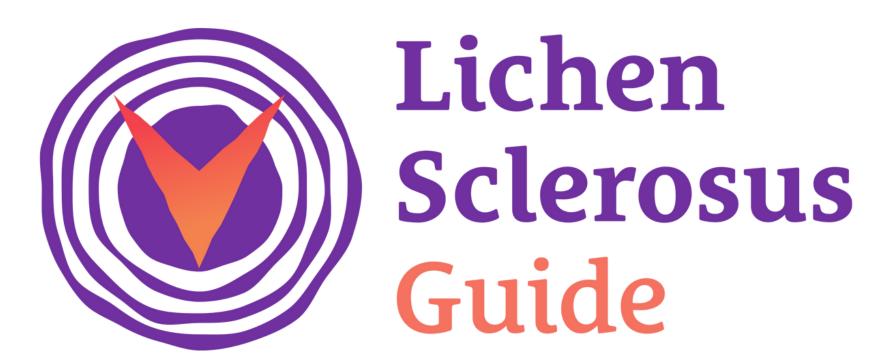
The Lichen Sclerosus Guide

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





Sophie Rees (University of Bristol), Clare Baumhauer (Patient contributor), Zoe Breen (Patient contributor), Neelam Heera-Shergill (Patient contributor), Lisa Kirby (Nottingham University Hospitals NHS Trust), Jaclyn Lanthier (Patient contributor), Rheanne Leatherland (University of Nottingham), Rosalind Simpson (University of Nottingham) and Caroline Owen (East Lancashire Hospitals NHS Trust)

Find us today at lichensclerosusguide.org.uk









The problem

Vulval lichen sclerosus (LS) is a chronic progressive skin condition thought to affect 1 in 100 women.

Often people don't know much about it, even healthcare professionals. This leaves people struggling without a diagnosis, proper treatment, or good knowledge about their condition.



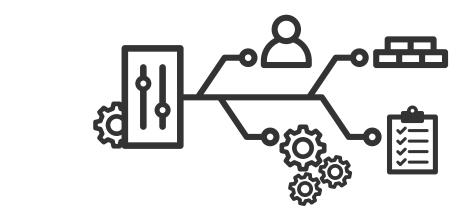
The problem

Signs and symptoms:

- Itching
- Painful sex
- Pain, soreness, burning
- Pale, white, or ashy patches
- Feeling of dryness
- Change in sensation
- Pain when going to the toilet
- Disturbed stream when urinating



Listen to Clare's story on BBC 5 Live







Missed opportunities for diagnosis

Missed opportunities for education

A need for information and tools for selfmanagement and living with vulval lichen sclerosus in the long term

Coproducing an online information resource about vulval lichen sclerosus



Mixed methods research to understand lived experience



Assembled dermatologists and patient contributors



Surveyed a large online support group (n=609) to refine topics and format



Co-wrote text and created animated videos explaining e.g. vulval anatomy, how to use treatment.





















Launched 17th January 2025







The LS Guide

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





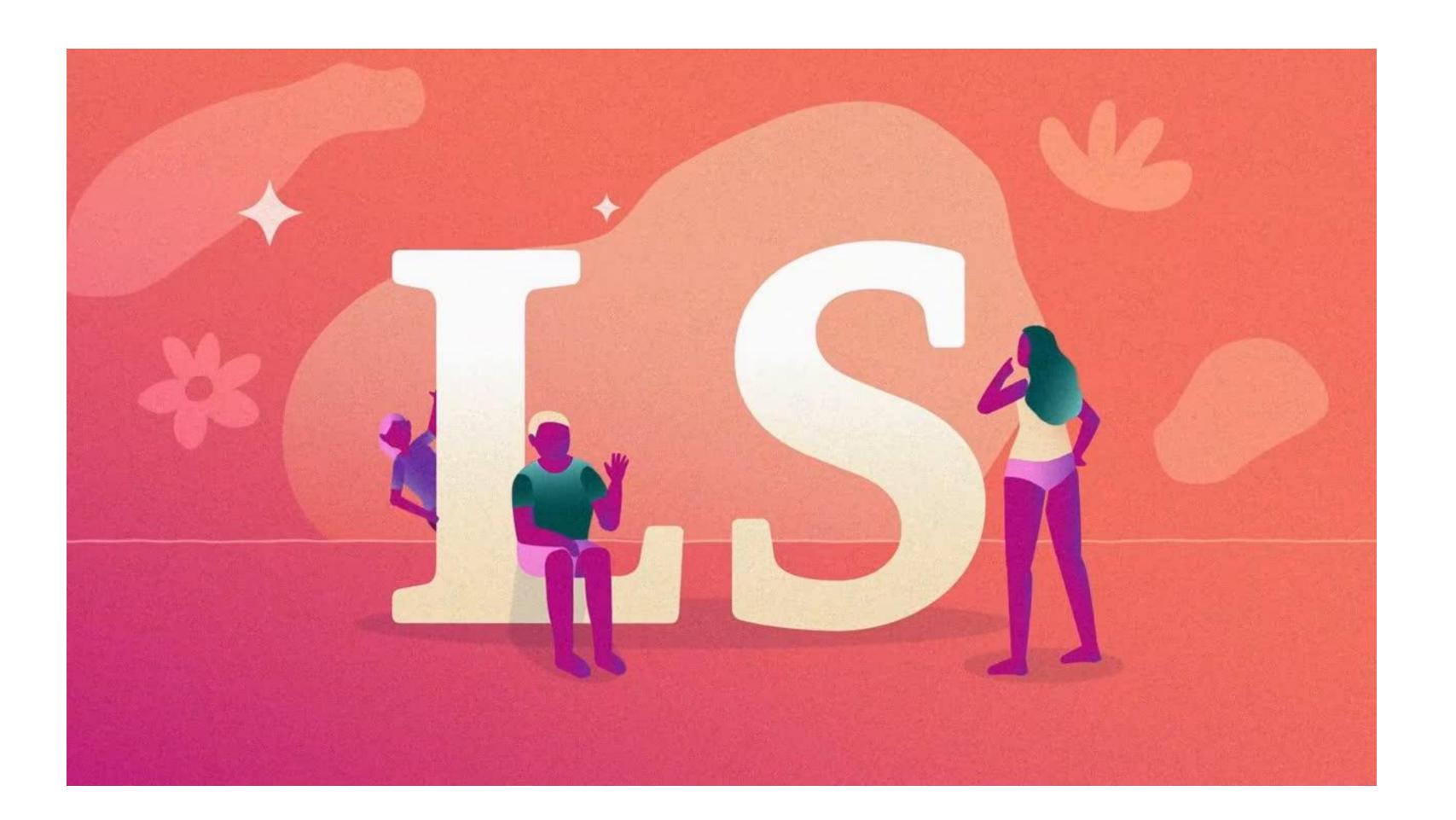
Home About this guide Information about ~ Information for ~ Resources \wp

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.



Videos









What is vulval lichen sclerosus? - The LS Guide









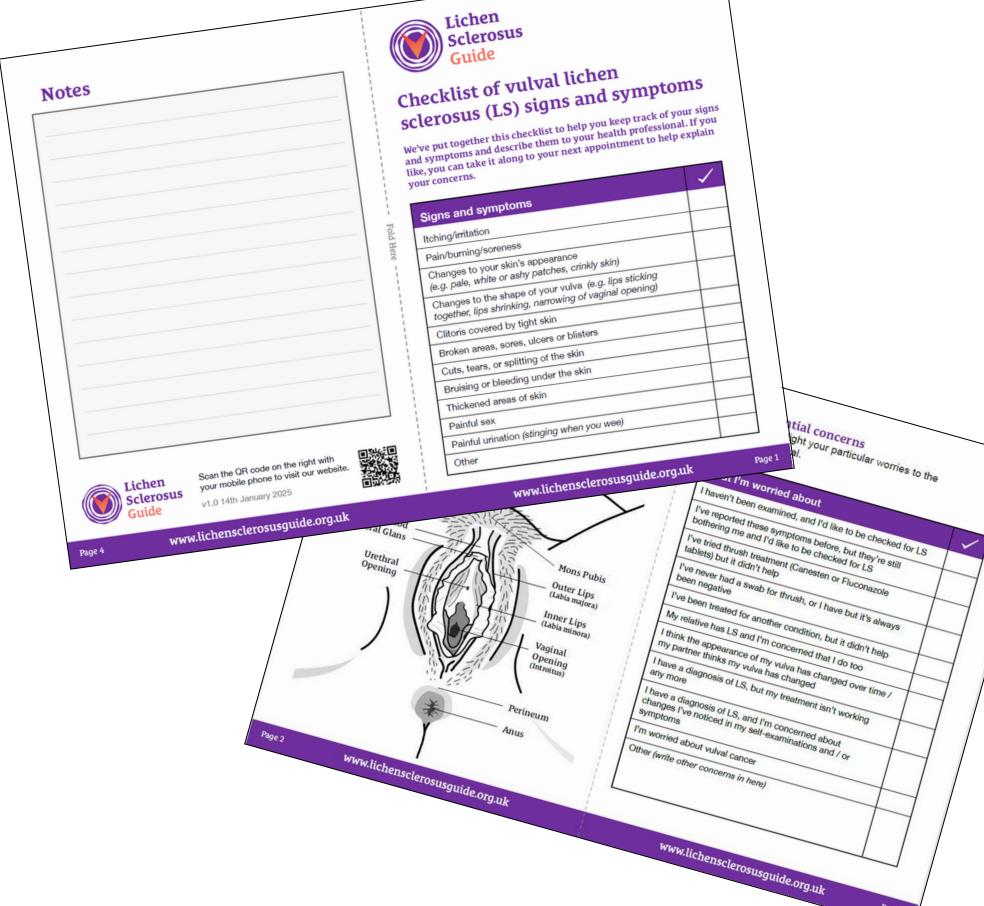


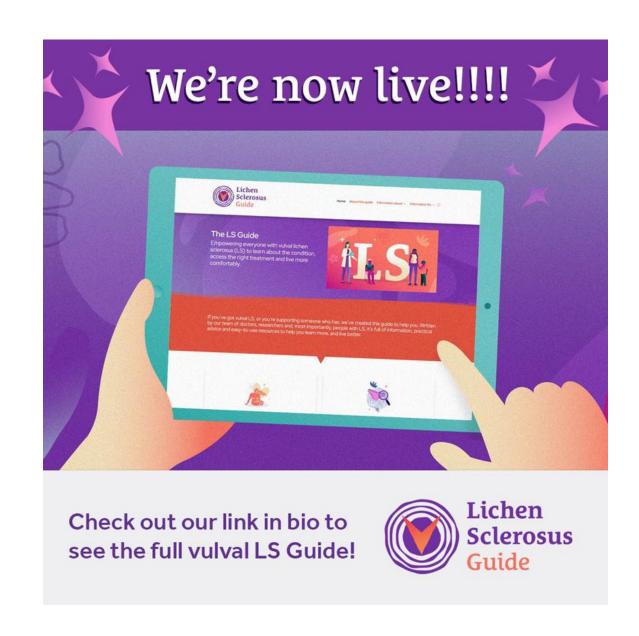
Anatomy of the vulva - The LS Guide

Resources

I can also uso m	Resour
I can also use my moisturiser as often as I like.	
Other treatments I use for my LS: This might be treatments you use all the time, some attentions. Lichen Sclerosus	S
My LS Treatmer We've put together this easy-to-us appointment appointment.	nt Plan
pating calm. Take	se plan to help you keep track
my topical steroid in	se to help you fill it in.
My doctor or nurse is	
Ven.	
number in	
Organised by my doctor.	e to two pea-sized
Lichen Lichen	to show you
Scan the QR code on the right	
veosite.	
Www.lichensclerosusguide.org.uk This is how often I need This is how often diagnosed: If I've just been diagnosed: Www.lichensclerosusguide.org.uk Www.lichensclerosusguide.org.uk	ized blobs or
This is how often. If I've just been diagnosed: Www.lichensclerosusguide.org.u The current guidelines suggest using your steroid:	application.
The current guide Once a day for the first month Once a day for the second month Then every other day for the second month Then every other day for the second month Clittoral Hood Clittoral Glans	1k Page 1 ora)
Then twice a week until you see completely calm Clitoral Glans	Inner Lips (Labia minora)
a review or your Lo. If I'm having a flare-up: Here The interpolation of the interpolation	Hill waginal
Use your steroid once a day until your LS feels completely Use your steroid once a day until your LS feels completely	Opening (Introitus)
Camilising	Perineum
If my LS is calm: If my LS is calm: LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using LS is a long-term condition, so most people need to keep using	Anus
If my LS is calm. LS is a long-term condition, so most people need are calm. LS is a long-term condition, so most people need to calm. LS is a long-term condition, so most people need are calm. LS is a long-term condition are calm.	*
from person to they'd like you to	hane to find out
agon the QR code on the right	with your mobile phone to find out topical steroid.
Scan the spent of apply a more about how to apply a	sclerosusquide.orq.uk
www.lichen	

www.lichensclerosusauide.org.uk





Successes

>137,000 views on the website since launch (January), from over 50 countries.

85% of patients say they feel more confident managing their condition because of the LS Guide (n=111).

"I came across this website by chance and it has taken away the fear. My mind now says I can deal with it." - Survey respondent

Promotion and getting it into clinical practice



Next steps

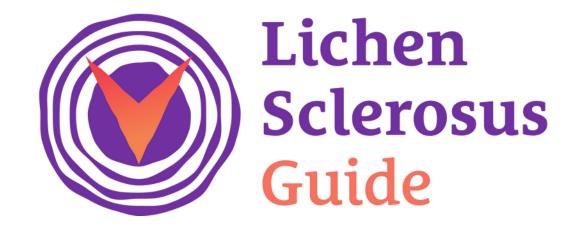


Optimisation and evaluation, expand to other groups



Continue embedding into clinical practice

Thank you!









In collaboration with







Animation and design by

