



Someone You Know May Have
L U P U S

**LUPUS
UK** 

About LUPUS UK

LUPUS UK is the only national registered charity supporting people with systemic lupus and discoid lupus and assisting those approaching diagnosis. We presently have over 5,500 Members, and a number of Regional Groups, who arrange medical talks, publish local newsletters, set up social occasions and organise fundraising events. LUPUS UK also produces an informative national magazine with lupus articles, letters, reports and photographs, and operates a strong Grant Programme for research purposes and welfare.

LUPUS UK's priorities are:

- **to help the lupus patient who may feel alone and isolated**
- **to assist those seeking a diagnosis**
- **to inform the public and the medical profession about lupus**
- **to improve national awareness about lupus and its impact**
- **to maintain a network of Regional Groups and Contacts**
- **to fund further research into the causes and towards a cure**



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Reg. Charity No. 1051610 & SC039682

What is lupus?

Systemic lupus is an illness of the immune system, a condition in which the body's defense mechanism begins to attack itself through an excess of antibodies in the blood stream, causing inflammation and damage in the joints, muscles and other organs. Discoid lupus is usually a condition of the skin alone, but in a very few patients might develop into systemic lupus.

The disease may be triggered by various means and can present in a bewildering number of ways, even to the extent of mimicking other diseases such as rheumatoid arthritis or multiple sclerosis. The cause of lupus is not positively known though research has provided evidence implicating genes, hormones and infections including viruses. Lupus is an uncommon, complex condition that can affect any part of the body and can cause many different symptoms. 90% of lupus patients are female. It currently takes an average of seven years to diagnose. Men and young children can also be affected by lupus.

With its many symptoms, lupus can often be overlooked by a GP or consultant which may delay final diagnosis and a vital start to necessary treatment that may contain the disease and limit potential damage to the kidneys, heart, lungs or brain.

Those diagnosed usually receive ongoing treatment to lessen the impact of the many symptoms but there may be side effects. Lupus can adversely affect the lives of those with the disease and their families, and may influence relationships with friends and work colleagues.

The Triggers of Lupus

Lupus can be triggered:

at puberty

during the menopause

after childbirth

after viral infection

through sunlight

as a result of trauma

after a prolonged course of certain medications

Lupus is often triggered in people where there is existing family history of lupus and/or other immune system illnesses, such as rheumatoid arthritis.

What are the symptoms of lupus?

Although there are many possible manifestations of lupus, those listed below are some of the more common. Lupus is a disease which can present in many different ways, rarely do two people have exactly the same symptoms, and these can vary in number.

- **Joint/muscle aches and pains**
- **Butterfly rash over cheeks**
- **Kidney problems**
- **Heart and lung involvement**
- **Extreme fatigue and weakness**
- **Oral/nasal ulcers**
- **Increased risk of miscarriage**
- **Hair loss**
- **Rashes from sunlight/UV light**
- **Depression**
- **Flu-like symptoms and/or night sweats**
- **Inflammation of the tissues covering internal organs with associated chest and/or abdominal pain**
- **Poor blood circulation causing the tips of fingers and toes to turn white then blue on exposure to cold (Raynaud's)**
- **Haematological disorders including anaemia**
- **Seizures, mental illness or other cerebral problems**
- **Headaches, migraine**

An individual with lupus may have four or five symptoms. Some of these might recede, and/or others develop.

*The two major symptoms in lupus appear to be
Joint/muscle aches and pains • Extreme fatigue and weakness*

Some pointers

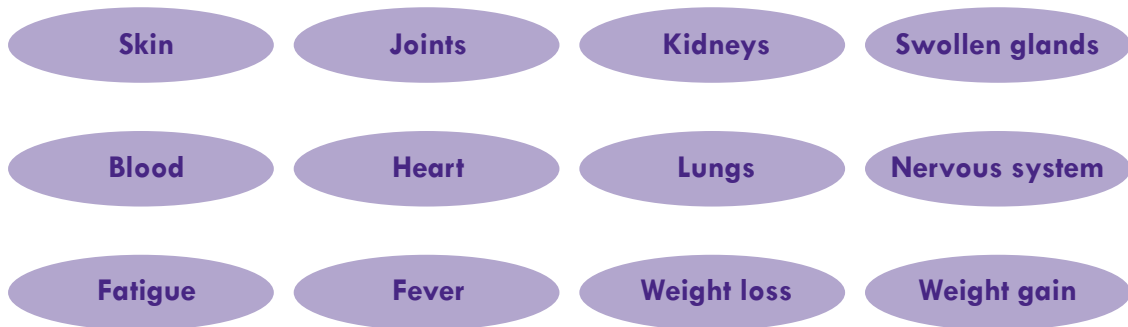
Study of many thousands of lupus patients across the world has led to the recognition of the following as possible early pointers of lupus. Only one or two of the pointers may be in evidence.

- **Rashes, facial or elsewhere**
- **Teenage migraine**
- **Agoraphobia/claustrophobia**
- **Finger flexing difficulty**
- **Menstrual cycle problems**
- **Dry eyes/mouth**
- **Teenage “growing pains”**
- **Teenage glandular fever**
- **Severe reaction to insect bites**
- **Recurrent miscarriages**
- **Family history of immune system illness**
- **Low lymph count**

The list is not exhaustive and, whilst the GP or specialist should be mindful of the above possibilities, he or she will be guided by the diagnostic criteria.

How is lupus diagnosed?

Lupus is a disease of many manifestations and each patient's profile or list of symptoms may be different. The specialist may need to investigate any of:



In arriving at a firm diagnosis the physician will normally expect at least four of a list of 11 internationally accepted symptoms to be present (either currently or at any time since the onset of the illness). These criteria include one or more positive blood tests, and the patient's/family medical history will also be taken into account.

Diagnosis is usually achieved through a rheumatologist but other specialists may also be involved, eg dermatologists, nephrologists (kidney), cardiologists, obstetricians.

What are the treatments?

- **Non-steroidals, Aspirin etc** - anti-inflammatory drugs (NSAIDS), used for patients who mainly have joint/muscle pain. Aspirin, heparin or warfarin may be prescribed in the case of patients needing anticoagulation treatment.
- **Anti-Malarials** - these are of help in patients with skin and joint involvement. The drugs may be sufficient for patients with moderately active lupus to avoid using steroids. Hydroxychloroquine and mepacrine are most commonly used.
- **Steroids** such as prednisolone have been vital in the improvement in lupus care and in some cases are lifesaving. They have a profound effect on inflammation and suppress active disease. The dosage depends on the severity of the symptoms. Once the disease is under control the dosage might be reduced gradually and/or it might be possible for the patient to transfer to other medication.
- **Immunosuppressants** - these drugs are widely used in more severe disease. The most commonly used are azathioprine, methotrexate and cyclophosphamide. Regular blood testing is required initially 2-3 weekly, and thereafter 4-6 weekly whilst on such medication.

Doctors will usually only keep the patient on high impact medication for as short a period as possible. **There is at present no cure for lupus** but careful monitoring of the disease and a treatment programme with medication adjusted as appropriate, enables the condition to be controlled; most patients being able to live a normal life span.

Lifestyle

The lupus patient will need to adjust to the demands of the illness and the impact of medication. The majority will then be able to regain quality in their everyday lives, and the following 'rules' can help:

- **Ask for help if needed, from family, friends, health professionals**
- **Offset fatigue by rest, and by pacing daily activities**
- **Become well-educated about lupus**
- **Avoid exposure to direct sunlight and fluorescent lights**
- **Try to keep stress to a minimum**
- **Develop new hobbies and skills if able and desirable**
- **Be open with family and friends about the unpredictability of lupus**

What some have said:

"Having lupus is like having your mind in fifth gear and not being able to get your body out of first."

"It's the tiredness. Even if you could sleep all day and all night it wouldn't help."

"Finding people who understand what you're talking about and going through makes all the difference in the world."

"Because you look well, nobody understands the way you're feeling."

"I was told all my symptoms were in my head. I began to think I was a hypochondriac."

"I badly needed information. LUPUS UK provided it and put me in touch with my local Group, giving me the opportunity, if I wished, to talk and meet with other people with lupus."

Help from LUPUS UK

Through membership of LUPUS UK you can obtain:

- **advice that will help you towards the diagnosis**
- **a comprehensive patient pack**
- **regular mailing of LUPUS UK News & Views magazine**
- **diagnosis criteria and information**
- **access to National Contacts who are mostly patients**
- **books, leaflets and DVD**
- **membership of local Groups, including newsletters**
- **advice on many aspects of lupus management**

If you are the partner, family member or friend of someone with lupus, we would welcome your membership of the charity in a supporting role.



To become a member,
please complete the application form below.

Membership Application

I/We should like to apply for membership* of LUPUS UK
and receive the national magazine, LUPUS UK News & Views, three times a year.
I/We enclose a cheque/P.O. payable to LUPUS UK or join online at **www.lupusuk.org.uk**

Title _____ First Name _____

Surname _____

Address _____

_____ Postcode _____

Tel no _____ Date of birth _____

Email _____

I would like LUPUS UK to treat any donations that I make
as Gift Aid Donations.

I confirm that I have paid income tax/or capital gains tax
at least equal to the tax that LUPUS UK reclaims
(25p for every £1 given)

Signed _____

Date _____

Membership Fees

Single membership £10pa

Joint/Family membership* £15pa

**members at the same address receiving one
magazine per issue*

Membership fee £.....

*(plus donation**if wished,thank you)* £.....

TOTAL £.....

***Please sign Gift Aid Declaration if applicable*

Send this form and your cheque or postal order to:

LUPUS UK
St James House
Eastern Road
Romford
Essex RM1 3NH

*We will acknowledge your application and send
a welcome pack*

Please note: all membership renewals are due on 1st January

LUPUS

Systemic Lupus Erythematosus (SLE)

Lupus is neither infectious nor contagious

People of Afro-Caribbean, Asian and other far eastern heritage have a higher incidence of lupus

**Learn more about lupus and join LUPUS UK at
www.lupusuk.org.uk**