

Living with
**LICHEN
PLANUS**



UK Lichen Planus

A Patient's Guide

LICHEN PLANUS affects around 1-2% of the population and is thought to be an auto-immune disease which can affect the skin, oral or genital mucosa and more. The cause is unknown.

UK Lichen Planus (UKLP) was set up by Bridie Nelson in November 2007 to fill the gap in support for those living with the disease Lichen Planus (LP). The group is open to members worldwide, however treatments discussed are based on those used in the UK.

This support group is run **by** those living with LP **for** those living with LP. We understand only too well the isolation and fear of living with a disease your family and friends have probably never heard of. So we are able to offer support and true understanding of what it feels like to be newly diagnosed with this disease as well as offering practical tips and ideas on how to cope day to day.

UK Lichen Planus brings those living with LP together to share information and provide mutual support.

We also encourage members to take an active role in their treatment and we welcome women and men with all forms of lichen planus.

So if you are one of the 1 - 2% of the population living with LP, join us to share your experiences, ideas and tips in a safe and respectful environment.



informing



supporting



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LICHEN PLANUS

Lichen planus is an inflammatory skin disease which commonly causes an itchy rash of small purplish bumps. Often the arms, legs, back or inside of the mouth are affected, however it can also affect the genital area including the vagina or penis. Lichen planus may occasionally involve the nail, hair and scalp or the skin around the anus (back passage). Very rarely, it may involve the oesophagus or tear ducts. It is possible to have the disease in one area without ever having a problem elsewhere.

WHAT CAUSES IT

The cause of lichen planus is unknown. We know that it is NOT caused by infection, hormonal changes or ageing, and is not because of anything that you did or didn't do. It results from inflammation in the skin. There may be a problem with our immune system, the system that protects a person from infection. In lichen planus the system may be overactive, making proteins that cause inflammation in the skin, mouth or in the genital area. This is referred to as an autoimmune reaction. Occasionally medicines can start this reaction. Why the lesions develop in some places and not others is not known. Lichen planus is NOT contagious and cannot be passed to a sexual partner.

There is no absolute cure for lichen planus. However, in some cases, lichen planus seems to come and go of its own accord and it is possible that it will disappear completely. There are many treatments used to treat lichen planus and treatment needs to be selected to fit your problem. Different people respond to different things. The medications will control but often will not cure the lichen planus. In some cases, usually oral and genital LP, treatment is a long process and close follow up with you and your caregiver is important.

Usually the disease can be treated with creams and ointments, although some disease if causing no symptoms, will not need any treatment. Generally topical steroid ointments are used safely in this condition. These may be strong (potent) steroids (Dermovate) or milder ones combined with tetracycline (Trimovate) which may have an additional helpful effect. Erosive disease can be more difficult to control but most respond to strong topical steroid ointments or steroid and antibiotic creams. Some of the new creams and ointments to suppress the immune reaction such as tacrolimus (Protopic) or pimecrolimus (Elidel) may also be used. Occasionally oral or 'other' medication to suppress the immune reaction may be needed.

For scarring and narrowing of the vagina and / or the entranceway, dilators may be advised. Rarely, surgery is needed.

SKIN LP has shiny flat-topped bumps of different sizes, purple in colour and often crossed with white lines called Wickham's striae. They are usually found on the inner wrists, forearms and ankles, but can affect any part of the skin. LP may be very itchy. New lesions appear while others are clearing. Occasionally the skin discolours after the lesion has cleared and this can remain for some time. This form of LP often clears on its own.

SKIN LP, how you can help yourself:

1. Wash with plain warm water, no soap or bubble bath etc.
2. Shampoo your hair over a basin if possible, to avoid contact with affected skin.
3. Use an emollient to moisturise, some find Aloe Vera gel helps to soothe the itch, especially if used straight from the fridge.

what members say..

"Real people, sharing the pain, sharing solutions"

ORAL LP almost half of the cases of LP, the mouth is involved, and is often the only area to be affected. LP in the mouth may appear as white or red patches, white streaks, ulcers or painful red gums. It may not cause any symptoms or only be sore occasionally. Some spicy or acidic foods or hard foods may make the soreness worse. After appearing it is often present for life.

ORAL LP, how you can help yourself:

1. Avoid eating strong spicy foods, chilli, curry, citrus fruit, tomatoes or strawberries - anything acidic e.g. fruit juices.
2. Avoid sharp foods e.g. crusty bread or crisps.
3. Avoid drinking alcohol, spirits in particular.
4. Try sticking to fairly bland food when lesions are painful, porridge, softly boiled eggs, mashed potatoes etc.
5. Keep to your usual toothpaste if you can, otherwise in the short term, try an alternative like Aloe-dent which is very mild and non irritating.
6. Use a mouthwash which doesn't contain alcohol eg Dentyl, or an alcohol free chlorhexidine mouthwash and keep your mouth as clean as possible.
7. Your dentist may want to see you every couple of months if you have erosive oral LP, maintaining gum health is important to keep teeth healthy, and finding a hygienist who is familiar with LP management will help.

VULVAL / VAGINAL LP soreness, burning and rawness are very common symptoms. If the outer layers of the skin break down (erosions), these areas appear moist and red. There may be a white lacy pattern on the vulva. This pattern can also be seen around the edges of the erosions. The vulva may appear pale white or pink/red. Scarring with loss of the inner lips (labia minora) can be seen. The clitoris may be buried under scar tissue.

If the vagina is involved, intercourse can be painful. Erosions can occur inside the vagina in a patchy or generalized pattern. Some women have a sticky, yellow or yellow-green discharge, which

can be bloodstained, especially after intercourse. If the two surfaces of the vagina heal together, the vaginal opening can become narrowed. This is one reason why intercourse can be painful. Sometimes it is difficult for a doctor to perform an internal examination. Rarely, the skin may have thickened areas. These may have a warty appearance.

PENILE LP shiny flat-topped bumps are common on the penis and usually occur around the tip (glans). Sometimes the bumps can form rings. The erosive form of lichen planus is less common in men but may occur. This may increase the risk of penile cancer.

GENITAL LP, how you can help yourself:

1. Wash with plain warm water, no soap or bubble bath etc. and use a soap substitute e.g. aqueous cream.
2. Shampoo your hair over a basin if possible, to avoid contact with affected skin.
3. Use a plain emollient / aqueous cream and apply liberally before and after spending a penny, aqueous cream can also be used to wash with and is extremely soothing if chilled before application.
4. Some members find that ice packs are useful to reduce itching and swelling - if ice packs are not available, a pack of frozen peas will do the same job but do not apply directly onto the skin as this may damage skin further.
5. Use a good lubricant, there are many on the market such as YES, Astroglide, V Gel and Sensilube to name a few, these products are mucous like and very moisturising.
6. Try stockings instead of tights and go without underwear wherever possible.

what members say..

“UKLP has opened a door to a wealth of information on a disease I thought few others had.”

What is the outlook (prognosis) for people with lichen planus?

In general, the outlook is good. Without treatment, about half of cases of lichen planus affecting the skin clear within 6-9 months. It is unusual for the rash to last longer than 18 months. Oral disease tends to persist. Erosive disease of the vulva or penis tends to be more persistent. However, lichen planus can persist longer in people who are severely affected.

This is mostly in people who develop lichen planus mouth ulcers, and lichen planus of the vulva or penis.

What should I watch for?

Erosive lichen planus can carry a very small risk of developing local types of skin cancer, the risk is about 2%. Regular self examination is very important and if you become aware of any changes, or persistent, non-healing areas in your mouth or genital area, these should be reported to your doctor. If detected early treatment is very successful. It is important that your lichen planus is treated and you are followed regularly.

what members say..

“I thought I was alone, and that consultants were my only hope – but UKLP gives me practical advice from others with LP”



apply online:

www.uklp.org.uk

or by post:

Village Farmhouse
3 Donside Road
Alford
Aberdeenshire
AB33 8QB

Telephone:

07581 674274

(answer phone service only)

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Membership

Membership to the online forum costs just £5 for life and allows additional access to personal support from other members, a quarterly newsletter and a discounted place at the annual workshop.

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