

If you are searching for information for lichen sclerosus, it may be helpful to know that there are more questions from patients than there are answers for. There are many aspects of living with lichen sclerosus that the medical profession are still unable to give answers for. The other thing to be aware of is that the internet is now on overload with published medical papers, some of which are now very out of date and they have not been removed. There has been no work done on establishing which medical papers are still current and up to date. Remember other patients will have similar experiences to you and it may help you to feel less alone when you read them and join forums. However, everyone's case of LS is unique to them. When you read horror stories, it does not mean that everyone will go through the same thing. Most people do well with treatment and their symptoms are under control and these patients are less likely to share success stories because they have left their fear and anxiety behind them and they are in remission. You cannot know, when you read messages on forums if that person is still in difficulty or if they have got better and are perhaps not sharing their new found relief and good news. Drastic images on medical sites are usually worse case scenarios, which is why doctors like to take pictures. There would be no point in taking pictures of well managed LS because the vulva would just look normal. However, none of the medical sites (correct WLSS if we are wrong) show before and after images of white vulvas one month after treatment, when the improvement is almost unbelievably good in a high number of cases! Bear all these things in mind when you search the internet. If you do frighten yourself, remember that you can always make contact for one to one support.

## **LS the basics**

### **After diagnosis – what happens next?**

You should start treatment – preferably [BAD Guidelines](#) as minimum. The Internationally agreed treatment of choice is by very potent steroids (clobetasol propionate/Dermovate in the UK).

### **I have read a lot of bad information about using steroids and my gynaecologist says only to use it sparingly and my pharmacist says not to use it at all, what is the truth?**

Much of the fear of steroids and negative information on the internet has arisen as a result of misuse and poor medical instruction. Studies have shown that use of steroids as stated in the BAD Guidelines may resolve symptoms in most patients. Sometimes you may need to treat for longer but your doctor should advise you. Maintenance treatment may be required, if so, twice a week, is effective, well tolerated and safe.

Stick to the treatment plan even if your symptoms improve quickly. However, this condition is different in everyone and some people may need more treatment and some less.

You may find improvement within a few weeks but everyone's needs are varied and some people make take longer. It is essential for you to make sure that your doctor has given you specific information on how long to treat for and how much medication to use and where to apply the treatment.

### **Use treatment sparingly**

This is a popular term used by some doctors and it gives no real indication of how to use the treatment. If you are given this information do try to get the doctor to explain how much he/she really wants you to use! You could also ask if the doctor wishes you to treat in accordance with the [British Association of Dermatologists guidelines for treating lichen sclerosus](#).

Obtain information about using soaps/emollients – these form the basis of good skin care and can decrease and help to control symptoms. (More information to follow.)

### **What you may need to know:**

#### **What happens if the treatment does not work?**

You need to return to see your doctor. You may have severe disease that needs more treatment and the BAD Guidelines state that uncontrolled symptoms must be seen again.

#### **What happens if the treatment seems to make things worse?**

You need to see your doctor to find out why things seem worse. It may be that you may have got an infection e.g. thrush and your doctor can take a swab to test for this. Rarely, you may become allergic to your steroid treatment. A treatment review and change of steroid can be useful.

**What do I do if my symptoms return and I have been discharged from the vulva clinic?** Flare ups or return of symptoms is common and should resolve with a week's treatment, if it does not, you need to be seen again.

#### **Why use steroid treatment?**

To control symptoms and to improve the pallor of the skin and to reduce scarring (fusion of labia, clitoral hood).

#### **What happens if I do not treat/use conventional treatment?**

In most people the symptoms and condition will progress and pallor and scarring may worsen.

#### **Do steroids thin the skin?**

Treating the LS areas of skin reduces the inflammation and allows the skin to return to normal. Over use of steroids may thin skin however this is due to overuse or misuse.

#### **How will I know when it is better?**

You will stop itching. Sex should become more comfortable and there should be less splitting and if you examine yourself you may well find that the paleness and bruising (purpura) have improved or gone.

#### **How common is LS?**

Thousands of men, women and children suffer from LS all over the world. It is impossible to get an accurate figure and estimates vary from 1 in 30 to 1 in 1000. Many doctors now feel that earlier references to LS being 'rare' are no longer applicable.

#### **What is the role of HRT/Oestrogen replacement in LS?**

Women with LS may also have all the same problems as women without LS after the menopause and may need some hormone replacement treatment as well as treatment for LS and usually local HRT (applied to the vulva / vagina). Treatment may help lubrication during sex and may help to make the skin less fragile and less prone to splitting. However, it does not treat the lichen sclerosus itself.

#### **Fear of cancer**

The fear of LS becoming cancer is very common and the best way to overcome your fears is to realise that vulval cancer is less common than the fear that people have. More than 1000 women a year will get vulval cancer, but there are other conditions that cause vulval cancer. Penile cancer is also associated with LS and the signs of early cancer are the same to look for

as in women. Cancer does not affect young children. The early signs need to be reported to your doctor as soon as possible. Early signs of cancer may be increased soreness, lumps, raised warty areas of skin that may be pale or darker in colour, and ulcers or sores that do not heal quickly. It is important to remember that not all lumps will be cancer and doctors are always pleased to be able to reassure patients. In view of the risk, patients are advised to make regular vulva self-examination. See video

<http://www.channel4embarrassingillnesses.com/video/how-to-check-yourself/how-to-check-your-vulva/>

### **What happens if I am one of the small number of women who get cancer? Is there treatment available?**

Like all other cancers, vulval cancer needs to be detected and reported to your doctor as early as possible. The treatment involves surgery. The amount of surgery will depend on how soon the cancer is found and a biopsy is usually performed to confirm the diagnosis. If found early, the surgery will be less and many women find that they are still able to enjoy intimacy with their partners after healing takes place.

**This page has been written by Fabia Brackenbury (founder of this group) asking questions and replies are by Professor Fenella Wojnarowska, Professor Emeritus – Dermatology, Oxford**

The following information below has been added from the Australian site [www.caredownthere.com.au](http://www.caredownthere.com.au) Written by doctors. The only comment this group would make is that in the UK steroid ointment is preferred to 'cream' – it may be that ointment is not available in Australia. This group endorses the views shared in this information from Australia.

### **LS and cancer of the vulva**

We know that patients with LS are at risk for vulval cancer. It does appear however that treatment minimises this risk. Vulval cancer looks like a lump or ulcer or a sore that doesn't heal. If you suspect you have LS and something like this develops, see your doctor right away.

This is why it is important to have a definite diagnosis made with a biopsy to confirm LS.

### **What treatment is used?**

There are two phases of treatment for LS

**Getting better**

**Staying better**

**Getting better**

It is now really well proven that potent topical cortisone cream is the best treatment for LS. The response is rapid and usually complete. LS is easy to treat, so long as you accept the need for cortisone.

Cortisone creams are extremely safe and effective for LS. There is **NO DOWN SIDE**. It is much safer to treat this condition than not to treat. There is no other well proven, effective topical treatment. **PLEASE DO NOT DENY YOURSELF THIS TREATMENT BECAUSE OF ANYTHING YOU HAVE READ ABOUT HOW DANGEROUS CORTISONE CREAM IS.**

### **Staying better**

Almost all patients with LS need ongoing treatment with weak cortisone cream to stay well, prevent scarring and minimise the risk of possible cancer. This treatment is also very safe long term in LS. There are very few risks and side effects if it is monitored regularly. Again, **DO NOT DENY YOURSELF EFFECTIVE MAINTENANCE TREATMENT**. See your doctor regularly for monitoring and reassurance that all is going to plan. This includes cancer checks. There are some doctors who don't believe that patients with LS need long term follow up. We don't agree with this approach. Early detection of vulval cancer could save your life.

### **Well controlled Lichen sclerosus**

This group asked one of the consultant authors, of the BAD Guidelines what information was given in her clinic when she discharged patients and this is the information kindly provided.

After treatment in the clinic, your lichen sclerosus is now well controlled and further follow-up will be done by your GP.

It is important that the vulva is examined annually and you will need to make an appt with your GP for this. Using the emollient as a soap substitute should be continued and if you get any itching, then you can use your prescribed steroid ointment once daily until the symptoms resolve (usually within one week).

It is important that you see your GP urgently, and do not wait for your routine appointment, in the following situations:

- You develop any persistent red areas, lumps, sores or small cracks in the skin that do not disappear after using your steroid ointment once daily for one week

If your symptoms of itching etc do not resolve after using your steroid ointment once daily for one week.

If you develop any new symptoms

You can then be referred back to the clinic for further assessment and advice.

**This group also recommends you read the handout from American Dermatologist, Libby Edwards, who is a past President of the ISSVD. [Use this link.](#)**

