

LUPUS

A Guide for Patients



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

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.

LUPUS UK acknowledges with gratitude the assistance of Prof. Graham Hughes (London Lupus Centre, London Bridge Hospital) and Prof. Caroline Gordon and colleagues (Queen Elizabeth Hospital, Birmingham) in the provision of clinical information towards the production of these fact sheets.

LUPUS UK also thanks the Wooler Walkers (Northumberland) for their valued sponsorship towards the cost of producing the fact sheets.

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.

Non-medication measures

- a. Rest, adequate sleep, modifying activity during time of flare.
- b. Minimising stress: Major lifestyle modification and co-operation with and by family members, spouse, and employer to achieve this adjustment may be essential in keeping the disease under control. Pain clinics, an interested psychologist or psychiatrist may be helpful.
- c. Avoidance of provoking factors - sun, excessive heat, fatigue, certain medications and infections.
- d. Patient awareness of early symptoms, which may signal a flare and prompt reporting of these to their physician allowing earlier treatment.

What is the outlook?

In summary, SLE is a potentially serious disease, which can affect almost any system of the body. We do not yet know what causes it. The outlook for survival has improved in recent years and most patients with SLE will continue to have mild disease. If diagnosed early and treated appropriately at an early stage, lupus may settle and ultimately go into remission – i.e. the patient requires no medication. With co-operation between the patient, family and physician the problems associated with the disease can be significantly modified.

LUPUS UK

ST JAMES HOUSE, EASTERN ROAD
ROMFORD, ESSEX RM1 3NH
TEL: 01708 731251
www.lupusuk.org.uk

Published by **LUPUS UK**
Reg. Charity Nos 1051610, SC039682



© 2013 LUPUS UK.

LUPUS

A Guide for Patients

What is lupus?

Systemic Lupus Erythematosus: is a disease where the immune system becomes overactive; a chronic disease which affects one or many tissues of the body: skin, joints, muscles, blood vessels, blood cells, brain and nerves, internal organs such as lungs, heart, kidneys, gastrointestinal tract and/or the linings around internal organs. Inflammatory and immune responses account for many of the symptoms observed in systemic lupus.

Discoid Lupus (DLE): In general DLE is a benign disease affecting the skin, which rarely affects the internal organs, i.e. rarely becomes systemic. Most studies suggest that approximately 5% of patients with discoid lupus at some stage may suffer a generalised flare of the disease, involving joints, kidneys etc. and may progress to developing Systemic Lupus Erythematosus.

Drug-induced Lupus (DILE): can occur during the administration of certain drugs in susceptible individuals.

Who gets lupus?

Lupus affects women at least ten times as often as men, especially women in the childbearing years. It can, however, occur in children or old age. Afro-Caribbean, Asian and Eastern races are more likely to have lupus.

How does lupus affect the body?

Lupus is a highly variable disease. Potentially, it can affect every organ and tissue of the body. In any

individual patient, however, only some of these may ever be affected; the tissues and systems involved may change and the intensity of involvement may vary with time. The disease is very much an individual illness differing from person to person.

What are the features of lupus?

Fatigue, joint and muscle pain, flu-like illness, skin rashes (including the classical “butterfly” rash on the cheeks and nose), hair-loss and, more importantly, internal organ involvement including pleurisy, kidney disease and brain inflammation. Some patients with lupus have a clotting tendency and this can present, for instance, as a thrombosis in the vein or an artery.

How serious is lupus?

In terms of how disruptive the disease is to life, most SLE is mild and with appropriate care these patients can live a virtually normal life with only periodic, brief interruption during times of flare but no significant threat to their internal organs. They may, however, need to make certain adaptations to their home and lifestyle to make life easier at these times. For patients with major kidney or central nervous system or vascular involvement the disease requires much more intensive medical follow up and treatment and has a much greater impact on lifestyle. But even these patients can often have long periods of remission.

How is lupus diagnosed?

- Patient awareness of symptoms and accurate recording of these to the doctor is essential.
- Medical history and physical examination provide most of the data required for diagnosis.
- Laboratory tests help support the diagnosis

Blood tests Antibody Test, Blood Count (CB), Sedimentation Rate, Complement Studies, Blood Chemistry Tests.

Urinalysis Often 24 hour urine to evaluate kidney involvement.

Other Skin Biopsy, Chest X-ray and ECG (Electrocardiogram).

Other Studies Echocardiogram, Brain Scan, EEG (Electroencephalogram), Lung Functions Tests, Abdominal CT Scan, EMG (Electromyogram).

Occasional Tests Kidney Biopsy.

How is lupus treated?

Medication - type of medication is determined by the clinical manifestations, and severity of symptoms.

Non-steroidal anti-inflammatory agents are used for mild disease and painful symptoms – joints, muscle pain, pleurisy, headaches, etc. Some experimentation may be needed to find medication with the least side effect and greatest benefit.

Anti-malarials – Hydroxychloroquine is a useful drug in mild to moderate disease and can often control joint symptoms, pleurisy and skin involvement. Benefit usually occurs gradually over several months and this type of medication is frequently used with non-steroidal anti-inflammatory drugs (NSAIDs).

Steroids - Generally reserved for more serious manifestations of the disease (vasculitis, central nervous system, kidney, etc.) and very high doses may be required. It is sometimes necessary to use them for non-life threatening manifestations such as arthritis, pleurisy, but here the dose is kept minimal and for as short a time as possible.

Cytotoxic drugs - These are reserved for severe disease either not responsive to high dose steroids or requiring prolonged use of unacceptably high doses of steroids. Examples include: cyclophosphamide, azathioprine.

More information regarding medication can be obtained from the Lupus and Medication fact sheet available from National Office.