PATIENT INFORMATION LEAFLET

SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS



WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about subacute cutaneous lupus erythematosus (SCLE). It explains what it is, how it can be treated, and where you can find more information.

WHAT IS SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS?

Subacute cutaneous lupus erythematosus is an auto-immune 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.

If a diagnosis of CLE has been made, this does not necessarily mean the lupus is systemic (meaning that it will affect other parts of the body). Instead, it is one of the forms of lupus which chiefly affects the skin. The most common forms of cutaneous lupus are acute lupus, subacute cutaneous lupus erythematosus (SCLE) and discoid lupus erythematosus (DLE).

WHAT DOES SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS LOOK LIKE?

SCLE typically causes a red, scaly, raised and/or ring-shaped rash and usually affects areas of the skin exposed to sunlight, such as the 'V' of the neckline, scalp, arms and upper back. The face is usually unaffected.

ARE THERE ANY OTHER SYMPTOMS OF SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS?

Most people feel well; however, some people may notice symptoms such as fatigue or joint aches. In a small proportion of people with SCLE, there is evidence of lupus in other body organs (such as the kidneys and lungs) leading to a diagnosis of systemic lupus erythematosus (SLE). Your dermatologist will assess whether you have evidence of SLE by asking you detailed medical questions, examining your skin and taking blood and urine samples. This will allow them to determine whether you should see other specialists such as a rheumatologist to help diagnose and treat your condition.

WHAT CAUSES SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS?

SCLE is an autoimmune condition. This means that the body's own immune system attacks the skin causing inflammation. Environmental factors are also important. For example, sunlight (or other sources of ultraviolet light) typically causes a flare up of the rash and SCLE tends to be more active in people who smoke. SCLE is more common in women than men.

The condition can sometimes be caused by medications, including some blood pressure and antacid medications such as proton pump inhibitors (PPIs). It is important that you should not stop any medication without first discussing it with your doctor.

IS SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS HEREDITARY?

Sometimes lupus erythematosus and related conditions run in families, but this is rare. If you are affected by SCLE and become pregnant, certain antibodies called anti-Ro/SSA and/or anti-La/SSB from your blood can cross the placenta and, very rarely, affect your baby causing a rash and/or a slow heartbeat. If you are considering pregnancy, please discuss this with the doctor.

HOW WILL SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS BE DIAGNOSED?

Your doctor may be able to make a diagnosis of SCLE based on the appearance of your rash. In some cases, it is necessary to take a small sample of skin (a biopsy) to be examined under a microscope to confirm the diagnosis. The doctor will probably also take a sample of blood to test for certain specific antibodies (known as "extractable nuclear antigens (ENA)" or "anti-Ro/SSA and/or anti-La/SSB") which appear to be important in the condition. It may also be necessary to perform other blood and urine tests to look for evidence of SLE.

CAN SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS BE CURED?

There is no cure for SCLE. If a particular medication is suspected to have caused the condition, then once that medication is stopped the rash may settle. It is important to note that this may take a long time, more than 6 months in some cases. In the majority of cases of SLCE however, there is no cure but there are many treatments that can be used successfully to control it.

HOW CAN SUBACUTE CUTANEOUS LUPUS ERYTHEMATOSUS BE TREATED?

Avoiding ultraviolet light is essential as this can trigger flare-ups of skin disease and potentially SLE in some people with SCLE.

Local treatment:

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 (treatments applied to the skin), which may be offered in addition or as alternatives to topical corticosteroids include the topical calcineurin inhibitors such as tacrolimus.

Systemic treatment:

If the skin rash is more severe, widespread, or if topical treatment is ineffective, then oral medications may be used. The most commonly used treatments are the antimalarial drugs hydroxychloroquine and mepacrine, which may be used together. As these medications may take some time to work, some people may be prescribed oral corticosteroids for a short period of time. Occasionally, some people may need other medications as additional or alternative treatments, and these include methotrexate or mycophenolate mofetil.

SELF-CARE (WHAT CAN I DO?)

The most important thing you can do is to protect your skin from sunlight. This does not just mean avoiding sunbathing, but also exposure to the sun when out in the garden, walking, shopping, playing sports, or even driving a car. It is important to wear a broad spectrum sunscreen on all skin that is exposed to light, even on cloudy days - see below.

Remember, the sun is most intense at midday. It can be quite powerful even on a hazy or cloudy day. Lying under a sunshade does not protect the skin totally and ultraviolet rays from the sun can be reflected from water and snow.

Evidence suggests that people who smoke cigarettes have more severe skin condition, so it is important to speak to your dermatologist or general practitioner if you wish to be directed to the relevant services to help you to stop smoking.

Top sun safety tips:

Sun protection is recommended for all people. It is advisable to protect the skin from further sun damage (for example, by wearing a hat, long sleeves and a sunscreen with a high sun protection factor).

- 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.
 - Generally, 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. In the case of CLE, routine sun protection is necessary. This is because CLE can affect people of colour more severely and increase the risk of developing SLE. 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.

 If you become pregnant, your baby may be born with a rash or a slow heartbeat as the ENA antibodies are able to cross the placenta. For this reason, it is important to let your obstetrician or midwife know that you have subacute lupus erythematosus.

WHERE CAN I GET MORE INFORMATION?

Links to patient support groups:

The patient self-help group Lupus UK supports people with all forms of lupus; it has local branches around the country and arranges regular meetings, as well as supporting research into the condition. For further information, contact:

LUPUS UK St James House Essex, RM1 3NH Tel: 01708 731251 Fax: 01708 731252

Email: headoffice@lupusuk.org.uk

Web: www.lupusuk.org.uk

Web links to detailed leaflets: www.dermnetnz.org/immune/cutaneous -lupus.html

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.

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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