precautionary measures, such as amber window film or blinds, which screen out the blue spectrum. It is important for these patients to be assessed by a Photobiology Centre so they know what level and range of protection is needed.

How can I afford to buy so much sunblock?

Certain types of sunblock are available on prescription for people with a sun-induced disease like lupus. The general practioner (GP) usually prescribes the sunblock but the GP may want advice from a hospital specialist about which one to prescribe, how often and for how long. Sunblocks which screen out visible light as well are available on prescription. If you prefer a particular sunblock that is not available on prescription then you will have to pay for it yourself.

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

Yes, some drugs do help by damping down the immune responses and inflammatory processes. Steroids (for example prednisolone) will help to prevent and treat lupus manifestations due to sunlight. However, it is always best to be on the lowest possible dose of steroids, so avoiding UV light and wearing sunblock is important even if you are on steroids. Hydroxychloroquine (Plaquenil) seems to be particularly helpful at preventing rashes, arthritis and pleurisy which may be sun-induced, but is not a replacement for sensible behaviour. Other drugs (such as azathioprine, methotrexate, cyclophosphamide) which are often used for more serious disease or to keep the dose of steroids as low as possible may also reduce the risks of sun-induced flares.

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.

THE LUPUS UK RANGE OF FACT SHEETS

Further fact sheets are available as follows:

LUPUS Incidence within the Community
LUPUS A Guide for Patients
LUPUS The Symptoms and Diagnosis
LUPUS The Heart and Lungs
LUPUS and the Brain
LUPUS and the Kidneys
LUPUS The Joints and Muscles
LUPUS The Skin and Hair
LUPUS The Mouth, Nose and Eyes
LUPUS and the Feet
LUPUS Fatigue and your Lifestyle
LUPUS and Men
LUPUS and Pregnancy
LUPUS and Blood Disorders
LUPUS and Medication
LUPUS and Associated Conditions

LUPUS UK is the registered national charity caring for people with lupus and has some 7,000 patients in membership who are supported by 30 Regional Groups.

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Please contact our National Office should you require further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.

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LUPUS and Light Sensitivity

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LUPUS and Light Sensitivity

Systemic lupus erythematosus (SLE or lupus) is a multisystem disease with a tendency to cause skin rashes. These often appear on the skin after exposure to sunlight (for example face, neck, hands, and feet). These rashes are called photosensitive rashes and are one of the hallmarks of the disease (see Lupus The Skin and Hair fact sheet). Some patients complain of feeling unwell after going out in the sun, even for relatively short periods of time, (in extreme cases for as little as a few minutes). For example, they may develop migraine, nausea (feeling sick) or joint pains. The joints may even become tender to the touch and swollen. These are all manifestations of light sensitivity in lupus patients. Other aspects of the disease may be exacerbated after sun exposure, including fever, pleurisy (chest pains on breathing in), kidney disease and more serious nervous system problems such as epilepsy (fits). Patients with severe light sensitivity may also be adversely affected by fluorescent and halogen lighting, energy-saving bulbs or any very bright light.

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

It is the ultraviolet (UV) waves in the sunlight. Ultraviolet light in the UVA and UVB wavebands is responsible. (Some light sensitive patients may also be harmed by visible light, most commonly, but not necessarily only, in the blue spectrum). UV light damages cells in the skin (keratinocytes) causing them to die. In healthy people without lupus, these dead cells are cleared away quickly and any inflammation caused by the sun-induced skin damage is short-lived (sunburn). However in lupus patients, the skin cells may be more sensitive to sun-induced damage and there is increasing evidence that the dying (apoptotic) cells are not cleared away efficiently. As a result the contents of the dying cells may be released and cause inflammation. Also, cell contents such as DNA (the genetic material) and other molecules including Ro, which are never normally exposed to cells of the immune system, are available to generate (start) an immune response. Immune responses and inflammation are the normal reactions of the body to infection, but here they are being generated inappropriately by the dying cells and the body mounts an immune response against its own cell constituents (autoimmunity). The end result of this process in susceptible people with certain types of lupus is the development of characteristic photosensitive rashes. Antibodies to Ro, in particular, are often found in people with these rashes. Why the rashes affect only some parts of the body at any one time and are not always sun-sensitive is still not understood.

Why do some people with lupus get other disease manifestations after sun exposure?

The immune response to cell constituents results in the formation of these special proteins called antibodies. The antibodies are made by white blood cells called lymphocytes that circulate in the blood and both the lymphocytes and the antibodies can travel to different parts of the body.

These antibodies in lupus are directed against, and bind to, particular molecules such as DNA and Ro. These cell constituents may be released by other dying cells in the body as it appears that the inability to clear dying cells is not limited to the skin. Wherever the antibodies and their target molecules meet up and bind together, an immune complex is formed which can set up a series of inflammatory processes causing disease manifestations in that part of the body. Having said this, it is still not entirely clear why different people with lupus get certain disease manifestations and not others.

Do all lupus patients suffer from light sensitivity?

No, about 60% of lupus patients get sun-induced rashes and a further 10-20% complain of other clearly sun-induced problems. The role of sunlight in the remainder is unclear. Only a few people are confident that sun exposure definitely does not affect them, as they can go out for long periods and sunbathe without any ill-effects then or in the following weeks. Because new immune responses can take over a week to develop, the effects of sunlight will not necessarily be on the same day. In general, all lupus patients are advised to avoid sun exposure as it is one of the easiest ways of avoiding something which we know can make lupus worse. It is also advisable to be alert to the possible harmful effects of artificial lighting, computers and television sets. (It is possible to purchase screening devices which lessens the radiation coming from these appliances).

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

Yes, to a large extent photosensitive rashes and other sun-induced problems can be reduced by keeping sun exposure to a minimum and using sunblock regularly in the summer months (often from April to October). This also means not going to hot sunny countries or mountainous areas where there is more UV light than in the UK. In particular, beware of the increased UV exposure with snow, sea or other water due to additional light reflected on to the body (especially the neck and chin!). Even in the UK, it is wise to avoid going out in the sun in the middle of the day in summer. Sunblock should be sun protection factor (SPF) 25 or greater and effective against UVA and UVB light. It should be put on in the morning and reapplied during the day (at least once or twice) as it tends to get rubbed off or sweated away, particularly in warm weather, and don't forget your hands and feet!

Sunblock should be used even on cloudy days by light-sensitive people because UV light can penetrate the cloud layer and you can never tell what the weather will be like later on. It is also advisable to cover up with long sleeves and trousers and wear a wide-brimmed hat when out in the sun. The use of UV film on windows may also be necessary for those who are particularly sun-sensitive. Patients who are harmed by visible light will need to take further