

Information for patients/carers

How to treat lichen sclerosis

Remember that lichen sclerosis (LS) is a long-term condition and that you are likely to need long-term treatment. Although it may not be curable it is definitely treatable. It can often settle completely (go into remission) The aims of treatment are:

- To control your symptoms (such as itch and soreness) and hopefully achieve remission.
- To prevent flare-ups
- To stop the condition impacting on activities (exercise, sexual function etc)

We recommend that you see your GP every year to check that the LS is well controlled. These are the kinds of things to discuss:

- Are your symptoms well controlled? How many flare-ups have you had since you were last seen?
- Is the LS interfering with any activities (eg ability to pass urine, sexual function, exercise etc)
- What treatments are you using at the moment? Over the counter or fragranced products may make your condition worse.
- What steroid ointment are you using? How often do you need it? How much are you using? Please bring along your steroid tube to the clinic.
Are you remembering to apply a greasy emollient/moisturiser regularly e.g. Hydromol ointment, Cetraben ointment etc?
- Do you have any problems with leakage of urine? Do you need to wear pads?

Vulval self-examination

- Lichen sclerosis is not a cancerous or pre-cancerous condition, but there is a small increased risk of cancer (squamous cell carcinoma) in less than 5% females.
- It is important that you know what your vulva looks like so that you can optimise your treatment and notice any changes. Practice doing this with a hand-held mirror or by sitting in front of a floor length mirror in a good light - it will get easier!
- Look out for any raw areas, lumps or thickened rough areas that don't settle with your steroid cream.
- Make sure that you are applying the steroid cream to the areas of lichen sclerosis and not to areas of normal skin. The moisturiser can go anywhere.
- You are aiming to keep the vulval skin as normal a colour as possible. Look out for white areas, cracks, bleeding under the skin – these may be signs that the LS is active and needs more treatment.

Treatment and discussion points

- Most people need long term maintenance treatment with their steroid ointment to keep LS under control. On average this is twice weekly but you may need it a little more or less.
- Increase to once daily treatment with your steroid if you have a flare-up, and then once settled, restart your maintenance routine.

- It is rare for people to have problems (eg skin thinning) from using too much steroid cream. Active LS causes more damage to the skin of the vulva than the steroid cream. As long as you are applying it no more than once daily and to the affected areas you are very unlikely to have problems. A 30 gram tube should last at least 3 months.
- Remember to use emollients/moisturisers instead of soap and find a greasy emollient/moisturiser that you are happy to use regularly (preferably twice daily) too.
- Urine can irritate the skin so it is important to consider a barrier cream e.g. Cavilon etc. if you are leaking urine.
- Most forms of urinary incontinence are treatable – if you have urine leakage discuss this with your doctor and ask for a referral to your local incontinence services if necessary.

You may need to be referred back to the vulval clinic in some situations such as:

- If scarring is causing problems (eg causing problems with sexual function, reduced/weak urine flow)
- If your diagnosis is causing relationship problems or distress (you may benefit from the additional expertise of a psychosexual therapist)
- If you are not getting better with your prescribed treatment
- If the diagnosis isn't clear or if your doctor thinks you may have an additional diagnosis (it is not uncommon for women with LS to have other conditions such as recurrent thrush or vulval pain syndrome)
- If your doctor thinks you need a biopsy to rule out any cancerous or pre-cancerous changes.
- If your doctor thinks you may have developed an allergy to some of your creams.

Tips

- Incontinence pads and urine can irritate the skin, use scent-free pads and remember to use emollients and barrier creams
- A lack of vaginal oestrogen may cause dryness and painful sex, particularly after the menopause – discuss with your doctor the use of hormone treatments such as Vagifem or Ovestin cream.
- Remember to use lubricants for intercourse e.g. 'Yes' but be aware that some lubricants may cause irritation to the delicate vulval skin in some individuals. If this is the case a different one may need to be tried.