

# Patient information from BMJ

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## Systemic lupus erythematosus

Systemic lupus erythematosus (usually just called lupus) is a long-term condition that can affect many parts of the body. Most commonly, it causes joint pain, skin rashes, and fatigue (tiredness).

There is no cure for lupus, but treatments can help to relieve the symptoms.

Complications from lupus can sometimes lead to early death. But better treatments are making this much less common than it used to be. You can use our information to talk with your doctor about the best treatments for you.

### What is systemic lupus erythematosus?

Systemic lupus erythematosus (usually just called **lupus** or **SLE**) is what's called an autoimmune condition.

This means that the body's immune system, which usually helps protect us against infections, starts to attack some of the body's tissues.

If you have lupus, your immune system can cause inflammation (swelling) in some of your tissues and organs, including:

- the heart
- the lungs
- the kidneys, and
- the brain.

Without treatment, this swelling can cause serious problems. Even with treatment, some people with lupus will die early because of the condition.

This is because lupus and some of its treatments can lead to problems such as heart disease and kidney disease.

### Who gets lupus?

People of any age or sex can get lupus. But it's most commonly diagnosed in **women of childbearing age**. This means the time between starting puberty and the menopause.

# Systemic lupus erythematosus

Lupus is also more common in people with **African or Hispanic ancestry** rather than white Northern European ancestry, and in **people who smoke**.

Lupus can be caused by several things, including:

- your **genes**. About 40 in 100 people who have a parent with lupus will get also develop it
- an **infection**. Some infections seem to make your immune system over-react, which can cause lupus
- some **medications**. Drugs that can sometimes cause lupus include some antibiotics, antifungals, and drugs for treating arthritis and seizures.

## What are the symptoms?

Lupus can have many symptoms, because it can affect many parts of the body, including the skin, the nervous system, the digestive system, and the joints. The most common symptoms can include:

- skin rashes. These are often on the face, and can sometimes be caused by sun exposure
- fatigue
- weight loss
- fever
- mouth ulcers
- hair loss
- joint pain
- Raynaud phenomenon, which causes color changes, numbness, and pain in the fingers and toes in cold weather, and
- stomach problems, including pain, vomiting, or diarrhea.

If your doctor thinks that you might have lupus, they will probably want to do some tests. These will probably include **blood and urine tests**, and possibly an x-ray or other type of **scan**.

These tests might not be able to tell for sure if you have lupus. But they can often find or rule out other things that might be causing your symptoms.

## What treatments are available?

The aims of treatments for lupus are to:

- improve your quality of life as much as possible
- keep you as healthy as possible, to reduce your chance of dying early. Most people with lupus don't die because of it
- prevent damage to your organs and body tissues, and

# Systemic lupus erythematosus

- reduce the chance of side effects from treatments.

## Learning about lupus

One of the most important things you can do is to learn as much as you can about lupus. This helps you to play a major part in managing your condition and your treatments.

Your doctor should be able to direct you to good information about lupus. Lupus is complex and there's a lot to learn. But you can take it in at your own pace.

## Nondrug treatments

Drug treatments are important for people with lupus. But there are several important things that you can do for yourself that don't involve medications.

## Sun protection

Sun exposure can make lupus worse. In sunny weather, people with lupus should:

- stay out of the sun as much as possible
- wear protective clothing, such as long-sleeved tops, long trousers or skirts, and hats, and
- use good-quality sunscreen.

## Diet

There is no special diet recommended for people with lupus. But there are a few things to bear in mind. For example, people with lupus are advised to:

- eat a generally healthy diet including plenty of fresh fruit and vegetables
- avoid too much salt if you have high blood pressure
- try to keep to a healthy weight
- take vitamin D supplements. This is because people with lupus are advised to stay out of the sun (sunlight is how we usually get most of our vitamin D). Your doctor can advise you about vitamin D supplements, and
- avoid herbal remedies. These can interact with medications, which can cause harm.

## Exercise

It's hard to think about exercise when you feel tired much of the time. But it's important to do what you can, in order to stay as healthy as possible, both physically and mentally.

You can talk with your doctor about what you feel capable of doing. Most people find it much easier to exercise when doing something they enjoy. But you should always stop exercising if you feel uncomfortable or in pain.

## Mental health

It's not surprising that some people with lupus find that it can make them feel low.

# Systemic lupus erythematosus

Of course, support from family, friends, and online communities can make a huge difference. But many people find that **talking treatments** help with feelings of depression, as well as with fatigue and even pain.

Your doctor might be able to help you access help such as cognitive behavioral therapy (CBT) and psychotherapy, if you feel that they might help.

## Smoking

Smoking seems to make lupus worse. It also interferes with how some of the drug treatments work. So it's a good idea to quit smoking if you have lupus. Your doctor is a good place to start if you need help to quit.

## Medications for lupus

Several types of drug are useful for treating lupus. For example, some drugs treat the symptoms, such as pain and rashes, while others help to calm down the immune system to stop it attacking your joints and organs.

### Medications for pain and inflammation

The main drugs used to treat joint pain and swelling are **non-steroidal anti-inflammatory drugs (NSAIDs)** for short). You might have heard of some of these, such as ibuprofen and naproxen.

These drugs can cause stomach problems. So if you need to take them for a long time your doctor should prescribe something to protect your stomach.

At times, some people need stronger anti-inflammatory drugs called **corticosteroids** (usually just called steroids). These drugs can be very helpful, but when used for long periods they cause serious **side effects**. These can include:

- diabetes
- thinning of the skin
- weakened bones, and
- mood changes.

So your doctor will want to prescribe steroids at the lowest possible dose for the shortest possible time. They should also discuss the possible side effects with you.

### Medications for calming the immune system

Some drugs help to calm the immune system so that it can't attack the body. These are called **immunosuppressants**.

But of course the immune system is vital in keeping us healthy. So doctors usually only recommend these drugs for people with severe lupus, or when other treatments haven't worked.

# Systemic lupus erythematosus

If your doctor suggests that you need this type of medication, they should talk to you about extra things you might need to do to stay healthy while taking them.

## Biological medications

Biological drugs are fairly new. They are based on the body's own tissues, so that they should act in a more natural way.

The biological drugs used to treat lupus target specific parts of the immune system that cause lupus symptoms.

Like immunosuppressants, these drugs tend to be used in people who don't do well with other treatments.

## Treatments to help with symptoms

Many of the drug treatments mentioned above are aimed at controlling lupus. But there are treatments that help with individual symptoms.

Some of the drugs mentioned above help with this, too. For example, NSAIDs and steroids can help with **joint pain and stiffness**.

Treatments for other symptoms include:

- mouthwashes and creams to help with **mouth ulcers**
- artificial saliva for a **dry mouth**
- eye drops for **dry eyes**, and
- creams to treat **rashes**.

You can talk to your doctor about these and any other symptoms you might have. They might be able to prescribe something that will help.

## What to expect in the future

Lupus can cause serious complications, such as heart problems. And some of the treatments that help can also cause problems. So your doctor will want to monitor you and your treatment regularly.

For example, you might need to have **regular blood tests**, and have checks for any side effects of treatments.

While it's true that some people die from complications of lupus, good treatments have made this far less common than it used to be. Most people with lupus live largely normal lives.

More than 90 in 100 people with lupus are still alive 10 years after they are diagnosed.

Note: this doesn't mean that people aren't expected to live longer than 10 years with lupus: it's just that it's hard to do follow-up studies for longer than 10 years.

## Lupus and pregnancy

Having lupus while pregnant makes miscarriage more likely, but you can still become pregnant and have children if you have lupus. About two-thirds of women with lupus have a normal pregnancy.

Even so, if you have lupus and become pregnant, you should be managed by a specialist obstetric (pregnancy) team.

If you become pregnant or are planning to, you can talk to your doctor about:

- what special treatment and monitoring you will have during your pregnancy
- what you need to know about lupus and pregnancy, and
- what lupus medications are safe to take while pregnant.

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