sting when they pee. If so, using a gentle stream of warm water to dilute the pee as it comes out can make a big difference. A [peri bottle](#) can make this easier, and is also a good way to gently rinse any pee off the skin afterwards.

Applying a fragrance-free emollient moisturiser, (preferably an oil-based ointment) can help soothe, protect and moisturise the skin. Emollients can be used as often as necessary, but ideally at least twice a day, and at least 20 minutes after steroid treatments (to give the steroids time to absorb). It's often helpful to keep emollients in the bathroom, so they can be reapplied after showers, baths or using the toilet.

Read more and watch our video about [applying topical steroids and emollients](#).

It's also common for people with LS to develop constipation, so try to make sure the person you're caring for is well hydrated and eats plenty of high-fibre foods. If you think constipation is becoming a problem, you might need to talk to their doctor, nurse or consultant about laxatives or medicines to soften their poo. If pelvic floor dysfunction seems to be contributing to the constipation, they might also be referred to a [pelvic floor physiotherapist](#).

## Vulva checks

Once a month, it's a good idea for people with LS to have a vulva check. If that's something the person you're caring for can do for themselves, you might just want to remind them when it's time. If they're unable to check themselves, you'll need to do it for them, with their understanding and consent.

A vulva check involves examining [each part of the vulva](#), including the mons pubis, clitoris, labia majora and minora, vestibule, vaginal opening, fourchette, perineum and perianal skin. Look for changes in colour or texture, for example new moles or dark spots, growths, cuts or fissures, a new patch of thicker skin, or new loss of pigmentation (where the skin loses colour). If you see any changes, note them down and let their doctor know. [Read more and watch our video about vulva checks](#).



## Looking out for flare-ups and complications

When you're doing a vulva check, or any time you're helping the person you're caring for wash, dress or go to the toilet, keep an eye out for signs that their LS is flaring up, or any complications like bleeding, tearing or infection. If you see anything you're worried about, talk to their doctor.

Likewise, if their pain is intense or increasing, tell their doctor and ask about [options for pain relief](#).

## Quality of life and overall wellbeing

Living with LS can be challenging, so try to stay optimistic when you're with the person you're caring for. If you can, encourage them to exercise, get a good night's sleep and try techniques for easing stress or anxiety. If you notice their mental health seems to be suffering, talk to their doctor and consider looking for a therapist, counsellor or support group.

## Respect and open communication

However challenging your role as a carer might be, try to always respect the privacy and dignity of the person you're helping. Discuss sensitive topics in a compassionate way and help them feel in control of their own healthcare decisions. Think of yourself as a partner in their health and wellbeing – be there to work with them, support them and empower them.

## Appointments

You might need to help the person you're caring for get to and from their medical appointments, whether they're seeing their GP, nurse, dermatologist, gynaecologist, pelvic floor physiotherapist or someone else. Be an advocate for them, whatever the healthcare setting, by asking questions, reporting concerns, seeking clarification and making sure they get the medical care and support they need.

## Support for you

Caregiving can be difficult at times, and it's important to take care of yourself, so you can look after the people who rely on you. Try to carve out some time to rest and relax when you can, and if you feel you need some support, don't hesitate to reach out. There are all sorts of carer support groups that meet online, or in person, and we've included some resources at the end of this page to help you.

## Asking for extra help

If you're looking after a loved one who's visually impaired, has mobility issues or is elderly, caring for them at home can be even more challenging. But you don't have to do everything on your own. If you feel you need help with their care, or their needs are becoming greater, talk to their GP or consultant, or get in touch with a carers' charity or organization. We've included some resources at the end of this page to help you.

## Useful links for carers

- [Carers UK](#)
- [The Carers Trust](#)
- [Carers help and support \(Citizens Advice\)](#)
- [Information on UK government benefits and financial support for carers](#)
- [Information on arranging social care for you or a loved one \(AgeUK\)](#)
- [NHS advice on social care and support](#)
- [LS Facebook support group](#)



# Information for partners

## Overview

Vulval lichen sclerosus (LS) doesn't just affect the people who have it. For partners especially, it can be a difficult condition to understand, putting extra pressure on relationships, communication, sex and intimacy.

But if your partner does get an LS diagnosis, they'll need your support and understanding. That's why it's so important to find out about the condition, get to know how your partner might be feeling, and take good care of the relationship between you.

To help you do that, we've worked closely with people who have vulval LS, and in this section, we'll be sharing their advice on supporting your partner.

## Getting a diagnosis

If your partner has [symptoms that could be LS](#), it's important they get a proper diagnosis, so they can be prescribed the right treatment and start feeling better. You'll find lots of advice on how that process works in our [Getting a diagnosis](#) section.

Getting an LS diagnosis can be upsetting. While your partner might be relieved to know what's wrong, they'll also be learning about a condition they'll have to live with long term. LS can't be cured, and although treatment can be effective at controlling symptoms, it isn't something they'll be able to forget about entirely.

Most people with a new diagnosis also want to research their condition online, and your partner might find the images they see distressing. They'll also learn that people with vulval LS have a slightly higher risk of vulval cancer. While this only happens to a small number of people, it's natural that your partner might find this very frightening.

While all of this is sinking in, your partner might be tearful and distressed. They'll need you to be supportive and reassuring, and the more you understand LS, the better you'll be able to do that.

## Educating yourself about LS

One of the best things you can do to support your partner is take the time to learn about LS. Our website's been created by doctors, researchers and most importantly, people with LS, so exploring the different sections will give you a better idea of what life is going to be like.

We've included advice and information on:

- [What LS is and what signs and symptoms to look out for](#)
- [The anatomy of the vulva](#)
- [Getting a diagnosis](#)
- [Navigating the healthcare system](#)
- [Treatment of vulval LS](#)
- [How the condition may develop over time](#)
- [How to make everyday life more comfortable](#)

But one of the most important things to learn is what LS really feels like for your partner. Some people describe the pain as being like someone holding a flame to their vulva, and the itching as being like chickenpox. Everyone's different, so ask your partner what it's like for them; listening and making them feel understood is hugely important.





## Sex and intimacy

Lots of people with LS still enjoy an active sex life, whatever that looks like for them and their partner. Some are able to carry on as they always have, while others find that making some changes or trying new things really helps.

However, for many people, LS makes sexual intimacy difficult, and the pain, discomfort, tearing or bleeding they experience means they just don't want, or feel able, to do it. Even very gentle touching, stimulation or penetration can for some people be extremely painful, not just at the time, but for days afterwards. This might only be the case during a flare-up, or it might be in between flares as well.

It's not their fault, and it's not yours, but it can still be very difficult to talk about. The loss of intimacy and feelings of guilt or shame (from both sides) can put a strain on relationships, so it's important to talk to each other, be patient and respect your partner's boundaries.

If your partner is finding sex too difficult at the moment, it's understandable for you to be upset too. Try to remember that while you might be distressed by it, your partner will be feeling all of that on top of the everyday pain and discomfort of LS. They may be also feeling they've let you down, or be struggling with their self-esteem or body image.

Give them (and yourself) time. When their symptoms are more under control, they may feel ready to be more intimate again. If they do, lubricants and condoms can help to minimise friction, discomfort and the risk of infection. But remember, sex doesn't have to be about penetration, and intimacy doesn't have to be about sex. Even if they don't want to try again, you can still explore alternative ways to be close to one another and make each other feel good.

[Find out more about sex and LS.](#)

## Being in it together

While it won't cure LS, having a healthier lifestyle can be helpful, and that's always easier to do when you do it together. Trying to take regular [exercise](#), eat a balanced diet and reduce stress are things both of you can get involved in – and feel the benefits from. So try to be positive, encourage these healthy steps and celebrate the small victories you both achieve. You can also help by being aware of what triggers your partner's symptoms and making simple switches to things like the soaps and detergents you use at home.

## Going to appointments

Like with any medical condition, having someone by your side at appointments can make a big difference, so talk to your partner about whether they'd like you to be there with them. If so, make it a priority to go to as many appointments as possible, so you can understand what's happening, ask questions and give them the support they need – on the day and afterwards.

[Read more about diagnosis, referrals, check-ups and support.](#)

## Helping with treatment

Your partner might be completely able to take care of their own treatment, staying on top of their treatment plan, [checking their vulva](#), and applying their steroid creams and [emollients](#). But if not, they might need you to help. Talk to them about how they're feeling and coping, offer to help if they'd like you to, and listen to them and their doctors so you feel confident about what to do. [Find out more about treatment.](#)



## Dealing with flare-ups

Even if your partner's LS is well under control, flare-ups in their symptoms can happen, and they can be extremely uncomfortable, painful and distressing. When this happens, your partner might not feel able to go out, and prefer to stay at home where they're more comfortable. They might also find it eases their symptoms to go without underwear.

Everyone's different, so find out what makes your partner feel better and how you can help. It might be that they'd love you to run them a warm bath with epsom salts, give them an ice pack wrapped in a soft towel, get them an antihistamine or just cuddle them on the sofa.

## Getting support, for both of you

It's natural for LS to put new pressures on you both individually and as a couple, so if you need some support, don't be afraid to reach out. Talking things through with someone else can help you see things from new perspectives, discover new coping strategies and build resilience. Many people with LS also find [psychosexual counselling](#) (also known as sex therapy) helpful.

Ask your GP about counselling or support groups, or look for a recommended counsellor you can talk to locally or online. To make sure you're in good hands, look for someone with accreditation from the British Association for Counselling and Psychotherapy (BACP).

# Information for health professionals

## Overview

While our LS guide is primarily aimed at people with vulval lichen sclerosus (LS) and their carers and partners, it's also a useful resource for healthcare professionals who want to improve, consolidate or refresh their understanding of vulval LS. This guide is about adult vulval LS, it doesn't currently contain specific information about penile LS, or children's LS (also known as juvenile or paediatric LS).

It's estimated that 1 in 100 women or people assigned female at birth have vulval LS (likely an underestimate), so there's every chance that you have patients with the condition, whether diagnosed or undiagnosed. We hope you'll use this guide to support those patients, and point them to it so they can understand and manage their condition.

A key message to healthcare professionals is that when someone presents with vulval symptoms, or is struggling with their LS, it is so important that they are taken seriously. People describe it as 'excruciating' to talk about it, so if they are willing to ask for help, they really need it. We know that LS is often diagnosed late, with many opportunities missed.

We haven't created specific, separate information for healthcare professionals, but we recommend you read through the site, which is broken down into short, digestible sections, including video content. We've also included [academic sources \(PDF, 216kB\)](#) if you'd like to take a deeper dive into any area.

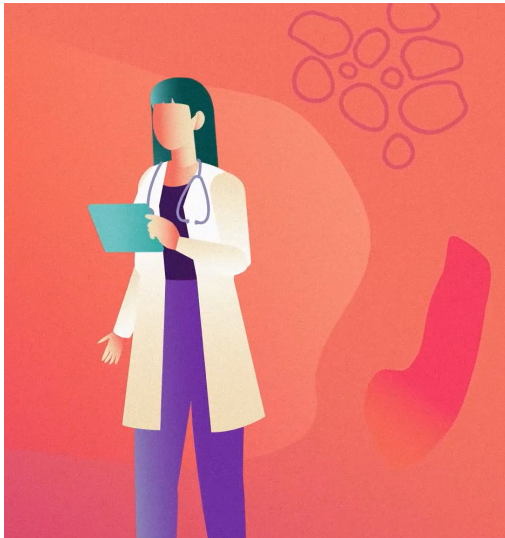
If you're a formal carer, you can learn more about looking after your clients within our [information for carers and partners](#).



## Treatment plan template

We've created a template treatment plan for you to use in your consultations with women with vulval LS. It is an aide memoire, designed to ensure your patients leave feeling confident in their treatment and their ability to self-manage. It includes diagrams which can be used to show the patient exactly how much topical steroid to use, and where to apply it.

Download the treatment template plan from the 'Resources' page of our website, or by following this link: [https://www.lichensclerosusguide.org.uk/files/2025/01/LSGuide\\_Treatment\\_Plan\\_v1.0.pdf](https://www.lichensclerosusguide.org.uk/files/2025/01/LSGuide_Treatment_Plan_v1.0.pdf)



## My LS Treatment Plan

We've put together this easy-to-use plan to help you keep track of your LS treatment. Take it along to your next appointment and ask your doctor or nurse to help you fill it in.

My topical steroid is called: \_\_\_\_\_

It might also be known as: \_\_\_\_\_

Its strength is:

Potent  Very potent

**This is how much I need to use each time.**

Generally, the advice tends to be to use one to two pea-sized blobs each time you put it on, but ask your doctor to show you the right amount for your body and your LS.



Ask your doctor to shade in how many pea-sized blobs or what proportion of a fingertip unit to use each application.

## Recommended resources

If you'd like to learn more, we strongly recommend familiarising yourself with the following sources.

- [The ISSVD's Practical Guide to Diagnosis and Management of vulval LS \(PDF, 6.6MB\)](#)
- [The British Association of Dermatologists \(BAD\) clinical guidelines for LS \(PDF, 1.2MB\)](#) (accredited by NICE)
- [BJGP Clinical Practice article](#) 'Vulval lichen sclerosus in primary care: thinking beyond thrush and genitourinary symptoms of the menopause'

We'd also encourage you to watch this [short film](#) about LS, based on interviews with patients. It's under four minutes long and gives hugely valuable insights into this common chronic condition.

