

LICHEN PLANOPILARIS

What are the aims of this leaflet?

This leaflet has been written to help you understand more about lichen planopilaris. It will tell you what lichen planopilaris is, what causes it, what can be done about it, and where you can get more information about it. It has been written for people suffering with lichen planopilaris.

What is lichen planopilaris?

Lichen planopilaris is a type of scarring hair loss which occurs when a relatively common inflammatory disorder of the skin know as <u>lichen planus</u> affects the hair bearing areas of the skin. Lichen planopilaris attacks the hair follicle causing its destruction and replacement with scar tissue. It is twice as common in women as it is in men and seen mostly in adults, with the commonest age of onset being in the mid-40s.

What causes lichen planopilaris?

The cause of lichen planopilaris is unknown but is likely to have something to do with the body's immune system. T-lymphocytes, a type of white cell, are known to be involved and the trigger is not yet known but could involve infection, medications or chemicals that are in contact with the skin. Lichen planus is not contagious.

Is lichen planopilaris hereditary?

No, lichen planopilaris is not inherited

What are the symptoms of lichen planopilaris?

Lichen planopilaris typically causes an intensely itchy scalp. The crown and vertex (top of the scalp) are most typically affected. Symptoms of pain, burning and scalp tenderness may be experienced. Lichen planus can also affect the skin, mouth, genitals and nails.

What does lichen planopilaris look like?



Lichen planopilaris causes redness around the base of a hair. It also causes scale around the hair and "plugging", which may give the base of the hairs a rough feel like a grater. Where hairs have been destroyed permanently the scalp may appear smooth and shiny. Any part of the scalp can be involved, it often occurs in patches but may lead to more extensive involvement. Facial and body hair may be affected. It is uncommon for the body to be affected by the rash of lichen planus.

Other related conditions include:

<u>Frontal fibrosing alopecia</u>; is a condition that often, but not exclusively, affects post menopausal women. It appears with a slow band like recession of the frontal hairline, and sometimes involves the sides of the scalp. Loss of eyebrow hair and body hair is also recognised in this condition.

<u>Graham Little Syndrome (Piccardi-Lasseur-Graham Little Syndrome)</u>; patchy scalp hair loss similar to classical lichen planopilaris accompanies loss of armpit and pubic hair and a bumpy skin rash on the body and limbs.

How is lichen planopilaris diagnosed?

A biopsy is usually required to confirm the diagnosis. This often involves removing at least 2 small areas of affected scalp skin under local anaesthetic and will leave small scars.

Can lichen planopilaris be cured?

The condition does tend to "burn out" eventually in most cases. . Where scar tissue has been formed the hair loss is permanent. Treatment aims to preserve remaining hair, and help control symptoms but will not cause regrowth of hair that has already been lost.

How can lichen planopilaris be treated?

Lichen planopilaris can be treated in various ways with topical treatments and tablets, although success rates can be very variable. Unfortunately there is no single proven effective treatment in this condition and despite trying multiple treatments some people fail to respond. Some patients choose not to have any treatment at all as this condition doesn't otherwise affect your general health. You may want to discuss treatments with your relatives, GP or friends



before deciding and you are welcome to bring someone along to appointments to help you make a choice.

Skin-Directed treatments

Topical Steroid Preparations. Localised areas can be managed by using strong steroid based preparations on the scalp in the form of lotions, gels, applications or mousses. With all steroid based preparations care must be taken to apply the treatment sparingly and to avoid getting it onto unaffected skin, especially delicate skin such as that on the face and around the eyes, as steroids can cause skin thinning. Topical steroid preparations can be particularly helpful in improving the symptoms of itch. However a steroid injection (known as 'intralesional steroids') can be a more effective treatment if a limited area is affected. However steroid injections have a higher risk of causing adverse effects such as skin thinning or dimpling of the skin.

Topical Calcineurin Inhibitor Creams and Ointments. Although not licensed for this indication, these topical treatments work like topical steroids to settle local inflammation. They can therefore be useful in the management of lichen planopilaris and do not have the potential for skin thinning seen with topical steroids. Side effects include stinging on initial application (this usually improves with time). Excessive sun exposure, sunbathing and sunbeds should be avoided while using this treatment.

Tablet Treatments

<u>Corticosteroids</u> A short course of steroid tablets may be given to try and quickly reduce inflammation caused in severe cases, with the hope of halting hair loss. However side effects such as high blood pressure, diabetes, osteoporosis, weight gain *etc.* limit the long term use of oral steroids. Sometimes steroid tablets are given as a bridge while waiting for another longer acting treatment to take effect.

<u>Hydroxychloroquine</u>. Although slow to start working, this drug can be very useful in treating lichen planopilaris. Usually a minimum trial of 4-6 months is required to see whether the drug is effective, and if so it may be continued long term until the condition goes into remission. It is not certain how the drug works to stop hair loss. While you are taking hydroxychloroquine you will require regular blood tests and annual eye tests may be recommended.



Immunosuppressive drugs. Several different tablets are used to treat lichen planopilaris by suppressing the immune system with varying degrees of success. These are safer than taking steroid tablets in the long term but do have their own side effects and require close monitoring with reviews and regular blood tests. It is not recommended that women become pregnant whilst on these medications. Below are examples of these drugs and some of their main side effects and for fuller discussions please see the relevant patient information leaflet.

- <u>Ciclosporin</u>, can be beneficial to stabilise the disease but treatment is generally limited to 1-2 years due to the potential risks of side effects such as kidney problems, high blood pressure and increased risk of infections.
- Azathioprine, can be given long term but requires monitoring of blood count and liver function
- Mycophenolate mofetil, can be used long term but can cause stomach upset and requires monitoring of the blood count and liver function.
- Methotrexate, can be used long term but requires monitoring of the blood count and liver function. Alcohol avoidance is recommended with methotrexate and contraception for both men and women is advised

Other tablets: Tetracycline or doxycycline are antibiotics commonly used in the treatment of acne but can also be used to treat lichen planopilaris. They have few side-effects and don't require monitoring blood tests. Acitretin and isotretinoin are other drugs that have been used, however isotretinoin is preferred because acitretin itself can cause hair loss. You must not become pregnant on acitretin or isotretinoin, and monitoring of liver function and lipids is required. There is some evidence to show a diabetes drug called pioglitazone might also be helpful in the treatment of lichen planopilaris. This is generally well tolerated, but there are some safety concerns with its long term use, including a possible association with bladder cancer.

Other Treatments

Some individuals who have extensive hair loss from lichen planopilaris will choose to wear a wig or a hairpiece. These can either be bought privately or obtained through the NHS with a consultant's prescription (although a financial contribution is required). Your local hospital orthotic (surgical appliances) department will be able to advise you on the range of hair pieces available on the NHS and can recommend local suppliers. There are lots of



other ways of camouflaging hair loss that you can discuss with your consultant.

Sometimes, after a period of time, lichen planopilaris can "burn out" and gets no worse. Once it has been stable for a number of years it may be possible for permanent areas of hair loss to be removed or reduced in size by a small operation. Your doctor will let you know whether you might be suitable for such a procedure but usually they will not be available on the NHS. Similarly hair transplantation is another option that can be considered once the condition has stabilised but unfortunately isn't always successful if the condition reactivates.

Self care (What can I do?)

- Try active treatment for a minimum of 12 months.
- Join a hair loss support group.
- Seek unbiased medical help and be sceptical of the latest online solution.
- Eat a normal healthy diet; no particular food has been linked to lichen planopilaris.
- Stop smoking as smoking can interfere with the activity of the drugs and impairs skin healing.
- Use camouflage techniques to disguise the problem such as wigs, powders, hair fibres that are matched to your hair colour and hair thickeners.

Where can I get more information about lichen planopilaris?

Web links to detailed leaflets:

www.aad.org/pamphlets/lichen.html

www.carfintl.org

www.nahrs.org

http://dermnetnz.org/hair-nails-sweat/lichen-planopilaris.html

http://www.bad.org.uk//site/837/default.aspx



Links to patient support groups:

The cicatricial alopecia research foundation has two UK support groups;

http://www.carfintl.org/support.html

Most other hair loss support groups focus on alopecia areata but can offer useful advice for all patients suffering from hair loss.

Alopecia UK 5 Titchwell Road London SW18 3LW Telephone Number (020) 8333 1661

Website: www.alopeciaonline.org.uk

E-mail: info@alopeciaonline.org.uk

Alopecia Awareness
PO Box 461
Scarborough
YO11 9EN
Telephone number 07890 246 398

Website: www.alopecia-awareness.org.uk

E-mail: <u>michelle@alopecia-awareness.org.uk</u>

For details of source materials used please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: its contents, however, may occasionally differ from the advice given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel



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