

SLE (Lupus)

Systemic lupus erythematosus, often shortened to **Lupus** or **SLE**, is one of the 'autoimmune' diseases that can affect a wide variety of organs. This information is about lupus in general, and comes from [Arthritis Care](#). See also our information on [SLE and the kidneys](#).

What is lupus?

Systemic lupus erythematosus is a disease of the immune system - the system that prevents and fights infection.

In lupus the immune system becomes unbalanced resulting in the body reacting against healthy tissue. This is why the symptoms of lupus can vary so much. Occasionally the disease is caused by using certain drugs. This is known as drug-induced lupus.

Systemic lupus erythematosus (SLE) is classified as a rheumatic disease. It can cause inflammation in the joints and several of the body's organ systems. (For example: the skin, the kidneys and various other internal organs.) Hence the term systemic. The term 'lupus erythematosus' refers to the red rash on the face.

Discoid lupus affects the skin and is a relatively mild disease. Sometimes it is treated by a rheumatologist (a specialist in arthritis and rheumatic disease) but more commonly by a dermatologist (a specialist in skin disorders).

Who gets lupus?

25 years or so ago the diagnosis was always thought to imply a grave outlook because only those with the most severe disease were recognised. The situation is very different now. Doctors are now well aware of the condition and realise that it is often mild. Treatment has also improved greatly.

Discoid lupus is more common than SLE and is twice as common in women as in men.

SLE is about 10 times more common in women than in men. A study conducted in Nottingham in 1989-90 showed that the prevalence was 45.4 per 100,000 among women and 3.7 per 100,000 among men. SLE is also more prevalent among Afro-Caribbean groups. In one American study, the prevalence was 1 in 700 among

white women between the ages of 15 and 64. The prevalence among black women was 1 in 245.

The causes of SLE are unknown though recent research indicates the involvement of a weak genetic influence.

The initial diagnosis of SLE is most common among women of childbearing age. It is not uncommon for a young woman diagnosed in her 20s to recall having had symptoms in childhood. Occasionally lupus is diagnosed before puberty, when boys and girls are equally affected. With the onset of adolescence, girls take over. Lupus can also be seen in women after the menopause but this is rare.

It also appears that people with lupus can have periods of remission and flare-up in rather a similar way to rheumatoid arthritis.

What are the symptoms of SLE?

Lupus can present itself in very different ways from person to person. About 80% of people develop joint and muscle pain, skin rashes, fatigue and a general feeling of being unwell.

During a lupus flare-up the most common complaints are of flu-like symptoms (with or without fever), fatigue, muscle and joint pains. Often symptoms are reported to be worse before a menstrual period and they are often thought to be just pre-menstrual tension.

The following signs and symptoms are the most common:

Arthritis - The pain and inflammation of the joints occurring in SLE differs from that in rheumatoid arthritis. Although the arthritis can be very troublesome, the joints are rarely damaged, making SLE a less severe disease in this respect than rheumatoid arthritis. The pain and discomfort can seem to flit from one joint to another.

The joints most commonly affected are the hands, feet and knees but it can occur anywhere. Inflammation of the tendons and muscles can also occur.

Fatigue - People often report this as being the most disabling feature of SLE. Fatigue is not visible and people can have great difficulty in explaining to others how exhausted they can feel.

At first, most people find it difficult to accept the need for extra rest. However, this is an essential part of managing the disease and there is no need to feel guilty about it. Have realistic expectations about how much you can do and avoid 'overdoing' it even if you feel energetic.

Skin rashes - Skin rashes are common and almost any form can occur. People with SLE often develop facial rashes; these can vary from a mild redness on both cheeks to a more pronounced scaly rash. The famous butterfly rash over the bridge of the nose and cheeks is seen only rarely.

The skin rashes can occur on any part of the body, often on the areas exposed to sunlight. They usually clear up spontaneously but in some people the rashes can be very troublesome. Sometimes ulcers occur in the mouth and nose. Mild facial rashes can make you appear in excellent health although your skin is sore.

Having an invisible illness can be very deceptive.

Sun sensitivity - Many people with lupus are sensitive to sunlight and ultraviolet radiation. If you are affected in this way, you may find that the prolonged exposure to sunlight makes your arthritis worse or gives you rashes.

You should avoid sunbathing during the times when the sun is at its most intense, ie between 10am and 3pm. Use a high factor sunscreen at all times even in winter as ultraviolet rays penetrate through cloud.

Fluorescent lighting emits more ultra-violet light than normal light bulbs. If you are light-sensitive a simple, inexpensive plastic filter that can be wrapped round the tube and secured with a piece of tape is readily available. These can be very important in the workplace. An employer should be able to get these paid for by the Placement, Assessment and Counselling Team (PACT) which is part of the Employment Service.

Hair loss - Some people experience varying degrees of hair loss. Although this can be very distressing it is almost always temporary. Only in rare instances when hair follicles are scarred is the hair loss permanent.

Kidneys - Kidney involvement was thought to occur in 20-40 per cent of people with lupus and often caused them much anxiety. However, now that mild lupus is recognised, doctors realise this figure is overestimated and that kidney

involvement is rare in mild disease. Your urine may be tested at each visit to the clinic as a matter of routine to check your kidneys. With early detection, kidney involvement can be monitored and treated successfully if the need arises. The old anxiety that with every flare-up the kidneys will be further damaged is not well founded. See our separate information on [Lupus and the kidneys](#).

Depression - People with lupus may experience occasional periods of depression. Some experience depression as a reaction to long-term illness. For others it can be a result of the disease attacking the nervous system. Depression often strikes during a flare-up. However, in either case, these periods can pass without requiring special treatment.

Other symptoms - People with lupus can also have a variety of other symptoms including high temperature, blood disorders, miscarriage, headaches, weight loss, chest pain and abdominal pain. However, it is important to remember that the symptoms can vary greatly from person to person.

How is it diagnosed?

SLE is not easy to diagnose. It often resembles other forms of rheumatic disease such as rheumatoid arthritis.

Diagnosis can take many months or even a few years. Generally people are referred by their GP to a rheumatologist or kidney specialist who will make the eventual diagnosis.

The test most commonly used is the Anti-Nuclear Antibody (ANA) test. However, although this test is positive in over 90 per cent of people with SLE, it can also be present in other rheumatic conditions and sometimes in healthy individuals. Before a definite diagnosis is made, the individual's whole health picture and symptoms should be taken into consideration. Other blood tests, X-rays or perhaps a skin or kidney biopsy may be taken to help diagnosis.

What is the treatment?

Eighty per cent of people with SLE have it in a mild form that may not require treatment. For the rest, antiinflammatory tablets are often given to minimise joint pain and inflammation. If the associated inflammation is more severe, [steroids](#) can be used until the symptoms are under control. The drug may then be discontinued or reduced to a low dose.

NOTE: People taking steroids are always recommended to carry a steroid card. In the event of an accident or sudden illness, it is important that doctors know you are taking steroids as the dose may need to be increased. These cards are available from your pharmacist or GP.

For those with a combination of joint and skin problems the anti-malarial drugs chloroquine and hydroxychloroquine have proved useful. If these are recommended then an eye test is usually done before treatment commences. This may then be repeated once or twice a year as the drug can accumulate in the eye. If accumulation is detected on eye examination the drug will be stopped.

Other drugs called [immunosuppressives](#) (including **azathioprine** and **cyclophosphamide**) may be used to treat disease affecting the major organ systems and to reduce the amount of steroids required. If you are taking this combination of drug therapy you will have regular safety screening tests, eg blood tests. [More information on immunosuppressive treatment](#) is available.

Regular medical care is essential and it is important to follow your doctor's instructions and don't stop taking your medication without consulting the clinic. A combination of rest and exercise is essential and physiotherapy is often recommended to maintain joint mobility and muscle strength.

What will happen to me?

Each person with lupus is different and the duration and severity of the disease varies. However, with earlier diagnosis and improvement in treatment the outlook has much improved. In milder cases of SLE the prognosis is very good. In some people the symptoms can disappear completely over a period of time: this is usual in drug-induced lupus. Although serious complications can occur in a small proportion of people, SLE is no longer considered to have a bad outlook.

The majority of people with lupus can expect a normal lifespan.

The course of the disease is characterised by periods of remission when the person is free from symptoms and by periods of flare-up when the symptoms return or are not under control.

Lupus is not contagious, infectious or malignant. It does sometimes occur in families but it is not usually a genetically inherited disease.

How will I know if a flare-up is starting?

- An increase in severity of the following symptoms may indicate an impending flare-up:
- Increasing fatigue out of proportion to what is normally experienced
- increased joint pain and swelling
- recurrent high temperature
- unexplained skin rash
- involuntary weight loss
- generally feeling unwell
- recurrent mouth ulcers
- shortness of breath
- persistent headaches
- hair loss

A combination of one or more of these symptoms may signal the onset of a flare-up. This may be the time to visit your doctor for a check-up. Stress, over-tiredness and infections are known trigger factors for disease flare-up.

A brighter future

The treatment and outlook for people with lupus has improved out of all recognition in the last twenty years. Indeed it is as well to avoid any literature on the subject more than ten years old as it will probably be misleading.

Research into SLE continues and the disease is gradually being better understood. Treatments will continue to improve and possibly a cure may be found. Maintaining a positive outlook and living one day at a time are sound strategies for coping with lupus.

Where can I find further information?

Lupus UK	Lupus UK is a self-help organisation for people with lupus. This website is excellent, with lots of information, although it doesn't seem to be the official Lupus UK site but is run by one of their members. Has support groups and contacts throughout the UK. Lupus UK, St James's House, Eastern Road, Romford, Essex RM1 3NH. Tel: 01708 731251.
Lupus	Difficult to get into but has lots of top-quality information, with particularly good coverage of 'Hughes Syndrome' (anti-cardiolipin syndrome). Not surprising as it comes from a patient of Prof Hughes at St Thomas' Hospital, London
Arthritis Care	The information on this page comes from a leaflet published by Arthritis Care, with permission. Arthritis Care provides support and information about arthritis and lupus. 18 Stephenson Way, London NW1 2HD. Tel: 020 7380 6500.
Lupus.com	The list of contacts to other SLE-related sites is good. Many of these are by patients themselves and can be interesting
Hamline lupus info	This site is rather a mixed bag of information, but has good links to other sites.
Hairline International	Offers support to people who have experienced sudden hair loss. Hairline International, 39 St Johns Close, Knowle, West Midlands B33 ONN. (A4 SAE appreciated.) Tel: 01564 775281 (ansaphone).

The following books are useful:

- **Lupus: A Guide for Patients** by Graham R V Hughes, £3 including postage; available from Lupus UK, St. James House, Eastern Road, Romford, Essex, RM1 3NH.
- **The Lupus Book** by Daniel J Wallace, £13.50, published by Oxford

University Press 1995

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