

LUPUS

and
Light Sensitivity



LUPUS and Light Sensitivity

Being sensitive to sunlight is a well-recognised problem for many individuals with lupus. This factsheet explains some of the causes and ways to help.

Introduction

Systemic lupus erythematosus (SLE or lupus) is a multisystem disease with a tendency to cause skin rashes. When they appear on the skin after exposure to sunlight they are called photosensitive rashes and are one of the hallmarks of the disease (see 'LUPUS The Skin and Hair' factsheet). The rash may come out almost immediately after sun exposure, two weeks after sun exposure (e.g. a week after return from holiday) or just be worse in the summer. Patients with severe light sensitivity may also be badly affected by fluorescent and halogen lighting, unshielded energy-saving bulbs or any very bright light.

Also some patients may feel unwell after going out in the sun. They may develop fatigue, joint pains or kidney problems. These too are manifestations of light sensitivity. In contrast other patients find their pleurisy and kidney disease worse in the winter months, so each patient needs to keep a diary and work out what might be true for them and act accordingly.

What is it in sunlight that causes lupus rashes to develop and flare?

Ultraviolet (UV) waves in the sunlight are responsible. Some light-sensitive lupus patients are sensitive to the UVB wavebands; fewer to the longer UVA wavebands but most



to both UVB and UVA. A small percentage react to UVB, UVA and visible light. UV light damages cells in the top layer of the skin (epidermis) and if the damage is severe enough that it can't be repaired they die through a process called apoptosis. This sun-damage happens in

everybody's skin but is obviously at its most severe during sunburn. Normally most of these dead cells will be efficiently recycled. However in lupus patients, the fragmented apoptotic cells are not cleared away effectively leaving the cell's proteins vulnerable. The body's immune system may decide to attack these vulnerable proteins (Ro and DNA) triggering the production of antibodies against the contents of skin cells and thus the rash. This is called autoimmunity. But those antibodies generated by sun-exposure circulate in the blood and can travel through different organs. Damaged cells containing fragments of DNA and Ro proteins in other organs such as the joints may then be susceptible to attack from these antibodies and set up inflammation there.



Do all lupus patients suffer from light sensitivity?

Perhaps 60% of lupus patients get sun-induced rashes. But many lupus-rash patients with no history of photosensitivity, if tested with UV lamps on small areas of skin, have the same positive test that patients with sun-triggered rashes have. This can be true for lupus patients without skin involvement too.

Excepting those very rare patients where sunlight improves their rash, all lupus patients with a rash are advised to photoprotect.

Not all light-sensitive rashes in lupus patients are due to lupus. Up to 49% of lupus patients may have an unrelated light-sensitive rash called polymorphic light eruption (PLE). This usually starts within an hour or two of sun exposure and lasts at the most a week or two if sun is avoided. Like lupus, treatment of PLE is sun avoidance and sun protection. Supervised treatment with sunlamps is also used for PLE but this obviously can't be used for lupus patients. There are well-documented cases where SLE has first appeared or got a lot worse after sunbed use.



Can photosensitive rashes and other sun-induced manifestations of lupus be prevented?

Meticulous attention to sun avoidance and protection should achieve prevention in some and minimisation in others. Dark-skinned patients flare less with sun exposure but can be just as photosensitive.

UVB wavelengths peak between 11am-3pm so it is wise to avoid going out in the sun in the middle of the day in summer. If the rash is triggered through window glass as well then patients need to protect themselves throughout the day as here it is the UVA that is responsible and that is high from sunrise to sunset. Obviously there is increased UV in hot countries and at altitude, as well as additional UV being reflected from expanses of sand, concrete, snow, sea or other water.

After sun avoidance clothing is next. Dark, tightly woven fabric stops UVB and UVA; hold it up to the sun to make sure no light comes through, or look out for treated fabrics marked UPF (ultraviolet protection factor). UPF 50+ prevents transmission of 97.5% UV and many clothes are sold with this rating. So, long sleeves and trousers, high-necked tops, scarves, shemaghs or bandannas and gloves may be necessary as well as a large-brimmed hat and big sunglasses (marked CE or UV400) protecting against UVB and UVA.

In studies using sunlamps that would normally trigger a lupus rash, the use of a high factor, combined UVB and UVA-blocking sunscreen has prevented the development of the rash. If patients find that sunscreens are ineffective it is likely that the cream has been applied too thinly, often only a quarter of the thickness required, or it is being applied only occasionally, not everyday, all day, April through October.

Sunscreen creams may protect against UVB alone or UVB and UVA. In general choose a sunscreen of SPF50 or greater and 4-5 stars (UVA) for best protection. It should be put on in the morning 20 minutes before going out and applied to the rash and all areas where the rash might come. An immediate second application is more likely to achieve the desired thickness. It should be reapplied during the day at least once or twice. It should be used even on cloudy days because UV light can penetrate the cloud layer, especially UVA. Try several sunscreens, including those on prescription in the UK; find one that you like (there are tinted ones for darker skin), can afford and will use regularly. Sunscreens which screen out the blue in visible light as well as UV (Dundee cream) are available on prescription, usually through hospital pharmacies, but tend to be not as cosmetically acceptable.

The use of clear UV film on windows (blocking out all UVB and UVA) may also be necessary for those who are

particularly sun-sensitive. Patients who are harmed by visible light may benefit from amber window film.

Obviously each patient makes individual choices about the degree of sun avoidance and protection they embark on to achieve a good quality of life but knowledge of mechanisms at least gives them choices.

Will I need to take Vitamin D?

Probably. 90% of your vitamin D requirement comes from exposure to sunlight, only 10% from diet. In photoprotecting yourself you are at risk of having a low vitamin D which you need to keep your bones strong. It is easy for your GP to arrange a blood test and prescribe a permanent supplement if your level is low. There is some evidence to suggest that a low vitamin D level is one factor that may be associated with a lupus flare.

Do drugs provide protection against sun-induced flares of disease?

Yes. Hydroxychloroquine, mepacrine, steroid tablets and creams and protopic are the mainstays of treatment. Chloroquine may be used if the others have failed but extra care must be taken because of eye toxicity. Other drugs like methotrexate, mycophenolate mofetil, acitretin and thalidomide are also used. Being on tablets is not an excuse to stop or reduce sun avoidance or protection.

All drugs can have side effects. If your lupus rash is not responding to treatment go through all your non-lupus tablets with your doctor or GP to see if one might be making your lupus rash worse. Thiazide diuretics, calcium channel blockers and proton pump inhibitors are common culprits as is terbinafine. Flares usually occur soon after starting a new tablet but sometimes patients can be on a tablet for a year or two before it flares the rash.

Practical Aids

Details of the practical aids mentioned above, as well as many others can be obtained by requesting a Product List for Light Sensitive Patients from LUPUS UK or visit www.lupusuk.org.uk/eclipse

The LUPUS UK Range of Factsheets

A range of factsheets are available as follows:

1. LUPUS Incidence within the Community
2. LUPUS A Guide for Patients
3. LUPUS The Symptoms and Diagnosis
4. LUPUS The Joints and Muscles
5. LUPUS The Skin and Hair
6. LUPUS Fatigue and your Lifestyle
7. LUPUS and Pregnancy
8. LUPUS and Blood Disorders
9. LUPUS and Medication
10. LUPUS and the Kidneys
11. LUPUS and Associated Conditions
12. LUPUS and the Brain
13. LUPUS The Heart and Lungs
14. LUPUS The Mouth, Nose and Eyes
15. LUPUS and Light Sensitivity
16. LUPUS and the Feet
17. LUPUS and Men
18. LUPUS and Mixed Connective Tissue Disease

LUPUS UK is the registered national charity caring for people with lupus and has over 5,500 members who are supported by the Regional Groups.

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Please contact our National Office should you require further information about the sources used in the production of this factsheet or for further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

LUPUS UK is certified under the requirements of the Information Standard.



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