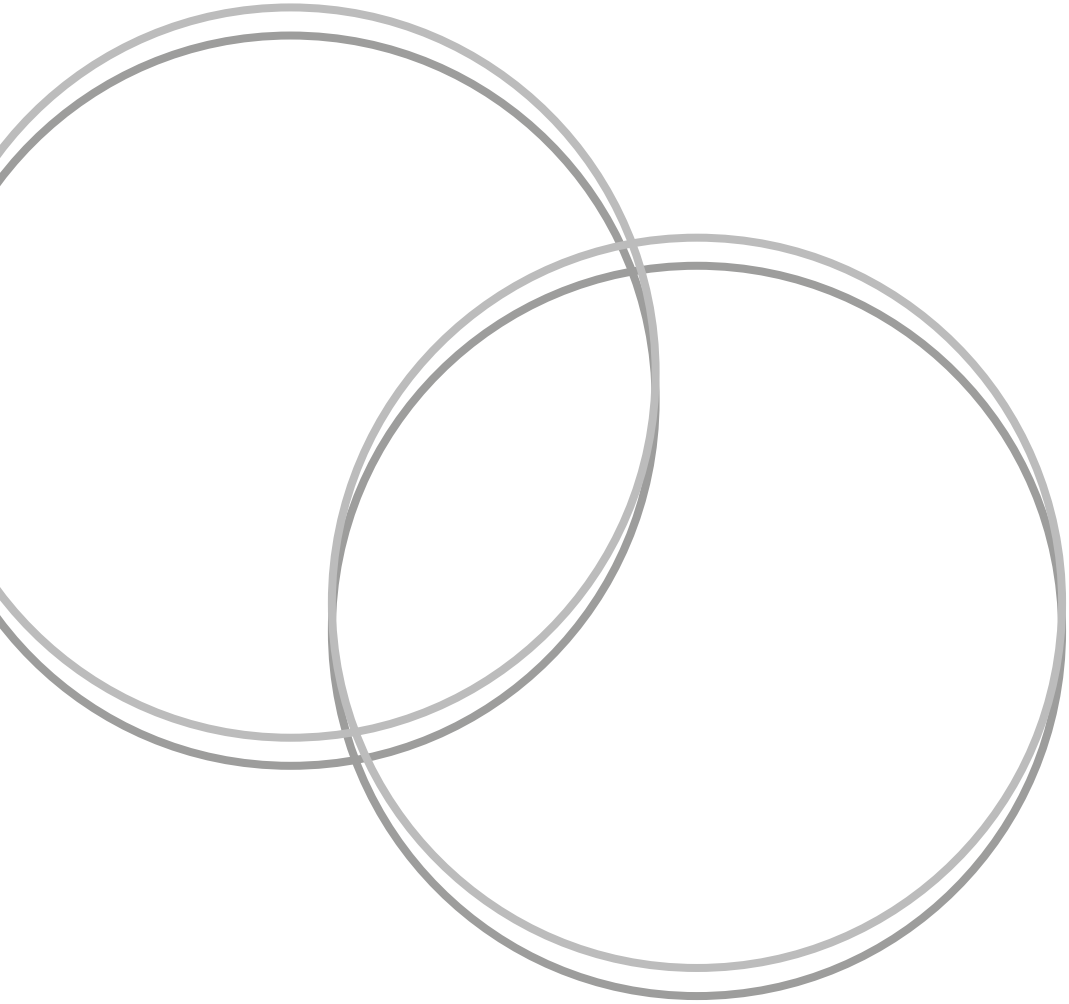
Oxford University Hospitals
NHS Foundation Trust

Effects of Vulval Lichen Sclerosus on sex and intimacy

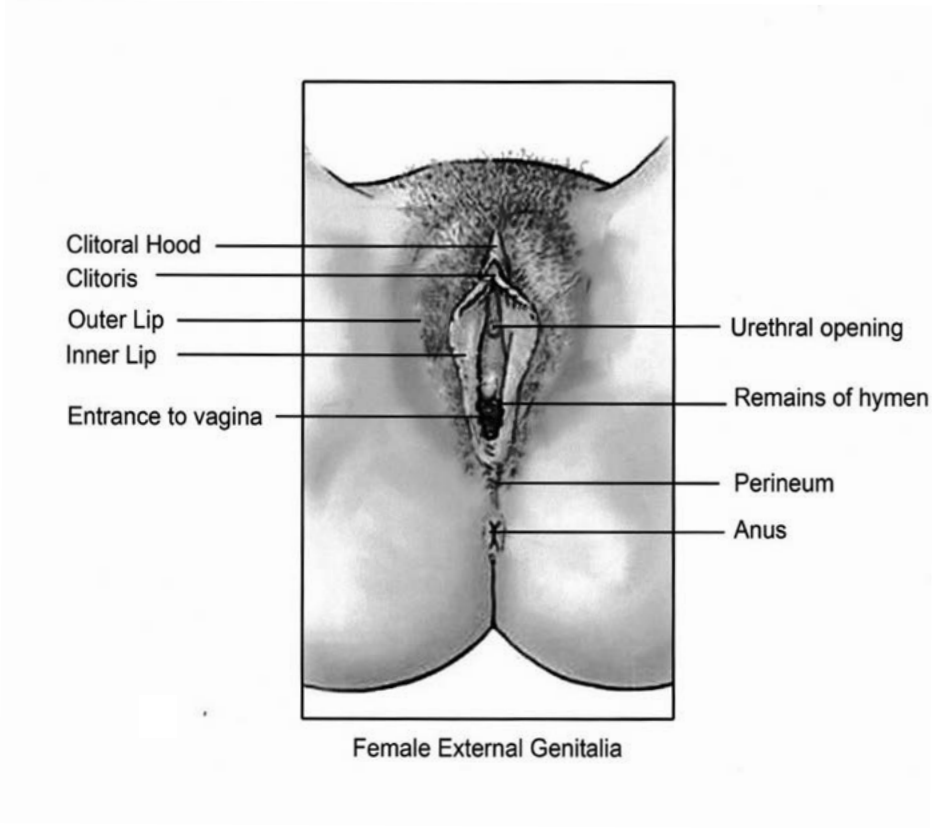
Information for patients



Introduction

Lichen Sclerosus (LS) is a common genital skin condition. Some people may find that this impacts their sex life. This leaflet outlines some ways LS may affect sex and things that can help.

Female external genitalia



Female External Genitalia

What is Lichen Sclerosus (LS)?

LS is a common skin condition which affects the non-hair bearing skin of the vulva (the external genital skin), the perineum (the skin between the vaginal entrance and anus) and the skin around the anus. LS can affect people of any age. Symptoms vary from mild to significant.

Occasionally LS can appear elsewhere on the body.

Common problems include itching, soreness, bruising, splitting of the skin, changes in appearance of the skin such as pale or shiny areas. The lips of the vulva can change in shape or size.

Symptoms can come and go over time, with good treatment symptoms are often completely controlled and if you do experience a flare-up you can increase your treatment.

Using treatment as prescribed regularly will prevent flare ups and progressive changes.

Effects on Sex and Intimacy

Whilst not all women will find their lichen sclerosus impacts their sex life others report a range of issues with intimacy which may make them or their partner anxious. These are some of the ways LS can impact sexual function.

Sore skin

LS often causes itching of the affected skin, but some people describe soreness, burning, stinging or pain.

If you are having intermittent or consistent discomfort, then it is understandable that you may feel nervous about sex. You may be worried that sexual touch or putting things inside the vagina will make your skin feel worse. These worries can lead to avoiding sexual contact with partners.

Skin that splits easily

Skin affected by LS can become thinner and more delicate. Some people find that the skin splits easily, or they get tiny tears in the skin, from touch or stretch. This may be from day-to-day activities such as wearing tight clothing, going to the toilet or riding a bicycle. It can also impact sex.

For some people, the LS can cause the inner lips of the vulva to stick down or stick together across the middle. If this skin is then stretched during sex, it can split. If this happens, it is sensible to use your steroid cream or ointment to this area of the skin as this will help it heal quickly and may stop it sticking together again.

Changes in appearance of the vulva

As well as the inner lips sticking down or together, the inner lips can often get smaller or disappear completely. Sometimes this can happen on one side and not on the other, so the lips look very different on the left and right.

Sometimes the skin around the clitoris is affected and can cover the head of the clitoris so that you cannot see it anymore.

Occasionally skin change means the entrance to the vagina becomes smaller, and this can cause issues with putting things inside the vagina.

LS can also cause changes to the colour of the skin. You can develop small areas which can be lighter or darker. You or your sexual partner might notice this change in appearance.

Any of these changes can change sexual sensations, or make you feel self-conscious about the appearance of your vulva. This can make you anxious. Anxiety about your vulva can make you much more aware of this part of your body which can be a barrier to relaxing during sex. Being anxious makes it much more difficult to get aroused properly.

Pelvic floor muscle tightening

The pelvic floor muscles form a hammock across the bottom of the pelvis between the legs. They attach to the base of your spine at the back and sweep forward to the front of your pelvis. They support your bladder, uterus and lower bowel.

The vulval skin lies directly over these muscles. If you are having itching, soreness or pain of this skin, or worrying about this skin a lot, then the muscles underneath can tighten in response to the skin discomfort or the anxiety.

Sometimes sexual touch, even if enjoyable, can cause the pelvic floor muscles to tighten. When the pelvic floor muscles tighten, they squeeze around the lower vagina which can make the vaginal entrance smaller and tighter. This can cause problems with putting something inside the vagina during sex and trying to push past this tight entrance can cause pain.

Applying creams all the time

Having to put steroid creams and moisturisers on your vulval skin multiple times a day may become repetitive, annoying, messy and time consuming. Some people get very fed up with this. Having these creams and moisturisers on the skin can put some people off sexual touch.

Although it can feel like all the above, remember that using your creams as prescribed will not only make the skin feel better now, but it will help prevent any further changes to your skin in the future.

Psychological impact

If you are experiencing any of the issues mentioned above, this can be distressing.

You may become more anxious about the vulval skin and having sex; this can lead to avoiding sexual contact with your current partner or avoiding relationships.

Many people will avoid day to day affection with a partner, and will try not to get involved with hugging, touching or kissing, as they fear this will lead to sex which they do not want at that time.

This can make people feel sad, embarrassed, guilty or worried.

If your partner does not fully understand the skin condition, the treatment involved, and the long-term effects, then they may not understand why you have withdrawn from intimacy.

Reduced sex drive

Many different things affect sex drive.

Some people experience thoughts and feelings about sex day to day (this is called "spontaneous sex drive") and if they have problems which interrupt pleasurable sex, this can happen much less often or go away completely.

Many other people experience sexual thoughts and feelings in response to pleasurable intimacy and touch with a partner (This is called "responsive sex drive"). If sexual touch becomes uncomfortable or anxiety provoking and their arousal is interrupted, they can lose this sex drive.

Lichen Sclerosus and the menopause

Lichen Sclerosus can often start or become worse in your 40s and 50s. This is around the same time people experience menopausal symptoms. Common menopausal symptoms affecting the vulva and sexual function include vaginal and vulval dryness, soreness, anxiety, worsening sleep, urinary problems, reduced sex drive, and increased difficulty with arousal. This can mean the symptoms of lichen sclerosus and the menopause can overlap, and it can be unclear which is causing which symptoms.

Some people use hormone replacement therapy (HRT) to help menopause symptoms. HRT as patches, gels, sprays or tablets do not always deliver enough hormone to the vulva and vagina to help symptoms in that area. Putting an oestrogen cream directly on to the vulval skin and/or oestrogen inside the vagina (tablets, pessaries, ring or cream/gel) can often be helpful for these genital symptoms and these locally applied preparations can be used alongside your other HRT.

Your doctor or nurse may advise some oestrogen replacement for the vulva and vagina as well as steroid and moisturisers for the lichen sclerosus, as we know using these treatments side by side often helps the most.

You can have sex after using an oestrogen cream on the vulval skin, excess cream can be wiped off. The tiny amount your partner may touch will not harm them. You can put an oestrogen vaginal pessary, tablet or cream up the vagina after sex if you are due to use it that night. The oestrogen vaginal ring (estring) can stay in during sex it is not necessary to remove it and most people and their partners do not notice it.

Ways to help sex and intimacy with LS

Optimise your LS treatment

For LS to affect sex as little as possible the vulval skin needs to be as healthy and flexible as it can be. This means using your topical steroid cream or ointment as prescribed. It also means using a plain moisturiser (often referred to as an emollient) on the vulval skin every day, to prevent dryness and keep the skin as supple as possible.

Treating your skin early and regularly when you have a flare-up of symptoms means that you can get the skin better more quickly and reduce the chance of long-term problems.

It is important to put your steroid cream / ointment on the correct bits of skin for them to work – if in doubt ask your doctor or nurse to show you – with a mirror or a diagram. Usually this is the non-hairy inner lips of the vulva, the vaginal entrance, the clitoral hood, the skin between the vaginal entrance and anus (the perineum) and for some people around the anus as well.

None of the creams used to treat lichen sclerosus would harm a partner if they came into contact with them. It is also ok to wipe excess cream off before sex and reapply it again afterwards, or delay applying your cream / ointment until after sex.

DO NOT USE OIL BASED LUBRICANTS, OR OINTMENTS BEFORE SEX WITH CONDOMS if you are relying on condoms for contraception. The oils in the ointment can affect latex in condoms and make them more likely to split.

Washing the genital area appropriately

People with LS should wash the genital area with an emollient to prevent the skin drying out. You can use the same one you are using to moisturise or choose a different one if you prefer it.

You can either:

- put some emollient on the vulval skin before you get in the shower, leave it on during your shower, then wash it off at the end which cleanses the skin
- ***or*** mix some emollient with a tiny bit of water in the palm of your hand – until it mixes to a consistency like a shower gel, then use this to wash.

Soaps, and even simple or gentle shower gels and washes are too drying for the delicate vulval skin. "Feminine washes" are not necessary, they can alter the pH balance of the vulval and vaginal area and cause discharge and other problems. Douching inside the vagina is not recommended – the vagina is self-cleaning.

Washing the genital area once a day is sufficient – more than this dries the skin.

Talk to your partner

It is well worth sitting down at a calm time to explain your skin condition to your partner, and how it affects you. They may not realise. You could use this leaflet to help explain if this helps introduce the topic. Explain to your partner that your doctor / nurse has recommended you let them know what is going on.

The benefit of your partner knowing that your skin is sore or needing treatment is that they can better understand that touch in this area may be different for you.

Often couples get into habits with their sex life – many people follow a "usual pattern" of what works for them as a couple. For some people this may involve experimentation, and trying different things, for some couples it may not.

If you are able to have a conversation with your partner to discuss the fact that things have changed for you physically, and this means you need to discover anew what is pleasurable for you, then you can work together to adapt to any changes.

This can be more helpful than leaving your partner to guess what will be comfortable for you or assume that you can have the same sex as before or assume that you don't want sex at all.

Quite often people avoid having any intimacy with a partner (a kiss and cuddle on the sofa) for fear that this will give a green light for sex that they fear will be painful. Discussing in advance with your partner that you would like some intimacy but may not be comfortable to have sex exactly as you used to, can be very helpful.

It is usually easier to discuss these things in advance rather than waiting until you are both naked and halfway to the bedroom to bring up the topic. You will need to keep communicating during touching and sex to let your partner know how it is going. Although this may feel less spontaneous it is important that you both feel good about sex.

What if I'm single……how do I broach this?

If you are currently single you may be worrying about the prospect of sex with new partners in the future.

It can be really helpful to rehearse a short sentence or two that you feel comfortable to say to someone, should you find yourself wanting to get intimate. For example:

"….I just want to let you know that I have a skin condition called LS. Please can we take sexual touch a bit slowly and see how it feels. I would like you to let me know what you like; and I will let you know what is good for me."

This can take a lot of pressure off you, and a potential partner.

Sex is a menu

Culturally we often think of 'proper sex' as putting something in the vagina. But sex actually involves lots of different types of touch and play that can lead to arousal, and these are sex too, not "just foreplay".

When vulval skin is sore or delicate, and pelvic floor muscles may have become tight and uncooperative then penis (or finger, or toy) in vagina sex can be uncomfortable. But touch to other parts of the body may be enjoyable and arousing, and touch to the vulval skin on the outside may be pleasurable if the skin is not being stretched. Sometimes gentle pressure to the skin feels better than rubbing.

What we are trying to say is……..sex is a menu.

If one part of the menu seems tricky then as a couple, there are a number of approaches you can take. You can avoid spending time together entirely. You can avoid physical touch, in case it leads to 'sex' that could be painful or difficult.

Or, you can decide as a couple that you try other options on the menu.

The Menu

Eye contact
Holding hands
Snuggle on the sofa
A good snog
Hands up t-shirts
Back stroking/massage
Ear lobe sucking
Reading erotica to each other
Tops off touch
Trousers off touch
Touch through pants
Slow kissing the body
Naked cuddles
Dry humping (clothes on)
Touch to genitals (with lube)
Oral sex
Sharing fantasies
Genital – genital touch (with lube)
Vibrator touch anywhere on body
Vibrator touch on genitals (through underwear or bare)
Finger in vagina
Vibrator in vagina - special slimline offer
Penis in vagina
Strap on in vagina
Anal touch
Finger/toy/penis in anus
Orgasms, or not
Naked cuddles – desert size
More kissing
More stroking
Chocolates

Dating

One of the habits that often develops in longer term relationships is that couple time gets pushed to the bottom of priority lists. This means sex comes second to work emails, shopping lists, household chores and Netflix. If something like a health condition interrupts sex then it can be really helpful to deliberately set aside some time as a couple for intimacy, with time for communication. This is a date.

At the start of relationships people often get the feeling that sex takes no effort – they just fall into each other's arms. However, when we are dating at the start of relationships, we put aside time to prepare for our date, book a restaurant (with an attractive menu!), chose a film. We go home from work early to shower and change and are careful to arrive on time. The date involves at least a few hours of undivided attention, eye contact and conversation. All of this then leads to what seems like spontaneous sex……but in fact we have been looking forward to it for days.

Established couples often find that revisiting "dating" can be helpful. Deliberately protecting time to be together as a couple without interruptions gives an opportunity for both emotional and physical intimacy.

Lubricants (lube)

Lubricants help sex. If skin is delicate, sore or dry they are especially important. Don't wait to find out you are feeling a bit dry – use a lubricant proactively for **any** sexual touch.

When genital skin is sore or dry, especially during or after the menopause, people often don't get so much natural lubrication coming down from the vagina when they are aroused. This doesn't mean you are not aroused in your head, but the body's response doesn't always match what our head is wanting. If in a sexual situation your vulval and vagina remain dry this can give your head the message " you can't be aroused really" which can switch arousal off. Specialists in sexual function recommend using a good lubricant always for sexual touch to prevent this problem.

There are different types of lubricant available. It is best to choose one that is as plain as possible (no scents or added tingle).

Water based lubricants: these are thin and slippy, they evaporate quite quickly so you may need to add more. They are suitable for use with condoms and all sex toys.

Examples:

- YesWB (www.yesyesyes.org)
- Sylk (sylk.co.uk)
- Some of the PjurMed range (uk.pjurmed.com/all-products)

Oli based lubricants: these are thicker and last longer; they can provide delicate skin with a protective layer before touch. They are not suitable for use with condoms.

- *Example:* YesOB (www.yesyesyes.org)

It is often nice to put an oil-based lube onto the vulval skin, then for a partner's touch use some water based lube on top. The water-based lube slips over the oil based one giving a sensual glide.

Silicone based lubes: these are thinner than oil-based lubes but super slippy and last longer than water based lubes

- *Example:* some of the PjurMed range (uk.pjurmed.com/all-products)

Helping arousal

If you have had a gap in regular sex for a while, or things have been uncomfortable, then arousal can become less easy. These are some ideas that may help to reawaken arousal:

Spend some time, alone or with your partner, discovering what touch is pleasurable for you – concentrate on your whole body not just the genital area. You might start with a shower or a bath focussing on how touch feels whilst you wash and have the water run over your body.

You can then extend this to exploring gentle genital touch (with lube!)

Often vibration can be a good sensory input to help arousal. If you have never tried a vibrator before now may be the time! Not all vibrators are big phallic objects to go up vaginas. There are hundreds of different designs of vibrator intended for use on the external vulval area – or anywhere on your body.

Examples can be found at:

- www.sh-womenstore.com
- www.jodivine.com
- plasticfreedom.co.uk/collections/sex-toys
- thepelvicpeople.com

Some people find some information and guidance around (re) introducing sensual touch helpful, either alone or with a partner. Have a look at the FERLY app (free for 1 week then affordable for a year) which has been developed by sex therapists. FERLY uses short audio guides to give you ideas, information and some guided exercises including relaxation breathing, body mapping and touch.

Pelvic Floor Exercises

If pelvic floor muscles have become tight in response to sore vulval skin, or painful sex, or anxiety then it can be helpful to practice exercising the muscles to take conscious control of them. Learning to properly relax your pelvic floor muscles as well as learning to squeeze them is important. If you think your pelvic floor muscles may be part of the problem with sex being difficult then ask your doctor or nurse for further advice.

It is important to know that while sex may have changed having LS does not mean that you cannot have an enjoyable sex life. If you have questions ask your doctor or nurse who will be able to give you advice or direct you to someone who can.

Oxfordshire Sexual Health Service

Churchill Hospital
Old Road
OX3 7LE
www.sexualhealthoxfordshire.nhs.uk

Department of Dermatology

Churchill Hospital
Old Road
OX3 7LE
www.ouh.nhs.uk/services/departments/specialist-medicine/dermatology/

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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