

# DISCOID LUPUS ERYTHEMATOSUS

## WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about DLE. It tells you what it is, what causes it, what treatments are available, and where you can find out more about it.

## WHAT IS DISCOID LUPUS ERYTHEMATOSUS?

Discoid lupus erythematosus is an autoimmune disease. In this condition, the body's immune system, which is meant to protect against infection, mistakenly attacks the skin. It is part of a group of auto-immune skin disorders known as 'cutaneous lupus erythematosus (CLE)' that share related clinical and laboratory test findings.

In a small number of people, the lupus can affect other parts of the body, including internal organs – this is known as systemic lupus erythematosus (SLE). DLE carries a lower risk of developing SLE than other types of lupus. For most people with DLE, the risk of developing SLE is small, especially if only a limited area of skin is affected (about 5 of every 100 people with **localised DLE** might develop SLE). This risk is a bit higher if DLE affects larger areas of the skin (about 15 out of every 100 people with **generalised DLE** might develop SLE).

### *Key features of DLE:*

- Persistent, long-lasting red or pink scaly patches of skin.
- Localised DLE – this means the patches are most often found in specific areas of the skin, such as the head and neck, including the scalp and ears.
- Generalised DLE – this means that the patches can spread in larger areas of the body.
- Inflammation without appropriate treatment may lead to permanent skin damage such as scarring, hair loss/alopecia and darker or lighter pigmentation changes.

## WHAT CAUSES DISCOID LUPUS ERYTHEMATOSUS?

The cause of DLE is not fully understood but it is thought to be an autoimmune condition.

Our immune system protects us by making antibodies to fight off infections. In an autoimmune condition, such as DLE, the immune system mistakenly attacks the body's own tissue. In DLE, the immune system wrongly targets the cells in our skin, as if they are harmful. It then makes antibodies in order to damage them.

DLE can affect anyone, but it is more common in females than males. It is also more common in people of African ancestry.

Rarely, DLE can affect children. In such cases, it can increase the risk of subsequently developing systemic lupus erythematosus (SLE).

Factors that may increase the risk of DLE or make it worse include exposure to sunlight, stress, infection, smoking and trauma.

## IS DISCOID LUPUS ERYTHEMATOSUS HEREDITARY?

Some families may carry genes that increase the risk of developing DLE. However, it is not entirely clear how the affected genes do this, or to what degree they influence the condition. It is thought that a combination of

environmental factors and genetics contribute to the development of DLE.

## WHAT DOES DISCOID LUPUS ERYTHEMATOSUS FEEL AND LOOK LIKE?

Occasionally the affected areas of skin can be uncomfortable or itchy. In most people, there is no effect on their general health.

DLE commonly affects the face and areas of the scalp, but occasionally can spread to other areas such as the arms, legs and torso. It may also affect the eyes, lips, mouth and ears. The rash is made up of red scaly patches, which tend to clear eventually, resulting in thinning, scarring or colour change in the skin. The scaling can sometimes be quite thick and look like a wart. When the scalp is involved, hair in the affected area may be lost permanently.

## HOW CAN DISCOID LUPUS ERYTHEMATOSUS BE DIAGNOSED?

A doctor may be able to diagnose it by examining the skin. However, in most cases, a biopsy will be needed to confirm the diagnosis. This means that a small sample of skin will be taken and examined under a microscope. Other tests may be performed including blood and urine tests.

## CAN DISCOID LUPUS ERYTHEMATOSUS BE CURED?

No. Like many autoimmune conditions, DLE is generally a lifelong condition. However, there are treatments available that are usually effective and can help keep symptoms under control.

## HOW CAN DISCOID LUPUS ERYTHEMATOSUS BE TREATED?

### *Local and topical treatments:*

Strong or very strong [corticosteroid creams and ointments](#) are commonly offered as a first line treatment. They can be used safely even on the face under the direction of your dermatologist.

Other topical treatments which may be offered in addition, or as an alternative to

topical corticosteroids, are [topical calcineurin inhibitors](#), pimecrolimus and tacrolimus. These treatments do not contain steroid, and they act on the immune system to help reduce inflammation.

In some patients with localised patches, [injections of corticosteroids](#) may be very effective.

### *Oral treatment:*

If the skin rash is more severe, widespread, or the local treatments do not work, then oral medications may be offered. The most commonly used oral medications are the anti-malarial drugs [hydroxychloroquine](#) and [mepacrine](#), which may be taken at the same time. As these medications may take some time to work, some patients may be prescribed [oral corticosteroids](#) for a short period.

Occasionally, some patients may need additional medications, which include the immunomodulatory drugs [methotrexate](#) and [mycophenolate mofetil](#).

There are ongoing studies on other newer medications for DLE, but these are not currently available outside clinical trials.

## SELF-CARE (WHAT CAN I DO?)

If you smoke, we strongly recommend that you stop. Smoking can make this condition worse and may also result in a poor response to treatment.

### *Top sun safety tips*

Sun protection is recommended for everyone. It is advisable to protect the skin from further sun damage.

- Protect your skin with clothing. Ensure that you wear a hat that protects your face, neck and ears, and a pair of UV protective sunglasses.
- Make use of shade between 11 am and 3 pm especially when it's sunny.
- It is important to avoid sunburn, which is a sign of damage to your skin and increases your risk of developing a skin cancer in the future. However, even a



tan is a sign of skin damage and should be avoided.

- Apply a high sun protection factor (SPF) sunscreen of at least 30. However, if you have an organ transplant, it is recommended to use SPF 50, which has both UVB and UVA protection all-year round. Look for the UVA circle logo and choose a sunscreen with 5 UVA stars as well as a high SPF, like this:



- Use this sunscreen every day to all exposed areas of skin, especially your head (including balding scalp and ears) and neck, central chest, backs of hands, forearms and legs, if exposed.
- Apply plenty of sunscreen 15-30 minutes before going out in the sun (ideally, apply it twice) and reapply every two hours when outdoors. You should especially re-apply straight after swimming and towel-drying, even if the sunscreen states it is waterproof.
- Make a habit of sunscreen application, applying sunscreen as part of your morning bathroom routine. If you have an oily complexion, you may prefer an oil-free, alcohol-based or gel sunscreen.
- Keep babies and young children out of direct sunlight.
- The British Association of Dermatologists recommends that you tell your doctor about any changes to a mole or patch of skin. If your GP is concerned about your skin, you should be referred to see a consultant dermatologist or a member of their team at no cost to yourself through the NHS.
- No sunscreen can offer you 100% protection. They should be used to provide additional protection from the sun, not as an alternative to clothing and shade.

- Routine sun protection is rarely necessary in the UK for people of colour, particularly those with black or dark brown skin tones. However, there are important exceptions to this. For example, sun protection is important if you have a skin condition, such as photosensitivity, vitiligo or lupus, or if you have a high risk of skin cancer, especially if you are taking immunosuppressive treatments (including organ transplant recipients) or if you are genetically pre-disposed to skin cancer. Outside of the UK in places with more extreme climates, you may need to follow our standard sun protection advice.
- *Regardless of skin colour, you should still protect yourself from other risks to your health during especially hot weather, such as overheating, heat exhaustion or heatstroke. Follow NHS advice on <https://www.nhs.uk/conditions/heat-exhaustion-heatstroke/>.*
- *Babies and children can easily overheat, which can be very dangerous to their health. Take additional precautions to avoid them getting sun stroke or heat stroke, such as making use of shaded areas and keeping them hydrated.*
- It may be worth taking vitamin D supplement tablets (available from health food stores) as strictly avoiding sunlight can reduce your vitamin D levels.

#### **Vitamin D advice**

The evidence relating to the health effects of serum vitamin D levels, exposure to sunlight and vitamin D intake, is inconclusive. People who are avoiding (or need to avoid) sun exposure may be at risk of vitamin D deficiency and should consider having their serum vitamin D levels checked. If the levels are low, they may consider:

- taking vitamin D supplements of 10-25 micrograms per day
- increasing intake of food rich in vitamin D such as oily fish, eggs, meat, fortified margarine and cereals.

## WHERE CAN I GET MORE INFORMATION ABOUT DISCOID LUPUS ERYTHEMATOSUS?

*Patient support groups providing information:*

LUPUS UK

Email: [headoffice@lupusuk.org.uk](mailto:headoffice@lupusuk.org.uk)

Web: [www.lupusuk.org.uk](http://www.lupusuk.org.uk)

Tel: 01708 731251

Changing Faces

Email: [info@changingfaces.org.uk](mailto:info@changingfaces.org.uk)

Web: [www.changingfaces.org.uk/](http://www.changingfaces.org.uk/)

Tel: 0300 012 0275

*Weblinks to other relevant sources:*

[www.dermnetnz.org/immune/cutaneous-lupus.html](http://www.dermnetnz.org/immune/cutaneous-lupus.html)

Jargon Buster:

[www.skinhealthinfo.org.uk/support-resources/jargon-buster/](http://www.skinhealthinfo.org.uk/support-resources/jargon-buster/)

*Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.*

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: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

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

### BRITISH ASSOCIATION OF DERMATOLOGISTS

#### PATIENT INFORMATION LEAFLET

PRODUCED | FEBRUARY 2008

UPDATED | JANUARY 2011, FEBRUARY 2014, JULY 2017, APRIL 2021, NOVEMBER 2024

NEXT REVIEW DATE | NOVEMBER 2027

