

# **DISCOID LUPUS ERYTHEMATOSUS (DLE)**

#### 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?

The term 'lupus erythematosus' is applied to a group of related disorders. 'Discoid' lupus erythematosus (DLE) is one of these often confined to the skin and is not commonly associated with symptoms from other organs. It is characterised by persistent, localised, red or pink scaly patches of skin most often on the head and neck, including the scalp and ears. Less often the rash can be more generalised. Uncontrolled inflammation may lead to permanent skin damage e.g. scarring hair loss/alopecia, darker or lighter pigment changes or scarring.

#### What causes discoid lupus erythematosus?

The cause of DLE is not fully understood but is thought to be an autoimmune disease. We all have an immune system which makes the antibodies that are needed to fight off infections. Normally these antibodies do not attack our own tissues. However, in an autoimmune disease, the immune system makes a mistake and fights our own body instead. The mistake made by the immune system in DLE is to view the cells in our skin as 'foreign' and to make antibodies that damage them. The disease is more common in females than males. It is also more common in patients from particular ethnic groups.

Although DLE is uncommon in children, it is associated with increased risk of progression to systemic lupus erythematosus or SLE. Factors that may increase your 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 disease. It is thought that a combination of environmental factors and genetics most likely contribute to the development of DLE.

## What are the symptoms of discoid lupus erythematosus?

Occasionally the affected areas of skin can be uncomfortable or itchy. When the areas resolve they may also cause permanent scarring, hair loss and changes to the colour of the involved skin. In most patients, there is no effect on their general health.

# What does discoid lupus erythematosus look like?

DLE commonly affects the face and areas of the scalp containing hair but occasionally can spread to other body sites including arms, legs and torso. It may also affect the eyes, lips, mouth and ears. The rash comprises 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 resemble a wart. When the scalp is involved, hair in the affected area may be permanently lost.

## How can discoid lupus erythematosus be diagnosed?

A doctor may be able to make a diagnosis after an examination, but in most cases it is necessary to take a small sample of skin (a biopsy) to be examined under a microscope in order to confirm the diagnosis. 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 treatments:

Strong or very strong corticosteroid creams and ointments are commonly offered as a first line treatment and 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 the topical calcineurin inhibitors,

pimecrolimus and tacrolimus. In some patients with localised patches, injections of corticosteroids may be very effective.

#### Systemic treatment:

If your skin rash is more severe, widespread, or if these measures do not work then oral medications may be used. The most commonly used medications are the antimalarial drugs hydroxychloroquine and mepacrine, which may be used in combination. 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.

# 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 all people. 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 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.
- Use a 'high protection' sunscreen of at least SPF 30 which also has high UVA protection. Apply sunscreen generously 15 to 30 minutes before going out in the sun and make sure you reapply frequently when in the sun.
- 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 at no cost to yourself through the NHS. You can check your doctor's qualifications by searching for them on the GMC register – a Consultant Dermatologist will be listed as being on the Specialist Register for Dermatology.

- 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.
- 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?

Web links to patient support groups:

#### LUPUS UK

- St James House Eastern Road Romford Essex, RM1 3NH
- Tel: (01708) 731251
- Email: mailto:headoffice@lupusuk.org.uk
- Web: http://www.lupusuk.org.uk/

## **Changing Faces**

- The Squire Centre 33-37 University Street London, WC1E 6JN
- Tel: 0300 012 0275 (for support and advice)
- Tel: 0300 012 0276 (for the Skin Camouflage Service)

Email: <u>skincam@changingfaces.org.uk</u>Web: https://www.changingfaces.org.uk/

Weblinks to detailed leaflets:

http://www.dermnetnz.org/immune/cutaneous-lupus.html

Further information on <u>hydroxycholoroquine</u>, <u>methotrexate</u> and <u>mycophenolate</u> <u>mofetil</u>

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

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