



**[www.lupusuk.org.uk](http://www.lupusuk.org.uk)**  
**01708 731251**

Registered charity nos: 1051610, SC039682

# LUPUS

(Systemic Lupus Erythematosus)

A disease in which the body's immune system becomes over active. This affects the blood, and in turn, almost any organ in the body.

# Lupus

- Neither infectious or contagious
- No known cure at present
- No two people experience lupus in the same way
- Early diagnosis is important

# Immune system

- “A highly organised and versatile defence network, essential to the health of the individual”
  - Protects the body from infection
  - Produces:
    - \*antibodies (recognition and defence)
    - \*complement (disposal)
    - \*cytokines (co-ordination)

# Auto-immune disease

A disease in which the body produces antibodies that attack its own tissues, leading to the deterioration and in some cases to the destruction of such tissue.

Many autoimmune diseases involve a particular part of the body:

- Diabetes (pancreas)
- Multiple Sclerosis (nervous system)

In lupus, any part of the body can be affected, including the core of each cell of the body (DNA). This leads to the many symptoms and complications of the illness.

# Lupus

People with lupus undoubtedly have a disordered immune response:

Including:

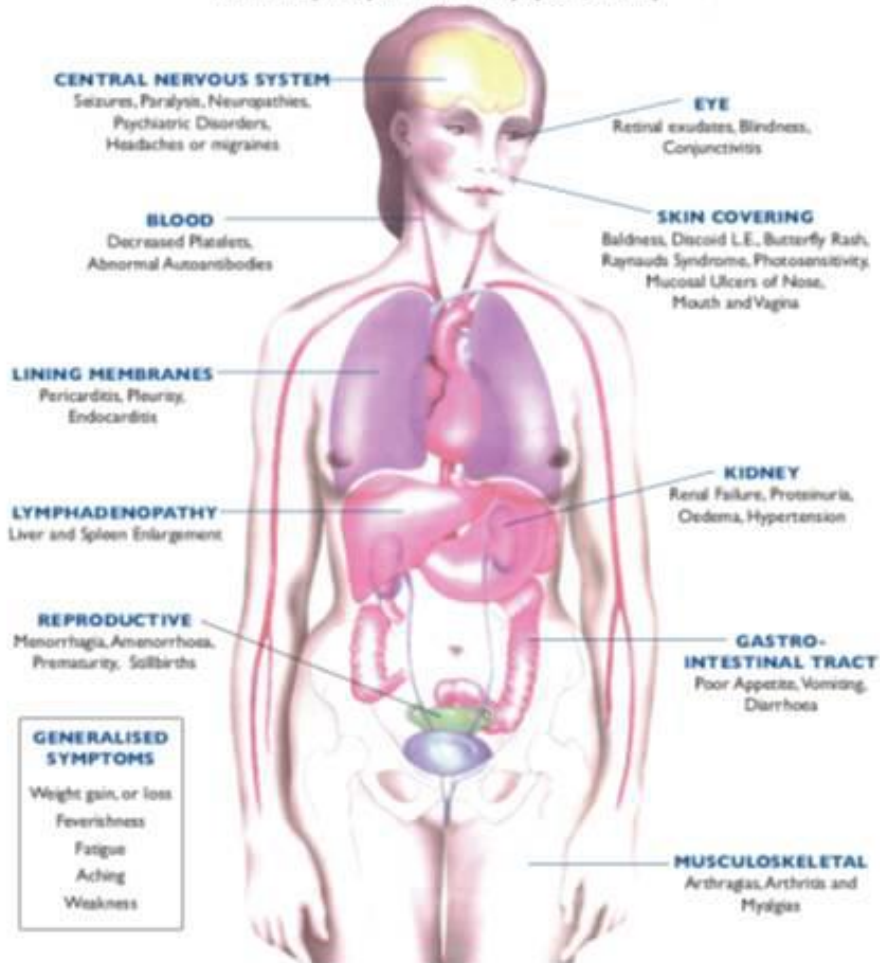
- Impaired T cell regulation and antibody production
- Immune complexes formed and deposited widely
- Complement system unable to function effectively

All leading to inflammation and possible tissue destruction

# LUPUS

(SLE - SYSTEMIC LUPUS ERYTHEMATOSUS)

Lupus is probably the classic multi-symptom illness  
Patients may have just a few of the symptoms, or many



## GENERALISED SYMPTOMS

Weight gain, or loss  
Feverishness  
Fatigue  
Aching  
Weakness

- LUPUS is presently incurable - the disease process is individualised and no two patients seem alike.
- Lupus is neither infectious nor contagious.
- 90% of all lupus patients are female, and men and children may also be diagnosed.
- Onset may be a slow progression or an acute process, and long delays in diagnosis are a regrettable reality.
- Major organ damage is possible for many patients.
- Lupus is probably genetic in origin and other factors can also contribute to the triggering of the disease.

FURTHER INFORMATION CAN BE OBTAINED FROM LUPUS UK (REGISTERED CHARITY NO. 1051618)  
St James House, Eastern Road, Romford, Essex RM1 3NH Tel: 01706 731251 Fax: 01706 73125

Please ask for a doctor, nurse or patient information pack.

Lupus can  
affect many  
parts of the  
body



# Which lupus symptoms do members have?

	%		%
<b>Fatigue (mental)</b>	<b>42</b>	<b>Fever</b>	<b>58</b>
<b>Fatigue (physical)</b>	<b>88</b>	<b>Depression</b>	<b>55</b>
<b>Rash</b>	<b>51</b>	<b>Heart Problems</b>	<b>10</b>
<b>Sensitivity to sun</b>	<b>60</b>	<b>Cold hands/feet</b>	<b>57</b>
<b>Joint pains</b>	<b>92</b>	<b>Sight problems</b>	<b>32</b>
<b>Kidney problems</b>	<b>21</b>	<b>Hearing problems</b>	<b>15</b>
<b>Hair loss</b>	<b>46</b>	<b>Easy bruising</b>	<b>57</b>
<b>Swellings</b>	<b>58</b>	<b>Dry eyes and mouth</b>	<b>48</b>

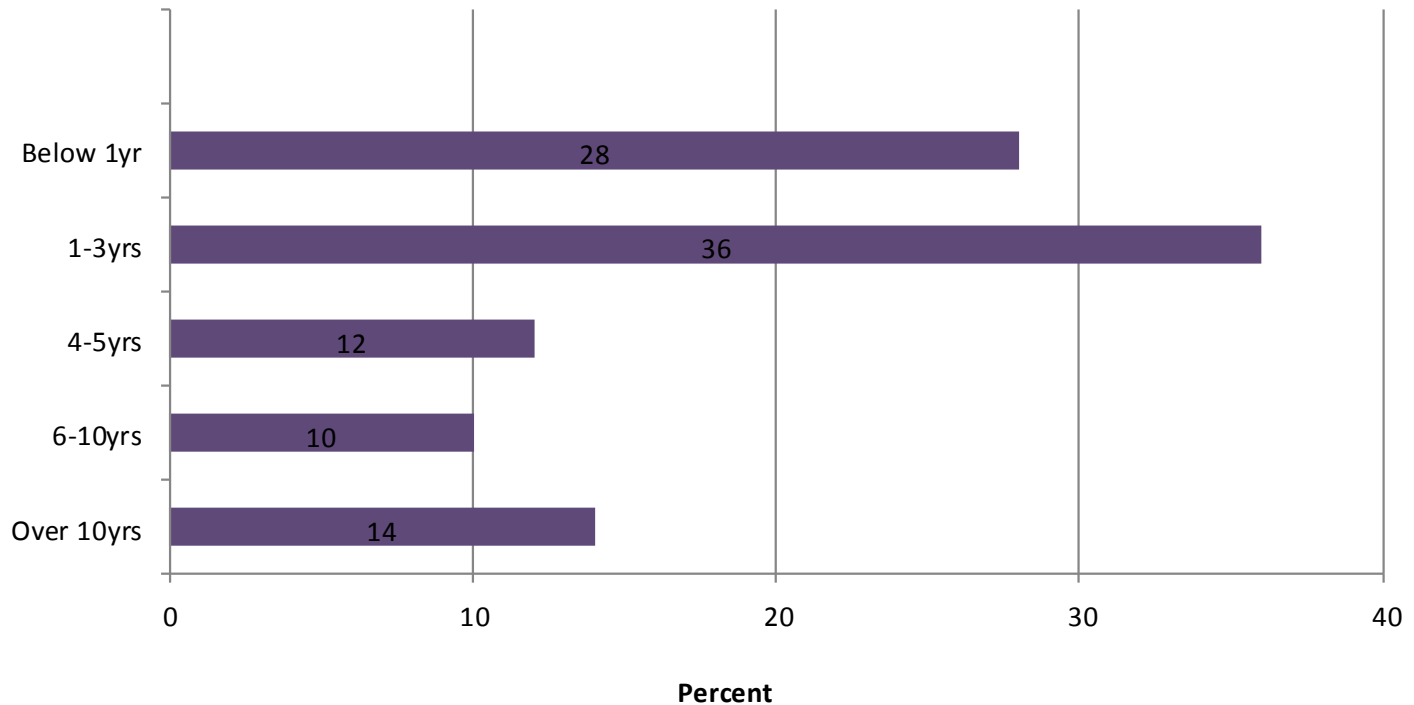
# Triggers

**Lupus can be triggered:**

- At puberty
- During the menopause
- After childbirth
- After Viral Infection
- After a prolonged course of certain medications

One or more of the above can trigger the illness in people who may have a predisposition to lupus

# How long did members wait for a diagnosis of lupus after onset of first symptoms?



# Who gets lupus?

- It can affect anybody
- Most commonly diagnosed in women aged between 15 and 45
- Affects approximately nine times as many women as men
- People of Black African origin are about three times more likely to be affected by lupus, this increases to four times for people of African-Caribbean origin.
- People of Chinese and South Asian backgrounds also have an increased risk of developing lupus

# Treatments

**Non-steroidal anti-inflammatory drugs** - Used for patients who mainly have joint/muscle pain

**Anti-Malarials** - Help patients with skin and joint involvement. These may be sufficient for patients with moderately active lupus.

**Steroids** - Have a profound effect on inflammation and suppress active lupus — in some cases are lifesaving. Dosage depends on severity of symptoms.

**Immunosuppressants** — Widely used in more severe disease. These can be milder forms of chemotherapy drugs used for the treatment of cancer. Regular blood testing is required.

**Biologics** — Newer therapies which target a specific part of the immune system. More expensive than other treatments. Benlysta (the first lupus specific treatment in 50 years) has not been approved for use by NICE).

# Tests

- Full blood examination
- Erythrocyte sedimentation rate
- C-reactive protein level
- Complement, C3 and C4
- Autoantibodies
- Tests of renal function
- Cardiac and pulmonary investigations, if evidence of involvement

# Living with lupus

## How lupus affected members lives

Activities changed	%
Given up work/study	39
Reduced time of work/study	31
Given up hobbies/activities	39
Reduced time on hobbies/activities	52
Cut down friendships	38
Given up close friendships	10
Stopped doing some routine household tasks	39
Stopped doing most routine household tasks	21
Stopped living on my own	5
Stopped carrying out own personal care	25

Base = 84 (multi responses possible)

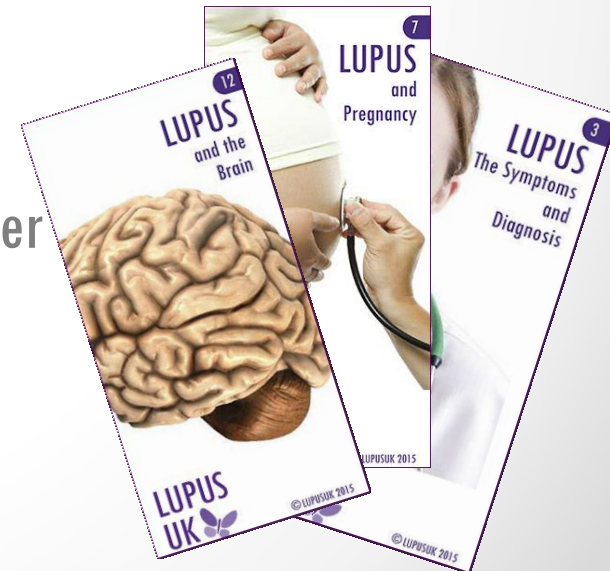
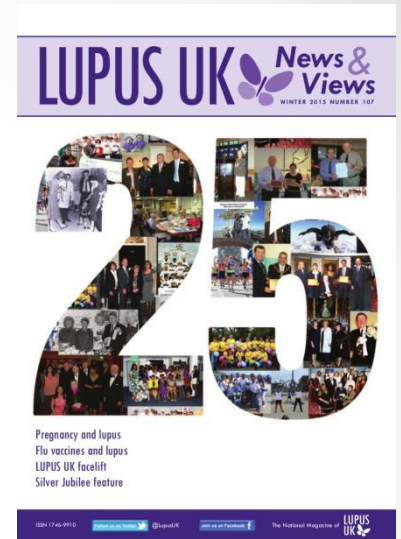
# LUPUS UK

- The national charity for people with lupus
- Supports people with lupus and those approaching a diagnosis
- Produces high quality information for patients, medical professionals, carers and employers
- Raises awareness of the condition amongst the public and medical profession
- Raises money for medical research and to fund specialist lupus nurses across the UK



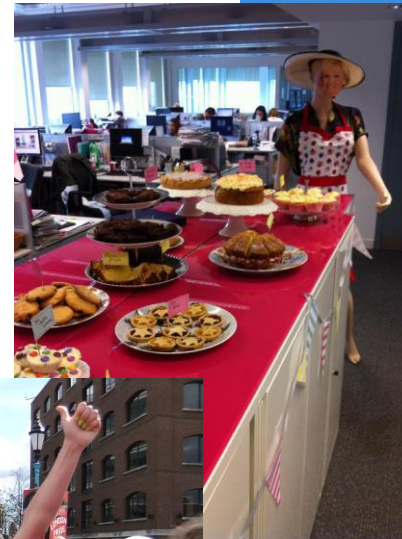
# LUPUS UK has:

- Approximately 5,300 members
- A number of Regional Groups throughout the UK who organise meetings, medical talks and fundraising events
- 100+ trained, volunteer telephone contacts who offer a 'listening ear'
- A wide range of informative publications and a magazine
- A user-friendly website packed with information: [www.lupusuk.org.uk](http://www.lupusuk.org.uk)
- A strong presence on social media: Facebook, Twitter HealthUnlocked



# LUPUS UK is funded by:

- Member subscriptions
- Sponsorship (eg. marathons, skydives)
- Donations
- Legacies
- Fundraising events



# What you can do

- Raise funds/sponsorship
- Help publicise lupus and take some leaflets
- Be a good friend or neighbour especially to people with long-term health problems





**Thank you for your attention**