

# Lupus

Lupus is the short name for the condition called systemic lupus erythematosus (SLE). It can cause various symptoms, the most common being joint pains, skin rashes and tiredness. Problems with kidneys and other organs can occur in severe cases. Lupus is an autoimmune condition. Treatment includes anti-inflammatory painkillers to ease joint pains. An antimalarial, called hydroxychloroquine, can help to prevent flares. Steroids and/or other medication to control the immune system are sometimes also needed.

## What is lupus?

Lupus is a persistent (chronic) disease that causes inflammation in various parts of the body. The severity of lupus ranges from mild to severe. There are two main types of lupus. Discoid lupus only affects the skin and is not discussed in this leaflet. The other form is systemic lupus, which involves the skin and joints and may involve internal organs such as the heart or kidney as well.

## Lupus symptoms

Lupus can cause symptoms in any of the many parts of the body it affects. You can find out more detail later in this leaflet. The most common symptoms include:

- A red rash over the nose and cheeks.
- Mouth ulcers.
- Tiredness due to anaemia (reduced number of red blood cells).
- Swollen glands (lymph nodes).
- Hair loss or thinning.
- Depression and anxiety.
- Chest pain.
- Joint pain.
- Headaches.

## Who can get lupus?

Lupus affects about 1 in 1,000 people in the UK. It is about six times more common in women than in men. It most typically develops in women between the ages of 15 and 49. However, anyone at any age can be affected. It is more common in people of Afro-Caribbean, Asian, or Chinese descent.

## Is lupus hereditary?

Lupus does tend to run in families. People who have a parent or sibling with lupus are more likely to get it too. However, this risk is still low. Even in identical twins, if one twin has lupus the other only has a 1 in 4 chance of developing it too. So although there is some hereditary factor, clearly other factors are involved in whether a person develops the condition or not.

## What causes lupus?

Lupus is an autoimmune disease. This means that the immune system (which normally protects the body from infections) mistakenly attacks healthy cells. This can cause symptoms and may damage the affected parts of the body.

It is not known why lupus occurs. Possible triggers of lupus include infections, smoking, or sunlight. Hormonal changes may play a role in lupus, which could explain why it is much more common in women.

Drug-induced lupus is a condition where lupus-like symptoms develop as a reaction to certain medications (such as minocycline or hydralazine). Drug-induced lupus tends to be milder than other forms of lupus, and usually goes away after the drug is stopped.

## Symptoms of lupus in detail

The symptoms and severity of lupus vary tremendously between people. Many people have tiredness (fatigue), weight loss and a mild raised temperature (fever). In addition, one or more of the following may develop.

### Joint and muscle pains

Most people with lupus develop some joint and muscle pains. Sometimes only a few joints are affected, whereas other people have many joints affected. The small joints of the hands and feet tend to be the ones affected most. The pains may 'flit' from joint to joint. Joint stiffness is common and is usually worse first thing in the morning. Mild joint swelling may occur but severe arthritis with joint damage is unusual.

### Lupus rash and skin changes

## The butterfly rash of lupus



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A red rash which develops over the cheeks and nose is common (the 'butterfly rash'). Other areas of skin exposed to sunlight (hands, wrists, etc) may also develop a rash. About 6 in 10 people with lupus find that their skin is very sensitive to sunlight (called 'photosensitivity'). Various other rashes may develop. The blood vessels just under the skin may also be affected and cause poor circulation to the fingers and toes (Raynaud's phenomenon).

## Mouth ulcers

Mouth ulcers are more common in people with lupus.

## Lupus and hair loss

Some hair may fall out (alopecia). Any hair loss tends to be minor and cause hair 'thinning' rather than bald patches. However, quite serious hair loss sometimes develops, although the hair often grows back when lupus is less active.

## Blood and lymph

A mild anaemia is common. Other blood problems, such as reduced numbers of white blood cells or platelets (the cells that help with blood clotting), are less common. A tendency to form blood clots is an uncommon complication. Some lymph glands may swell.

## Heart and lungs

The tissues that cover the heart and lung (the pleura and pericardium) may become inflamed. This can cause pains in the side of the chest (pleurisy) or central chest pains (pericarditis). The actual heart or lung tissue is less commonly affected.

## Kidneys

Around 1 in 3 people with lupus may develop inflammation of the kidneys, which can lead to the kidneys leaking protein and blood into the urine. This does not usually cause problems unless the disease is very severe. Chronic kidney disease is an uncommon complication.

## Brain and nervous system

Mental health problems in lupus are fairly common and include depression and anxiety. Although mild depression can be part of the disease itself, it can also be due to your reaction to having a serious illness.

It is not uncommon for people to have difficulties in coping with having lupus. It is important to share any feelings you have with your doctor, as treatment can be really beneficial. Occasionally, inflammation of the brain can lead to epilepsy, headaches, migraines and other conditions.

## How lupus affects the body

In some cases, the symptoms develop quite slowly. At first they may be confused with other problems, as there are many possible causes of joint pains and tiredness. Sometimes several symptoms occur together. Symptoms range from mild to severe. For example:

**Mild lupus.** People with mild lupus have mainly joint and/or skin symptoms. These are unpleasant symptoms but are not serious or life-threatening. There may be any combination of the following:

- Joint pains
- Muscle pains
- Skin symptoms
- Tiredness
- Mild hair loss

**Moderate lupus.** This includes some inflammation of other parts of the body apart from joints and skin. This may include:

- Inflammation of the lungs - pleurisy.
- Inflammation of the heart - pericarditis.
- Inflammation of the liver - hepatitis.
- Inflammation of the joints - arthritis.
- Mild kidney inflammation.
- Inflammation of the scalp with hair loss.

**Severe lupus.** In some cases, severe inflammation develops which can cause damage to organs such as the heart, lung, brain or kidneys. This can even be life-threatening.

Typically, there are times when the disease flares up (relapses) and symptoms become worse for a few weeks, sometimes longer. These relapses tend to alternate with times when symptoms settle down (remission). The reason why symptoms flare up or settle down is not yet fully understood.

## How is lupus diagnosed?

Lupus is often a difficult condition to diagnose, as the symptoms can be very similar to many other conditions.

If your symptoms suggest lupus then your doctor will usually do some blood tests. Most people with lupus have an antibody called antinuclear antibody (ANA) in their blood. (Antibodies are small proteins that are part of the immune system.) Another antibody called anti-double-stranded DNA (anti-dsDNA) is often present in people with lupus.

Various other antibodies are also associated with lupus. However, these antibodies can also be found in perfectly well people who do not have lupus, so the results must be considered in the context of your symptoms, and how likely

lupus is otherwise. Typical symptoms combined with high levels of certain antibodies usually indicate that you have developed lupus.

People with suspected lupus should be referred to see a rheumatologist (a specialist who deals in certain autoimmune problems, particularly ones causing joint problems). Rheumatologists use their expertise, alongside your symptoms, signs, and test results, to make the final diagnosis of lupus.

Once lupus is diagnosed, you will normally be advised to have regular checks and tests. For example, regular blood tests to check for anaemia, and urine tests to check for kidney problems. A blood test to measure a blood chemical called 'complement' (another part of the immune system) can assess the activity of the disease. The level of this chemical reflects how 'active' the disease is.

Other tests including scans and X-rays may be advised to check on the function of the heart, kidneys and other organs if the disease is thought to be affecting these areas of the body.

## Lupus treatment

Although there is no cure for lupus, this condition can usually be controlled and symptoms eased. Most people with lupus are seen regularly by a specialist who advises on treatment. The treatments may vary from time to time, depending on the severity of the disease or flare-up of symptoms and also which parts of the body are affected. Treatment options include the following:

- Non-steroidal anti-inflammatory drugs (NSAIDs), which can help with muscle and joint pain.
- Hydroxychloroquine for skin problems, tiredness and joint pains.
- Steroid tablets to reduce inflammation if symptoms are severe.
- Immunosuppressants which work by damping down the immune system. These include azathioprine, ciclosporin, cyclophosphamide, methotrexate and mycophenolate mofetil, and biological medicines.

## What is the outlook (prognosis) for people with lupus?

Lupus is a long-term disease. However, most people with lupus lead active, normal lives. The outlook for people with lupus is much better than it was in the past. Modern treatments are more effective. For many people with lupus,

symptoms are mild or moderate with little risk to life. The joint and skin symptoms may continue, but can usually be eased with treatment.

For a few people, lupus is severe and can be life-threatening. Severe inflammation of the kidneys, leading to kidney damage, can (rarely) occur. Severe brain involvement is also rare but can be very serious.

However, modern immunosuppressive treatments have improved the outlook, even for people with severe disease. Some people find that symptoms settle in their middle age and that they can, on advice from their specialist, reduce or stop some of their medications.

## Lupus and pregnancy

Although fertility is not usually affected in people with lupus, some women with lupus have a higher chance of miscarriage. Women who have badly inflamed kidneys, due to lupus, may have high blood pressure in pregnancy. Most women with mild or well-controlled lupus at the start of pregnancy are likely to go through pregnancy with few problems. Women with very severe lupus might be advised against becoming pregnant, but this is rare.

Some medicines used to control lupus can cause serious harm to the fetus. If you are considering becoming pregnant, and you have lupus, plan ahead and see your specialist to discuss this; different medicines that are safe in pregnancy can be used. Extra blood tests can also be done prior to pregnancy to help give you an idea of how likely there are to be complications or problems due to lupus.

Some contraceptive pills may not be advised depending on disease severity. A doctor or nurse will advise on the best method of contraception.

## Living with lupus: tips

**Avoid the sun.** Strong sunlight can aggravate symptoms of lupus. Long-sleeved clothing and wide-brimmed hats are best in sunny weather. On hot sunny days you should wear a sunblock on exposed skin, with a protection factor of 25 or above that protects against UVA and UVB.

**Avoid, or stop, smoking.** Smoking makes lupus worse.

**Try to avoid infections.** If you have lupus you are more prone to infection, particularly if you take steroids or immunosuppressant medication. Avoid contact with people who have infections.

**Other autoimmune diseases** such as Sjögren's syndrome and thyroid problems are more common than average if you have lupus. These are sometimes tested for in people with lupus.