THE LUPUS UK RANGE OF FACT SHEETS

A range of fact sheets 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

What are the key messages to bear in mind?

Mouth and eye problems are common in lupus, but most of the time is irritating rather than serious. Most cases of mouth ulcers, dry mouth and dry eyes respond to fairly simple treatments. However a sudden new problem such as severe eye pain or decreased vision requires urgent attention from an eye specialist, usually via an Eye Casualty service, your own GP or even the out-of-hours GP service. You should also keep your lupus specialist informed of what is happening so that they can help keep a look out for other signs of a flare and adjust your general treatment as necessary.

LUPUS UK is the registered national charity caring for people with presently incurable lupus and has over 6,000 members who are supported by the 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
The Mouth, Nose and Eyes

How can lupus affect the mouth and nose?

One of the most common features of lupus is mouth ulcers. This often occurs during flares of the disease, and may be associated with joint pains, rashes and hair loss. Fortunately when the disease settles, the mouth ulcers settle as well in most people, although stress or tiredness can make the mouth ulcers worse. Mouth ulcers can be painful and uncomfortable. If they are an ongoing problem simple treatments such as antiseptic mouthwashes can be helpful, and sometimes steroid lozenges or paste are necessary. Occasionally the nose can also be similarly affected and is treated with Vaseline cream or, in more severe cases, steroid paste or nasal spray. In the vast majority of people these simple measures coupled with good control of the disease are all that is necessary. In the rare cases where ulceration of the mouth or nose is more severe then more specialist drugs may be required, such as dissolvable steroid tablets.

Don’t forget that there are things you can do to help. Keeping your teeth properly brushed and flossed, and giving up smoking and avoiding spices is even more important in people who have lupus than those that do not. If the mouth is particularly sore consider using a softer toothbrush.

Can the lupus skin rashes spread inside the mouth?

Some people with lupus can develop raised red areas of skin known as “discoid” lesions. If similar discoid lesions do occur in the mouth or nose, they can occasionally breakdown the lining to form an ulcer. This is rare in people with systemic lupus, but is sometimes seen in people with lupus which is more limited to the skin. Again teeth brushing, flossing and giving up smoking should be priorities. Depending on the type of lesion, steroid paste may be used, coupled with antimarial tablets such as hydroxychloroquine. People with discoid lupus sometimes worry about the reported increased risk of these lesions becoming cancerous. It should however be borne in mind that this is very unusual, only applies to the most extreme cases and that anybody with such severe disease would be closely watched by their specialist.

Having a chronic condition such as lupus may put you at slightly increased risk of some other conditions such as cold sores and thrush of the mouth. Thrush is also more common when receiving antibiotics or certain specialist drugs, such as cyclophosphamide infusions, so to avoid this complication anti-thrush treatments are given where necessary as a preventative measure (for example nystatin mouthwash).

Why do my eyes feel dry?

Around a third of people with lupus have some sort of eye problem related to their disease. Fortunately in most people only the surface of the eye is affected. This does not damage their vision and is readily treated with eye-drops. Much less commonly the disease may involve the inside of the eye or the visual pathways in the brain. This may reduce vision and usually requires systemic treatment, either by oral or intravenous routes. In this section, we will consider the different ways lupus can affect the eyes and the types of treatment available.

By far the commonest problem is dry eyes, usually as part of Sjogren’s syndrome. In Sjogren’s syndrome inflammation of the tear (lacrimal) glands results in fewer and poorer quality tears. This makes the eyes feel gritty, dry and they may look red. Although this may vary in severity, ‘dry-eye’ is generally a problem that requires long-term treatment with artificial tears (eye-drops). Milder cases are usually effectively managed by the GP although more severe cases may require additional advice from an ophthalmologist (eye specialist). Sjogren’s syndrome commonly affects the salivary glands causing the mouth to be dry as well.

How else can lupus affect the eyes?

Other eye-related problems are much less common; although they should be taken seriously as they may be painful or may affect eyesight. Lupus can cause inflammation of the white coat of the eye (“scleritis”), which may be very painful and is usually visible as a bright red patch on part or all of the white of the eye. This is a more serious condition than conjunctivitis, which is more common and is usually due to infection. Conjunctivitis is irritating rather than very painful and may be associated with a sticky discharge. Occasionally there is inflammation at the back of the eye either of the retina (“retinopathy”) or of the main nerve (“optic neuropathy”), either of which may affect one’s eyesight. Rarely the nerves to the muscles that move the eyes can be affected causing double vision. For this reason, any severe eye-pain, loss of vision or double vision should be reported to your doctor urgently. Treatment may require steroids, or other immunosuppressive medications once infection has been ruled out.

There is a wide range of eye drops available. They range from watery drops like hypromellose, which are convenient, but the effects of hypromellose eye drops do not last very long. To overcome this problem thick paraffins may be recommended as they are long lasting but they may blur the vision. Gels such as carbomer lie somewhere in between. Gels and most watery drops usually contain preservatives, which can cause irritation. If this is a problem then a preservative-free equivalent should be used. Mild dry-eye may only require the use of a watery drop or gel a few times a day, which can be increased as required. However more severe dry-eye will require frequent use of a combination of drops e.g. frequent gel by day with a paraffin at night. Other drops sometimes used in severe cases are sodium hyaluronate and acetylcysteine.

As well as giving replacement tears we can try to preserve the natural tears by blocking the tear ducts with either temporary or permanent plugs. The decision to use these has to be made by an ophthalmologist. These plugs are often extremely effective but may need to be used in conjunction with artificial tears.