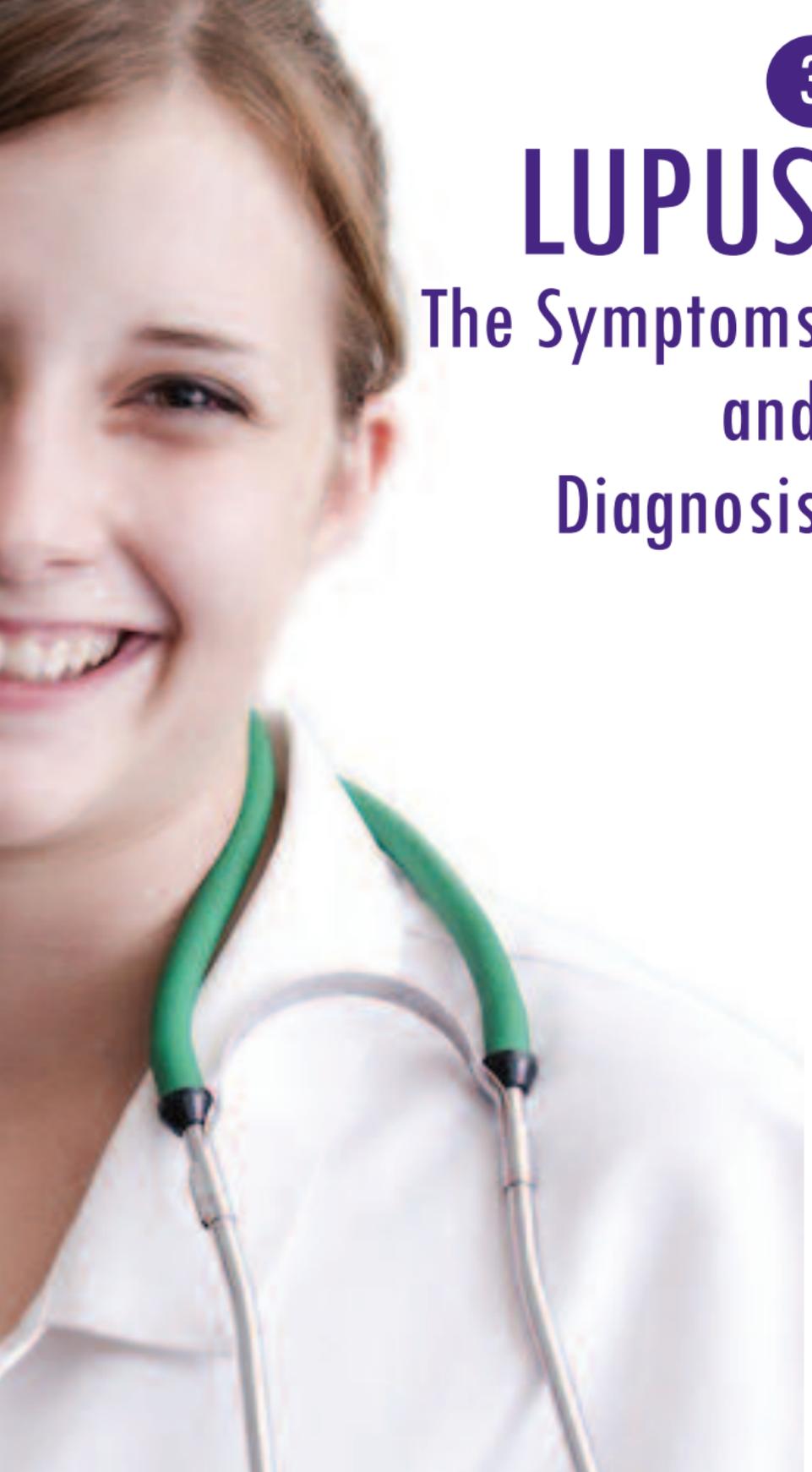


# LUPUS

## The Symptoms and Diagnosis



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## The Symptoms and Diagnosis

This factsheet gives a brief guide to the symptoms and diagnosis of lupus. Further information on some of the specific symptoms of lupus can be found in the LUPUS UK range of factsheets detailed on the outside back cover of this factsheet.



### General symptoms

People with lupus have symptoms that can range from mild to severe, and may come and go over time. Some of the most common symptoms include:

- \* Severe tiredness (fatigue)
- \* Weight loss
- \* Fevers
- \* Skin changes (including a red 'butterfly' rash across the cheeks and nose or other sun exposed areas and scaly rashes that can appear on areas not exposed to sunlight)
- \* Painful, stiff or swollen joints (arthritis)
- \* Poor circulation in the fingers and toes which causes them to become pale (Raynaud's)
- \* Hair loss
- \* Headaches
- \* Mouth/nasal ulcers
- \* Depression



### Fatigue

Almost 90% of lupus patients experience fatigue, making it one of the most common symptoms. Often it precedes the diagnosis by months or years and only when treatment has been successfully started does the patient realise how major a feature it had been. Symptoms may vary from severe, to fleeting or persistent and can form a vicious circle; if you are tired, you don't feel like exercising and if you don't exercise then often you become tired and lethargic. This can have a significant effect on quality of life and work.

There are currently no recommended drug treatments for fatigue, however there is some evidence that exercise is beneficial. It is important to maintain a correct balance between exercise and rest - exercise and rest intermittently as the body allows. Your body will tell you when it is time to rest. By increasing stamina you allow your body to gain more strength and muscle tone. Rest is important as it is needed to restore energy. Some people with lupus also try self-management techniques such as mindfulness meditation (learn more at [www.nhs.uk/Conditions/stress-anxiety-depression/pages/mindfulness.aspx](http://www.nhs.uk/Conditions/stress-anxiety-depression/pages/mindfulness.aspx)) and pacing to combat fatigue.



## Aches and pains

Joint and muscle pain will affect most people at some point during their illness. Unlike other rheumatic diseases such as rheumatoid arthritis, there is often very little to see in the way of joint swelling. It is not just the joints that are affected but the tendons and muscles as well. In the majority of cases, the joint inflammation does not progress to permanent damage.



## Fevers

Fever is usually a feature of a flare of the disease. Fever is unusual when the disease is in a quiet phase; thus in an adult or a child known to have lupus who develops fever, the possibility that a separate diagnosis - infection - might be present always needs consideration.



## Rashes

A wide variety of skin rashes occur in lupus. Traditionally these are sun-sensitive (photosensitive); perhaps 60% of lupus patients get sun-induced rashes, but this is not always the case. The most common rashes are malar rashes over the cheeks (butterfly rash) and discoid rash (red, sometimes circular, patches of skin with scaling). The rashes vary from pinkish discolouration through to blisters and small pinpoint “blood spots” (purpura). Most rashes in lupus have a tendency to come and go.



## Headaches

Headaches are common in lupus. In some patients a history of headache going back to their early teens is a feature of the disease. They may be part of the lupus itself or may be associated with a clotting (antiphospholipid) syndrome (see factsheet ‘Lupus and Associated Conditions’ for more information). They may or may not have a migrainous element with flashing lights and visual disturbances. In any patient with lupus who suffers from headaches a systematic search for known causes should be carried out including blood pressure checking and, very importantly, an examination of the blood for antiphospholipid antibodies (‘sticky blood’) and ultimately, if indicated, a brain scan.



## Depression/Anxiety

Depression is an important manifestation of lupus – in some it is the presenting sign of the disease. Depression is an integral part of lupus in some patients - indeed management of the lupus often itself lifts the depression. Although depression can arise in response to having a chronic painful illness, it is important for patients and doctors to recognise that lupus itself can cause depression, which can be quite severe. (For more information see ‘Lupus and Depression’ leaflet available from LUPUS UK).

Mild forms of psychiatric disturbances are relatively common in lupus, including anxiety attacks. Lupus doctors are now beginning to realise how common and important this aspect of the disease is. Clearly, any patient who feels that this is a major feature of the disease requires full neurologic examination, possibly including MRI, as well as testing for antiphospholipid syndrome.



## Diagnosis

In order for a physician to reach a diagnosis of lupus three essential steps are required:

- 1) A detailed overview of the patient's symptoms and past medical history
- 2) A detailed physical examination, which includes testing the urine
- 3) Tests - mostly blood tests but this may also involve other tests such as biopsy of the affected organs (eg kidney or skin)

SLE can 'mimic' other conditions. For example, if a patient has a fever associated with lupus, physicians will want to ensure this is not due to an infection. It is often necessary to undertake tests to rule out other conditions before a diagnosis of lupus can be made with confidence.



## Recommended tests for diagnosis and monitoring include:

**Positive anti-nuclear antibody (ANA)** - This test detects a group of antibodies directed against components of the nucleus of the cell, such as DNA and ribonucleoproteins (RNP). The individual antibodies include anti-DNA antibodies and the various anti-ENA antibodies (see overleaf). The ANA test is used as a screening test for these auto-antibodies which may then be identified individually by other tests. The ANA test is positive in 95-98% of people with lupus but only about 10% of healthy people. It can also be positive in people with related autoimmune conditions (sometimes called connective tissue diseases) such as dermatomyositis, polymyositis, and systemic sclerosis (scleroderma). It is sometimes positive in people with other types of disease such as chronic infection or certain malignancies (cancers). It is therefore not diagnostic of lupus, but it is important supporting evidence when other features (symptoms, signs and other laboratory tests) suggest lupus.

**Raised double-stranded DNA (dsDNA)** - This is the highly specific test for lupus. For some unknown reason the presence of antibodies against double-stranded DNA is the

hallmark of lupus. It is very specific for this disease and rarely found in any other condition. Strongly positive anti-DNA antibody tests provide almost total proof of the diagnosis. The level of titre of the antibodies provides a rough guide to disease activity and is used by physicians to monitor the ups-and-downs of the disease.

The **Extractable nuclear antigen (ENA)** panel tests for a range of other autoantibodies such as Sm, Ro, RNP and La. These may be found in lupus variants such as 'Sjögren's syndrome' and 'mixed connective tissue disease (MCTD)'.

### **Full Blood Count (FBC), Complement (C3 and C4) and Blood Chemistry Tests.**

Inflammatory markers such as C reactive protein (CRP) and Erythrocyte Sedimentation Rate (ESR).

A very low CRP in an otherwise inflammatory situation (elevated ESR) is strongly supportive of lupus.

### **Urine testing:**

Urine dipstick at diagnosis and clinic visits to check for blood and protein.

Urine albumin creatinine ratio if protein is present in the urine sample to evaluate kidney involvement.

### **Other:**

Skin biopsy of a rash or a kidney biopsy if the doctor is concerned that these organs may be affected by the lupus. Chest X-ray and ECG (Electrocardiogram).

Blood pressure.

Echocardiogram, Brain Scan, Lung Functions Tests, Abdominal CT Scan.



## **Who looks after a patient with lupus?**

Many different doctors can be involved in looking after people with lupus but rheumatologists (arthritis specialists) and nephrologists (kidney doctors) are most often involved. Since lupus is a complicated condition, it is usually a good idea for you to see doctors who specialise in treating the disease. Your GP will also make an important contribution to looking after your lupus and your general health. You may see a specialist lupus nurse as well.



## **Who gets lupus?**

Lupus affects women six to nine times as often as men, usually occurring in women in the childbearing years. It can, however, occur in children or post-menopause. People of Afro-Caribbean, Asian and Eastern ethnicity are more likely to develop lupus.

# The LUPUS UK Range of Factsheets

A range of factsheets is 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
19. LUPUS Bone Health and Osteoporosis

LUPUS UK is the registered national charity caring for people with lupus and has over 5,000 members who are supported by the Regional Groups.

This factsheet has been prepared using LUPUS UK factsheets already certified by the Information Standard. Should you require further information about the sources used in the production of this factsheet please contact National Office.

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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.

LUPUS UK is certified under the requirements of the Information Standard.



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