Lichen Sclerosus

This is a leaflet to help patients understand this skin condition that affects the vulva.

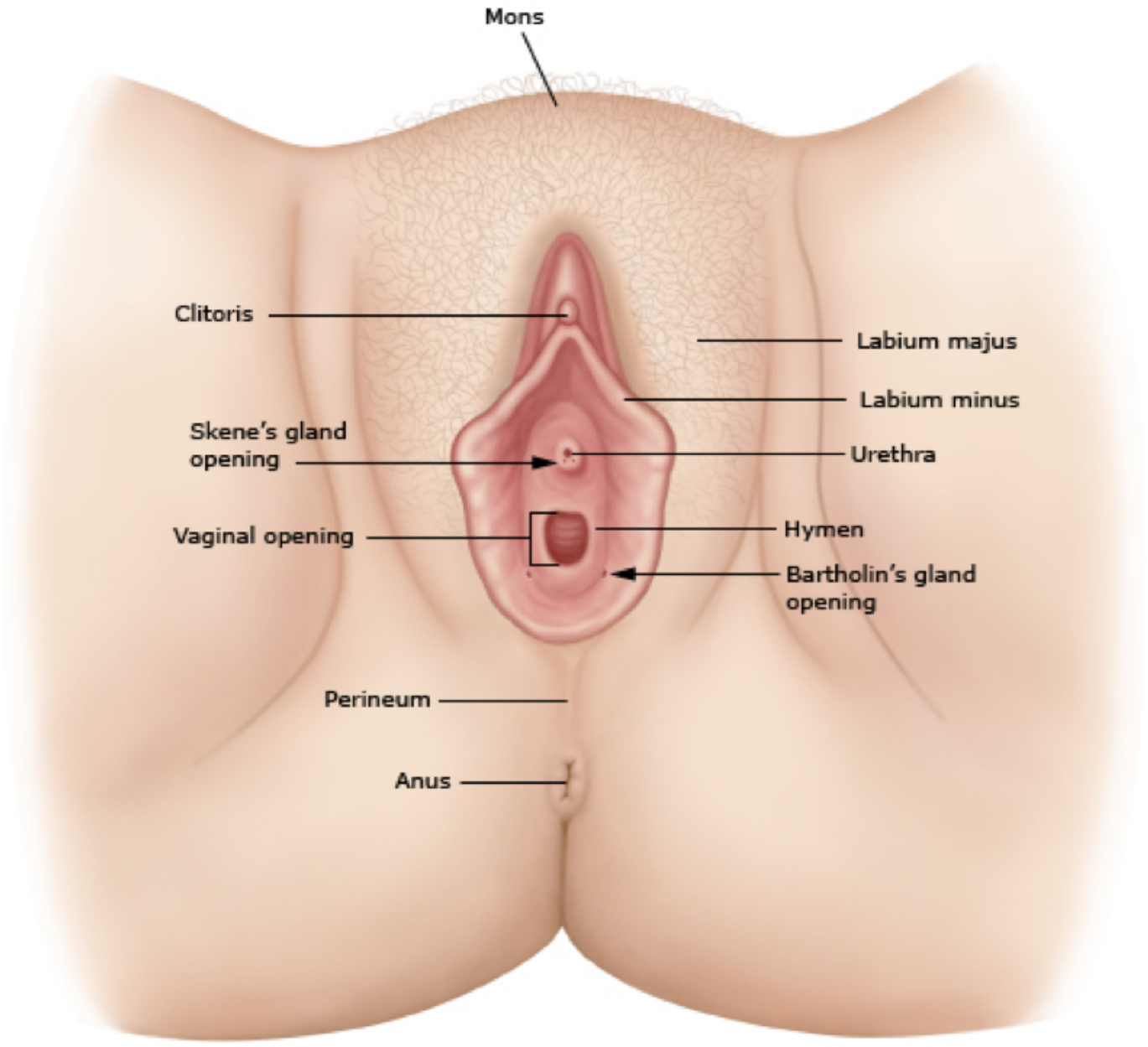
Lichen sclerosus is often a longstanding and sometimes, distressing condition that affects women of all ages and can sometimes affect men. It can also affect young children and teenagers. It most commonly affects women after the menopause.

What is Lichen Sclerosus (LIKE-in skler-O-sus)?

Lichen sclerosus is a chronic inflammatory skin disorder that most commonly affects the vulva (genital skin) of women. Less commonly it affects other areas of the skin, such as the anal area. It can occur at any age, but most commonly develops in middle-aged women. It is estimated that lichen sclerosus affects about 1 in 1000 women but it may be more common than this as some mild cases may go undiagnosed.

Understanding Lichen sclerosus: The normal vulva

Lichen Sclerosus



The vulva is a woman's external genital area. It includes two large, hair-covered folds of skin called the labia majora, which surround two thin and delicate folds called the labia minora. The labia majora and labia minora surround the opening of the vagina (birth canal) and the urethra (the tube through which urine is passed). The clitoris is positioned above the vagina and urethra. The anus (opening to the back passage) is separated from the vulva

by an area of skin called the perineum.

What are the symptoms?

The symptoms are the same in children and adults.

Itching or soreness of the vulval area that persists, despite treatment for thrush or other infections.

Pain may be a feature, including painful sex.

Splitting of the vulval skin, causing stinging and pain.

Small, subtle white spots may appear early on. These areas are usually slightly shiny and smooth. As time goes on, the spots develop into bigger patches, and the skin surface becomes thinned and crinkled.

More severe cases of lichen sclerosus produce loss of vulval features and scarring. This in turn may cause the inner lips of the vulva to shrink and disappear, the clitoris to become covered with scar tissue (clitoral hooding), and the opening of the vagina to narrow, sometimes causing urination difficulties and sexual problems.

Sometimes, Lichen sclerosus may affect other areas, such as anal area, causing difficulty in opening bowels. It does not affect the vagina or other parts of the female reproductive organs.

Lichen sclerosus may sometimes be graded as mild, moderate or severe depending on the degree to which the vulva is affected.

What causes Lichen sclerosus?

The actual cause of this chronic inflammatory condition is not known, but there appears to be a connection between lichen sclerosus and thyroid disease, vitiligo and other auto-immune diseases (1 in 4). There may be a genetic element as well and the condition may run in families. There may be a history of eczema or psoriasis.

It is not possible to get lichen sclerosus through sexual intercourse, it is not a sexually transmitted disease and it is not contagious.

Am I at risk of cancer?

The changes of Lichen sclerosus are not cancer, but in a few people they may, over many years, rarely develop into a type of skin cancer known as squamous cell cancer. This small risk is estimated at 3% (3 women in 100).

It is important to seek medical advice if your usual treatment does not work after a couple of weeks. Seek medical advice if you notice persistent itching in one place, unusual lumps, abnormal bleeding or changes in the texture of the skin or if you are concerned.

Can Lichen sclerosus be Cured?

The condition should be diagnosed early to allow the correct support and treatment to commence. Although, in some cases, the condition disappears on its own in the younger age group, the condition is chronic and there is no permanent cure.

How can Lichen sclerosus be diagnosed?

It can take several years and several visits to various health professionals before the diagnosis is considered. This can be very frustrating for the woman considered. However, once your GP suspects it, you may be referred to a specialist, a dermatologist or a gynaecologist with a special interest in vulval conditions.

A vulval biopsy, either under a local or a general anaesthetic is sometimes needed to confirm the diagnosis, especially if diagnosis is uncertain or if atypical features are noticed. This involves a tiny piece of skin being taken from the affected area which is sent for analysis. The biopsy itself does not hurt but may be uncomfortable for a few days.

You may also have a procedure called vulvoscopy, which involves looking at the affected areas using certain solutions under magnification (colposcope), to allow proper examination and to help in selecting the right area for biopsy. This procedure does not hurt at all, although the solution (acetic acid) may sting or feel cold for a few minutes.

Other conditions that can affect the vulval skin include eczema, chronic dermatitis, psoriasis, lichen planus, precancerous lesions (VIN – Vulval Intraepithelial Neoplasia) and rarely, vulval cancer. A tissue biopsy is often needed to differentiate these conditions.

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Treatment

Some women need no treatment.

General Vulval and Vaginal Care Measures: All women benefit with this advice

- Adopt an anti-inflammatory diet, eating mostly whole plant foods, rich in fruit, vegetables, wholegrains, beans and legumes and herbs and spices.
- Use non-soap-based washes and emollients.
- Use an emollient (moisturiser) cream instead of soap to clean the genital area. This is also soothing.
- Use water to cleanse but avoid over washing.
- Take showers rather than baths in general.
- Lubricants may be useful during sex, if it is painful. The regular use of water-based vaginal moisturisers can also help keep the area supple and make sexual intercourse less uncomfortable.
- Local vaginal oestrogen may be appropriate in some situations to help with vaginal atrophy, especially in post-menopausal women.
- The use of natural oils can be helpful and the daily application of natural oils such as coconut, Vitamin E or almond oil after a shower to lock the moisture in and around the vulval area helps many of my patients. Just massage the oil into vulval area and DON'T WORRY if some of the oil enters the vagina. It's safe. We eat oils!
- Use Non-Biological laundry detergents, preferably those without significant chemicals.
- An eco-egg with minimal chemicals to wash underwear may be helpful.
- Wear cotton underclothes and use soft unbleached toilet paper and soft towels.
- Opt for light coloured over dark underclothes as there tends to be more harsh dyes in the latter.
- Use kinder menstrual care products such as the menstrual cup, period pants, natural material pads or unbleached sanitaryware.
- Use incontinence pads and panty liners that are organic, unbleached and with fewer chemicals.
- Avoid underwear, especially at night to allow the genital area to breathe.
- Avoid synthetic underclothes and tights.
- Avoid perfumed toiletries, bubble baths, soaps and perfumes in the genital area. These may irritate the skin and can lead to increased dryness by removing natural body oils and beneficial bacteria, making symptoms worse.
- Avoid feminine wipes and toilet wipes, as they are usually laden with harsh chemicals
- Avoid fabric conditioners

- Avoid scratching, better to use a cold flannel
- Avoid tight clothes, which can make the area hot and itchy

Topical steroids:

A mild to ultra-potent steroid ointment (topical steroid) is the main treatment for managing vulval lichen sclerosus. Steroids reduce inflammation by reducing cytokines. It is usual to use the ointment regularly. Keep on with treatment for as long as advised. Irritation tends to ease after two weeks or so, but the skin may take about three months of treatment to look and feel better.

The skin may return to normal if lichen sclerosus is diagnosed and treated in its early stages. However, if the appearance of the skin has already changed a lot, the changes may not reverse much with treatment, even though symptoms of itch and soreness are often relieved.

After an initial intense course of treatment that may last from 2-12 weeks, you will usually be asked to keep on a small maintenance dose of the steroid ointment once or twice a week, to keep symptoms under control. Using the steroid too frequently can result in thinning of the skin and using it not often enough can result in soreness and itching.

Topical steroid ointments are safe in pregnancy and breast feeding, but it is advisable to check with your doctor first.

Usual recommended steroid regimen (can vary depending on severity) – use a pea sized amount of the steroid and apply on the vulval skin, focusing on areas that are particularly sore.

Ultra-potent topical steroids, e.g. Dermovate Ointment (Clobetasol proprionate (0.05%)

Once daily for two weeks

Alternate nights for the following two weeks, then twice a week for three months.

30 g of an ultra-potent steroid should last at least three to four months.

Ointments are better than creams as they contain fewer parabens which may irritate the skin.

Alternative regimens if there is evidence of secondary bacterial or fungal infection (use only until infection is cleared: short term)

An ultra-potent topical steroid with antibacterial and antifungal, e.g. Dermovate NN or generic equivalent (Clobetasol with neomycin and nystatin) or an alternative preparation that combats secondary infection (such as Fucibet cream) may be appropriate if secondary infection is a concern.

Topical calcineurin inhibitors such as Tacrolimus (0.1%) van be effective when used for a fixed period (16-24 weeks) but is not currently licensed and needs prescription by a specialist as long term safety regarding immuno-suppression is still to be established. Local irritation is the most common side effect. These are contraindicated in pregnancy and breast feeding.

It is important to follow general vulval hygiene measures as these will keep you more comfortable and will also keep the steroid ointment to a minimum. You may have flareups after sex or long walks, swimming or if you are stressed. In these situations, use the steroid ointment more frequently for a few days and slowly bring it back down to your usual regime.

Other treatments

Other creams may be used – topical anaesthetics, such as lignocaine jelly or instillagel.

Local vaginal oestrogen in some women is very helpful to ease vaginal dryness and having sex more comfortable

Surgery is very rarely needed. Sometimes if scarring is severe, this may need to be released.

Vulval and vaginal laser surgery to improve the collagen in the skin can help some women.

Follow up: Review at 4 months to decide maintenance regime and the strength of steroid to be used.

Further follow up in stable vulval Lichen sclerosus is on an annual basis with either the specialist or the GP, depending on compliance and symptom control. Some women can be discharged after the first year back to the community with appropriate advice for the patient and the GP while other women will need more regular follow up.

Women may be seen in dedicated vulval clinics and information and resources should be

provided to all women.

It is important to seek medical advice if your usual treatment does not work after a couple of weeks, if you notice persistent itching in one place, notice unusual lumps, abnormal bleeding, changes in the texture of the skin or if you are concerned.

Links for further help and information:

National Lichen Sclerosus Support Group

www.lichensclerosus.org

http://lichensclerosus.org/wp-content/uploads/2017/11/VHAC-leaf-artwork1.pdf

https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/gynaecology/skin-conditions-of-the-vulva.pdf

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