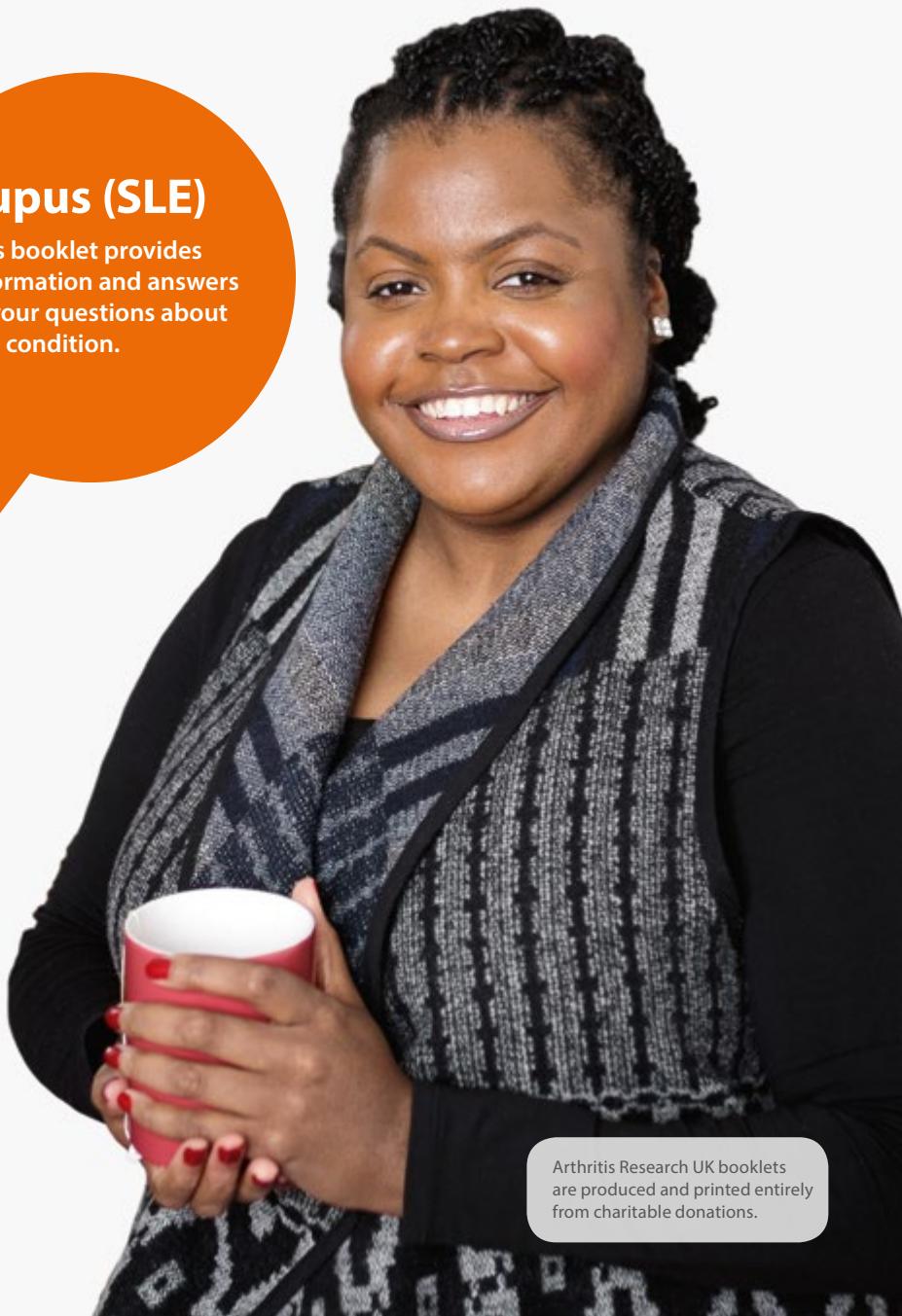


## Lupus (SLE)

This booklet provides information and answers to your questions about this condition.



Arthritis Research UK booklets are produced and printed entirely from charitable donations.

# What is lupus (SLE)?



Lupus is an autoimmune disease. There are two main types, but here we'll focus on systemic lupus erythematosus (SLE). We'll explain the symptoms and causes of lupus and how it's treated. We'll also look at what you can do to help manage your condition and suggest where you can find out more.

At the back of this booklet you'll find a brief glossary of medical words – we've underlined these when they're first used.

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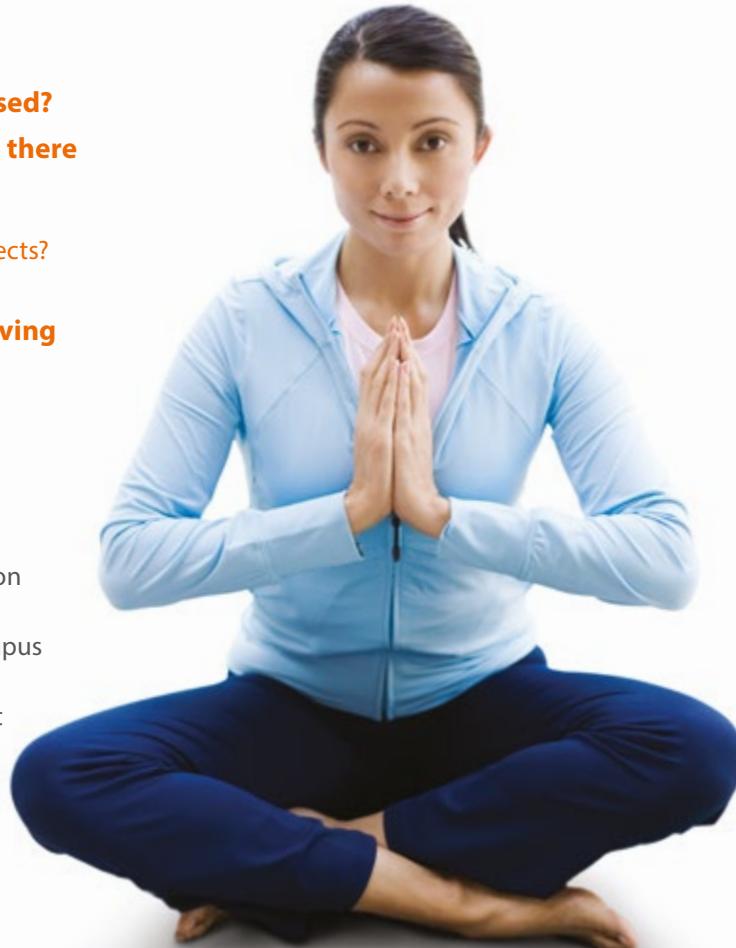
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# At a glance

## Lupus

There are two main forms of lupus.

These are:

- **discoid lupus**, which only affects the skin
- **systemic lupus erythematosus (SLE)**, which affects the skin and joints and often also involves the internal organs, including the heart or kidney.

This booklet only deals with SLE.

Lupus occurs when the immune system attacks the body's own tissues. It can cause inflammation in many different parts of the body, though most people will only have a few of the possible symptoms.

**Lupus is usually very treatable and typically responds well to a number of different types of drugs.**

- colour changes in the fingers or toes in cold conditions
- shortness of breath, or pain when breathing in.

Lupus can have more serious complications if the inflammation affects internal organs such as your heart, lungs, brain or kidneys. You will need regular check-ups with your doctor for early signs of these complications.

### What are the symptoms of lupus?

#### Possible symptoms of lupus include:

- joint pain
- a skin rash
- extreme tiredness (fatigue)
- fever
- weight loss
- headaches
- mouth ulcers
- hair loss
- swelling of lymph glands

### How is it diagnosed?

Some of the symptoms of lupus are the same as other, more common conditions, so you'll probably have a number of tests before the diagnosis is confirmed.

## ● What treatments are there?

Lupus can be treated with a combination of drugs, which will vary depending on your particular symptoms.

What treatment you require will also depend on whether your organs are involved and if so, the extent and severity of their involvement.

### Drugs may include:

- non-steroidal anti-inflammatory drugs (NSAIDs)
- steroid tablets, creams or injections
- conventional disease-modifying anti-rheumatic drugs (DMARDs)
- drugs to control high blood pressure and high cholesterol
- biological therapies.

## ● How can I help myself?

### You can help yourself by:

- not smoking
- protecting your skin from strong sunlight
- dressing to keep your hands and feet warm in cold weather
- resting when your disease is most active but otherwise taking regular exercise
- pacing yourself and planning your activities
- eating a healthy diet low in saturated fats.



## What is lupus?

Lupus is an autoimmune disease, which means that the immune system, your body's defence system, produces antibodies that attack the body's own tissues, causing inflammation. There are two main types of lupus:

- discoid lupus
- systemic lupus erythematosus (SLE).

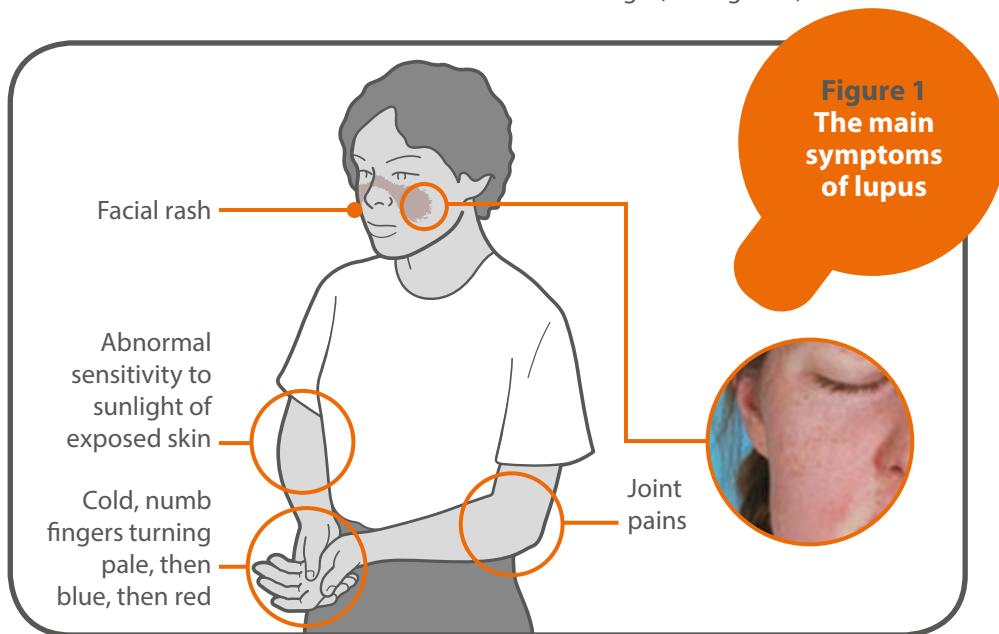
In this booklet, we'll focus on SLE, which is often just known as lupus.

## What are the symptoms of lupus?

Joint pains, skin rashes and extreme tiredness (fatigue) are the most common symptoms of lupus. Some people with lupus will only have these symptoms, though they can still have a big impact on your daily life. Fever, weight loss and swelling of the lymph glands are also quite common.

Lupus can affect many different parts of the body, and when internal organs such as the heart, lungs, brain or kidneys are involved it can be much more serious. But most people will only have one or a few of the possible symptoms, and many people will find that the symptoms come and go (see Figure 1).

Figure 1  
The main symptoms of lupus



#### Skin and mouth

It's common for a rash to develop over parts of the body that are exposed to the sun, including the face, wrists and hands. A butterfly-shaped rash over the cheeks and the bridge of the nose is especially common.

Some people with lupus notice that their fingers change colour in cold weather, going first very pale, then blue and finally red. This is called Raynaud's phenomenon and is caused by narrowing (constriction) of the blood vessels, which reduces the blood supply to the fingers or toes.

You may develop groups of mouth ulcers, which may come back repeatedly.

#### **i** See Arthritis Research UK booklets *Raynaud's phenomenon.*

#### Hair

Some hair loss is common and can be severe in some people with lupus, but once a flare-up is brought under control the hair will usually grow back.

#### Joints

Joint pain is common in lupus, especially in the small joints of the hands and feet. The pain tends to move from joint to joint and is often described as 'flitting'. Joint pain and swelling can be the main symptoms for some people, though lupus doesn't usually cause joints to become permanently damaged or deformed. About 1 in 20 people with lupus develop more severe joint problems. Fewer than 1 in 20 have joint hypermobility or a form

**A butterfly-shaped rash over the cheeks and the bridge of the nose is especially common.**

of arthritis called Jaccoud's arthropathy, which can change the shape of the joints.

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#### **i** See Arthritis Research UK booklet *Joint hypermobility.*

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#### Kidneys

Around 1 in 3 people with lupus have significant inflammation of the kidneys, and kidney damage can sometimes occur. Kidney inflammation can be treated successfully in most patients if it's identified early with regular urine, blood pressure and blood testing by your doctor. You must take any medication as prescribed by your doctor to make sure that your kidneys aren't permanently damaged.

#### Blood and blood vessels

Lupus can cause high blood pressure, particularly if the kidneys are involved. Steroid tablets, which are often used to treat lupus, can raise blood pressure particularly when used in high doses. Lupus can contribute to the development of high cholesterol, which should be checked yearly with a blood test and treated if necessary.

**Lupus is more common in younger women. Only about 1 in 15 cases of lupus begins after the age of 50 and it tends to be less severe in people who are over 50.**

**Lupus is about nine times as common in women as in men.**

Lupus may also affect the bone marrow, causing anaemia and a reduction in the number of platelets (cells that help the blood to clot) and/or white blood cells. Blood-related problems like anaemia tend to be more common in children with lupus.

Some people with lupus are more at risk of developing blood clots in veins or arteries. This problem is usually caused by antiphospholipid antibodies. Some of these autoantibodies can also affect pregnancy, causing an increased risk of miscarriage (antiphospholipid syndrome).

#### **i See Arthritis Research UK booklet**

*Antiphospholipid syndrome (APS).*

## Brain and nervous system

As many as 1 in 3 people with lupus may have migraines and may experience anxiety or depression. Some people have dizziness, memory loss or confusion. Rarely, lupus can cause fits (similar to epilepsy) or feelings of paranoia (similar to schizophrenia) – though these complications only affect a small number of people with lupus.

## Heart and lungs

Occasionally lupus directly affects the heart and lungs. More often, it causes inflammation in the lining tissues around the heart (pericarditis) and lungs (pleurisy), both of which cause breathlessness and sharp pains in the chest. Rarely, large amounts of fluid develop in these lining layers, causing severe breathlessness.

More recently, we've found that lupus may also cause narrowing of the blood vessels. This can lead to an increased risk of angina, heart attacks and strokes, so close monitoring and early treatment of factors such as high cholesterol and high blood pressure are vital.

## Other organs

People with lupus can suffer swelling of the lymph glands, which may cause discomfort.

Less frequently, lupus can affect the lining tissue of the gut (serositis), the gut, pancreas, liver or spleen, causing pain in the abdomen. Very rarely, lupus can affect the eyes, causing a painful red eye or changes in eyesight.

About one third of people with lupus develop an additional autoimmune disease. Examples include autoimmune thyroid disease, in particular the type which makes the thyroid gland underactive. Severe dryness of the eyes and mouth (Sjögren's syndrome) occurs in about 10% of people with lupus, and rheumatoid arthritis or inflammation of the muscles (myositis) can develop, but these are much less common.

#### **i See Arthritis Research UK booklet**

*Rheumatoid arthritis;  
Sjögren's syndrome.*



# Monique's story

**Monique was visiting family in the Caribbean, and she should have been having the time of her life. Despite being 25 and on holiday on a beautiful island, Monique wasn't enjoying herself. She was depressed, had lost her appetite and her energy levels were low.**

**Her family took her to a hospital to have tests, but nothing was discovered.**

One day later that holiday while Monique and her family were at the cinema, she became very unwell.

Monique said: 'When the movie was finished, I couldn't put my feet on the ground, I was in excruciating pain. It was like pins and needles multiplied by 1,000 times. I had to be carried out of the cinema. It was scary.'

Back in London, Monique went to a hospital for tests, which led to a diagnosis of lupus.

'I remember thinking, 'how can I get this? I'm young, fit and healthy'. It was a big adjustment for me and my family.'

Monique has had some tough times since her diagnosis nine years ago, particularly when she developed lupus nephritis, an inflammation of the kidneys that can affect people with lupus. It's potentially a serious problem and Monique had chemotherapy to treat it.

'Kidney involvement can happen quickly,' Monique said. 'Chemotherapy is not something to be taken lightly, but I couldn't consider for too long whether or not I'd have it.'

'It worked for me, but for others it hasn't been so successful.'

Another difficulty for Monique has been the fatigue brought on by her condition. She said: 'I have to plan ahead. I can only really do two to three things a week.'

'Sometimes you don't have to be doing much and you get this overwhelming need to sit or lie down.'

A healthy lifestyle is also important for Monique. She said: 'I try to sleep and eat properly. I've cut out red meat and swapped it for fish, chicken and vegetables. I also drink lots of water.'

While these changes have helped Monique, she has found it tough.

She said: 'I'm changing food habits of a life time, which is not easy, so that in itself can bring on depression as I think about 'my past life' compared to now.'

Monique helps to run the Enfield Lupus Support Group. 'The group has been extremely beneficial to help with depression,' she said.

'I go for coffee with the lupus ladies. There are things we share that really help.'

At the support group, members find talking to others who fully understand to be therapeutic. Meaningful practical and psychological advice is offered and there is real compassion and friendship.

Monique said: 'I don't really take anything for granted now. This condition has really taught me that.'



## Who gets lupus?

Lupus is more common in women of Chinese origin and most common in women of African or Caribbean origin. It tends to be more severe in those of Afro-Caribbean origin. Rarely, lupus can affect children, but it's unusual before the age of five.

## What causes lupus?

The immune system makes proteins called antibodies that fight infection. In lupus, the body also makes autoantibodies that attack the body's tissues. We're not sure why this happens, but it's probably due to environmental, hormonal and genetic factors.

Lupus isn't directly passed on from a parent to their children, but if you have a close relative with lupus you're at increased risk of developing it. Similarly, if you have lupus there's about a 1 in 100 chance of your child developing it in later life. Lupus isn't contagious, so you can't catch it from anyone else.

## What is the outlook?

Modern treatments have improved the outlook for people with lupus. However, it remains a variable and unpredictable condition and may even be life-threatening for people whose vital organs are affected.

! It's hard to predict exactly how lupus will affect you. Most people with lupus don't have the more serious complications, but your doctor and rheumatology nurse specialist will be on the look-out for these so that early treatment can be given if necessary.

Careful monitoring of the condition is needed so that potentially serious complications can be recognised and treated promptly. For example, some people with lupus will have a greater than usual risk of having a heart attack or stroke. Your doctor will take this into account, along with any other risk factors, such as smoking and raised cholesterol or blood pressure. They'll suggest treatments and lifestyle changes.

In young women, the risk of a heart attack or stroke would normally be very low, so although it's increased by having lupus, the overall risk is still low. Even so, it's a good idea to think about and discuss this with your doctor.

## How is lupus diagnosed?

! Many of the common symptoms of lupus can have other causes so your doctor will need to rule out other conditions.

A diagnosis of lupus is made based on symptoms, a physical examination and blood tests. Tests can help to rule out other conditions.

A number of different blood tests may be used:

### **Anti-nuclear antibody (ANA) test**

About 95% of people with lupus are ANA positive, but the test can sometimes be positive in people who don't have lupus, so it can't confirm the diagnosis.

### **Anti-double-stranded DNA (anti-dsDNA) antibody test**

About 70% of people with lupus have these antibodies. A positive test means that lupus is highly likely as the test is hardly ever positive in people who don't have lupus. The anti-dsDNA level usually goes up when lupus is more active so repeat tests may be helpful as a means of monitoring your condition and deciding on treatment.

### **Anti-Ro antibody test**

If you test positive for this autoantibody you may be more likely to get skin rashes and suffer from dry eyes or a dry mouth (Sjögren's syndrome). This autoantibody can pass across the placenta during pregnancy. If you

carry the anti-Ro autoantibody and decide to have a baby, your pregnancy will be more closely monitored.

### **Antiphospholipid antibody test**

A positive test for these autoantibodies may mean an increased risk of miscarriage and developing blood clots.

### **Complement level test**

Complement refers to a set of proteins in the blood that protect us from infections. Complement levels go down when lupus is more active.

### **Erythrocyte sedimentation rate (ESR) test**

This test assesses inflammation by measuring how quickly the blood cells settle at the bottom of a test tube. The ESR is often raised in lupus.

### **Kidney and liver function tests**

These include blood and urine tests, which are carried out regularly so any problems caused by the lupus or by drug treatment can be recognised and dealt with quickly.



A simple urine test can show if there's protein or blood in the urine. This test can help doctors recognise a problem in the kidneys at a very early stage. Further tests, such as kidney filtration tests, may be carried out if necessary. Those with kidney test abnormalities may be asked to have a biopsy which is the most accurate way of finding out how inflamed and damaged the kidneys are.

### **Blood cell counts**

Haemoglobin, white and red blood cells and platelets are all made in the bone marrow, so blood cell counts can help to show whether the bone marrow is affected, either by the disease or the drugs.

These tests can also be helpful in monitoring the condition after diagnosis – for example, a combination of higher levels of anti-dsDNA and falling complement levels (often accompanied by a high ESR test) is helpful in predicting a flare-up of lupus. If the C-reactive protein (CRP), another measure of inflammation, is raised, your doctor would also consider whether you have an infection.

A variety of tests are available to check how your heart, lungs, liver and spleen are working. Depending on which organs your doctor thinks may be involved, you may have x-rays, an ultrasound scan, computerised tomography (CT) scan or magnetic resonance imaging (MRI) scan.

### **Other concerns**

If you have symptoms such as fever, weight loss and persistent swelling of the lymph glands, your doctor may take a biopsy of lymph gland tissue to rule out cancer, which can also cause these symptoms.

## **What treatments are there for lupus?**

There's no cure for lupus at present, but the disease is most often very treatable and usually responds well to a number of different types of drugs – especially when treatment is started in the early stages of the disease.

### **Drugs**

The drugs used to treat lupus will depend on the severity of your disease and which parts of the body are affected. Your treatments will probably be changed or adjusted as your symptoms flare up or improve. Figure 2 shows the main groups of drugs used and how they can help. Most of the drugs described were originally developed for other diseases but were later found to be useful in lupus.

Two newer drugs are now sometimes used for the treatment of severe lupus – rituximab and belimumab. These are biological therapies which act against B-cells – the blood cells which produce antibodies. Research is continuing to find out which patients respond best to these drugs.

**Figure 2 Drugs used to treat lupus and their effects and features**

Treatment	Effects/Features
Non-steroidal anti-inflammatory drugs (NSAIDs) Examples: naproxen, ibuprofen	<ul style="list-style-type: none"><li>reduce inflammation</li><li>help with symptoms in the joints</li><li>often used for short periods</li></ul>
Steroid creams	<ul style="list-style-type: none"><li>useful for skin rashes</li></ul>
Antimalarials Examples: hydroxychloroquine	<ul style="list-style-type: none"><li>reduce inflammation</li><li>used alone or with steroid creams for skin rashes</li><li>also useful as a treatment for fatigue and joint pain</li><li>can help to lower cholesterol and control kidney disease</li></ul>
Steroid tablets (corticosteroids) Examples: prednisolone	<ul style="list-style-type: none"><li>used for short periods for complications such as pleurisy or pericarditis</li><li>may also be used as a longer-term treatment for other problems such as kidney inflammation or severe blood problems</li></ul>
Disease-modifying anti-rheumatic drugs (DMARDs) Examples: azathioprine, cyclosporin, cyclophosphamide, methotrexate, mycophenolate	<ul style="list-style-type: none"><li>used to dampen down the overactive immune system</li><li>may need to be taken for long periods, though the dose may be reduced if the disease becomes less active</li><li>will often control high blood pressure and have the added benefit of helping to prevent kidney problems</li><li>may be used along with steroid tablets to allow steroid dose to be reduced</li></ul>
Biological therapies Examples: rituximab and belimumab	<ul style="list-style-type: none"><li>remove or reduce the activity of B-cells (a type of white blood cell that produces harmful autoantibodies)</li><li>used for patients with lupus when conventional DMARDs aren't effective, though research into their effect is continuing</li></ul>
Steroid injections	<ul style="list-style-type: none"><li>can be injected into a muscle or vein as immediate treatment to help control a flare-up</li><li>can also be injected into the scalp if hair loss is a problem (though often the hair grows back by itself when the disease is brought under control)</li></ul>
Anti-hypertensive drugs	<ul style="list-style-type: none"><li>may be used to control high blood pressure</li></ul>
Treatments for Raynaud's phenomenon Examples: nifedipine tablets, iloprost injections	<ul style="list-style-type: none"><li>may be used to widen the blood vessels to improve circulation</li></ul>

# Make sure you carry an alert card if you're on steroids or biological therapies.

## ! Alert card – Biological Therapy

If you're being prescribed a biological therapy, such as rituximab, it's recommended that you carry a biological therapy alert card, which you can obtain from your doctor or rheumatology nurse specialist. Then if you become unwell, anyone treating you will know that you're on a biological therapy and that you're therefore at risk of its side-effects, including infections.

## ! Alert card – Steroids

When taking steroid tablets you must carry a steroid alert card, which records your dose and how long you've been taking it. If you become ill, or are involved in an accident in which you're injured or become unconscious, it's important for the steroid to be continued and also the dose might need to be increased. This is because the treatment may prevent your body from being able to produce enough natural steroids in response to stress, as normally happens in this situation. Your doctor, rheumatology nurse specialist or pharmacist can give you a steroid card.

## What about side-effects?

All drugs have some potential side-effects, and you and your doctor will need to balance the risk of side-effects with the need to control your symptoms. Sometimes this may mean taking additional medications to protect against the side-effects of others.

NSAIDs can sometimes have side-effects, but your doctor will take precautions to reduce the risk of these – for example, by prescribing the lowest effective dose for the shortest possible period of time.

NSAIDs can cause digestive problems (stomach upsets, indigestion, or damage to the lining of the stomach) so in most cases an additional drug called a proton pump inhibitor (PPI) will be prescribed, which will help to protect the stomach.

NSAIDs carry a small increased risk of heart attack or stroke. Your doctor will be cautious about prescribing NSAIDs, especially for long periods if there are other factors that may increase your overall risk – for example, smoking, circulation problems, high blood pressure, high cholesterol or diabetes.

Treatments such as calcium, vitamin D tablets and drugs called bisphosphonates may be given to guard against osteoporosis if you do need to take steroids at high doses or for long periods. You may be given DMARDs instead of high doses of steroids. These should be avoided, however, if you have lupus in your kidneys as DMARDs can cause further kidney problems.

If you have lupus, and especially if you're on a DMARD or biological therapy, you'll be more prone to infection. Take care to avoid contact with family and friends if they have infectious diseases like chickenpox or if they've recently been in hospital.

Live vaccines aren't recommended if you're on more than 10 mg of prednisolone daily or if you're on certain DMARDs or biological therapies. These vaccines include yellow fever, live typhoid and live oral poliomyelitis (polio). You should take this into account when planning a holiday. Check with your doctor if you think you might need these vaccinations.

Pneumovax (which gives protection against the most common cause of pneumonia) and yearly flu vaccines are well-tolerated and recommended.

#### **i See Arthritis Research UK**

**drug leaflets** *Azathioprine; Ciclosporin; Cyclophosphamide; Hydroxychloroquine; Iloprost; Local steroid injections; Methotrexate; Mycophenolate; Painkillers and NSAIDs; Rituximab; Steroid tablets.*

### Other treatments

If there's a significant build-up of fluid in the lining tissues of the heart or lungs, this may need to be drained using a needle and syringe.

Rarely, some people with lupus develop kidney failure, which may require dialysis or a kidney transplant. However, severe kidney damage can usually be prevented by early diagnosis and treatment of lupus. For this reason, you must take any medication as prescribed by your doctor.

### Self-help and daily living

**!** Although drugs are important in controlling lupus, there's a lot that you can do to help manage your symptoms. Lifestyle factors like following a healthy diet, exercising and not smoking will help to reduce your risk of developing the more serious complications of lupus.





### Managing a flare-up

Lupus is a condition that naturally improves and worsens at different times. Learning how to manage a flare-up of your symptoms lets you be more in control of your condition. The reasons for a flare-up can vary from person to person, but exposure to sunlight, too little rest time, infections and stress can all play a part. It can be useful to try to spot the things that lead to a flare-up and find ways of managing or avoiding them. Keep in touch with your rheumatology team, especially through your rheumatology nurse specialist and the telephone advice line available in most units. Some of the following points may also help.

### Fatigue

You may find you often experience fatigue, and it can be a big problem. If there's a specific cause, such as anaemia or an underactive thyroid gland, this can be identified by a blood test and treated. If no specific cause can be found, fatigue may be more difficult to deal with. Some medications such as hydroxychloroquine can help. Learning to pace yourself – finding the right balance between rest and activity – will help. Exercise improves fitness and stamina and can therefore help in overcoming fatigue, but you'll need to start very gently – ask to see a physiotherapist for advice about suitable exercises.

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**i** See Arthritis Research UK booklet  
*Fatigue and arthritis.*

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### Smoking

Many of the problems caused by lupus can be made worse by smoking. For example:

- Lupus and smoking can both cause narrowing of the blood vessels, causing circulatory problems and increasing the risk of strokes and heart attacks.
- Lupus can make you more at risk of respiratory infections, while smoking leads to long-term lung damage which can make these infections more frequent and severe.
- When lupus affects the kidneys it can lead to high blood pressure. Smoking can also contribute to high blood pressure, increasing the risk of strokes and worsening kidney disease.

While it can be extremely difficult to stop smoking, treatments are available that can help you to stop. Talk to your GP or call a smoking helpline to find out the ways they can help.

**!** **Giving up smoking is one of the most important things you can do to reduce the risk of the more serious complications of lupus.**

### Exercise

When the disease is active, you may not feel like doing very much and it's important to rest when you need to. However, too much rest will cause the muscles to weaken and may make you feel more tired, so you need to find the right balance between rest and exercise. Walking and swimming are

recommended as they can improve fatigue, fitness and stamina without putting too much strain on the joints. Even when you're having a flare-up, a small amount of exercise is helpful and you should have some gentle exercise that you can do even on a bad day.

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**i See Arthritis Research UK booklet**  
*Keep moving.*

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## Diet and nutrition

There's only limited evidence available on the effect of diet in controlling lupus, though there's some evidence that a diet low in saturated fat and high in omega-3, which is found in oily fish, may be helpful. You can also try taking fish oil supplements, but make sure that you use fish *body* oil, not fish *liver* oil. Be careful of any exclusion diets where large food groups are removed from the diet – you need all the nutrients that a well-balanced diet will provide. Consult a dietitian if you need more specific advice.

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**i See Arthritis Research UK booklet**  
*Diet and arthritis.*

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## Sunlight

Too much ultraviolet light from sunlight can cause a red rash across the cheeks and the bridge of the nose, often known as the butterfly rash. It can also sometimes cause problems with internal organs, to flare-up. Bear this in mind when choosing a holiday destination and discuss with your nurse specialist or dermatologist if in doubt. Keep out of the midday sun and wear a hat. Keep your skin covered or use suncream of SPF 50 or greater – which is available on prescription for people with lupus. You can also buy high-factor suncreams that include a tint and can be used as foundation make-up. Be careful when sitting under sun umbrellas on a paved area as the sunlight will be reflected onto your face.

## Raynaud's phenomenon

If you experience Raynaud's in your hands or feet, dress suitably for cold weather. Smoking is bad for the circulation and is likely to make symptoms worse. Regular exercise will improve your circulation.

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**i See Arthritis Research UK booklet**  
*Raynaud's phenomenon.*

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## Managing stress

Even if it doesn't affect the course of the disease, emotional stress can make your illness seem worse. Learn how to manage any stress in your life – you might want to try relaxation techniques such as meditation or using mindfulness CDs. Make sure you take time for yourself and talk to family and friends if you're finding things difficult. Support groups are also available. Your doctor may be able to refer you to a psychologist who can help with coping strategies.

Therapies such as cognitive behavioural therapy (CBT) may help. This is a talking therapy that can help you manage problems by changing the way you think and behave. It's most commonly used to treat anxiety and depression, but can be useful for other mental and physical health problems.

Regular exercise can improve feelings of stress, anxiety and depression, though you will need to balance this with rest due to fatigue and any other symptoms which your condition throws up.

If you have lupus, you may want to seek extra support at work. You could talk to your human resources department to see if there are any improvements that could be made to your physical working environment as well as any alterations to your working arrangements, which will help you manage your condition better and allow you to work to the best of your ability.

The Equality Act 2010 means that employers have to remove barriers in the workplace for people with a disability and financial support is available to help them do this. The Equality Act states that someone is disabled if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their abilities to do normal activities.

You may not think that the term disability is appropriate for you, but lupus can fall under this remit, and additional support may help you in your employment or education.

## Meeting others with lupus

Lupus is a difficult condition to live with and throws up many challenges, especially during periods of life when you may need more energy. Meeting others with lupus doesn't necessarily remove these challenges but it can help you to cope with them by sharing your thoughts and concerns with someone who understands. You may have access to an education programme through a lupus nurse specialist or you may wish to meet others through patient support groups such as LUPUS UK.

## Contraception

If you have lupus you should use contraceptive pills that contain only progesterone or low-dose oestrogen, or consider physical/barrier methods of contraception, such as condoms. This is because oestrogen can make the disease more likely to flare up.

If you're taking steroid treatment, you should avoid using the contraceptive medroxyprogesterone acetate (trade name Depo-Provera), which is given by injection. It increases the risk of developing osteoporosis because it reduces the levels of oestrogen in your body, which help prevent bone loss. The Mirena coil, which is progesterone only, is often recommended to women with lupus. Talk to your doctor if you're worried about your method of contraception.

## Hormone replacement therapy (HRT)

In the past there has been concern about HRT increasing the risk of flare-ups of lupus. However, recent research has suggested that it's relatively safe to use for short periods if symptoms of the menopause are severe and your lupus is otherwise well controlled.

## Complementary medicines

There's no scientific evidence that suggests any form of complementary medicine helps to ease the symptoms of lupus. But if joint pain is a particular problem, acupuncture may help. The pain relief may only last a short time to begin with but repeated treatments may bring longer-lasting benefits. You may need to visit a private practitioner as the treatment may not be available on the NHS.

Generally speaking, complementary and alternative therapies are relatively well tolerated if you want to try them, but you should always discuss their use with your doctor before starting treatment. There are some risks associated with specific therapies.

In many cases, the risks associated with complementary and alternative therapies are more to do with the therapist than the therapy. This is why it's important to go to a legally registered therapist, or one who has a set ethical code and is fully insured.

If you decide to try therapies or supplements, you should be critical of what they're doing for you, and base your decision to continue on whether you notice any improvement.

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**1** See Arthritis Research UK booklet  
*Complementary and alternative medicine for arthritis.*

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## Pregnancy and lupus

! Most women with lupus should be able to have a baby if they wish to, but it's best to discuss your plans with your doctor before trying to get pregnant so that your treatments can be altered if need be. Always plan a pregnancy, where possible, at a time when lupus is inactive and you're taking as little medication as possible.

A small number of women with very severe lupus may be advised against having a baby as pregnancy can put a great strain on the heart, lungs and kidneys. There's an increased risk of pregnancy complications in women whose lupus affects a number of different organs and who find it difficult to control their symptoms without certain medications.

If you're thinking of having a baby, always discuss your plans with your doctor or specialist nurse before you start trying. You may need to see an obstetrician with a special interest in lupus for further advice.



Doctors are naturally cautious about which drugs are used during pregnancy. Steroids are usually well tolerated and many people have used prednisolone, hydroxychloroquine and azathioprine throughout pregnancy without ill effects.

If you have high levels of antiphospholipid antibodies there's an increased risk of miscarriage. However, treatment with aspirin and/or heparin reduces this risk, and there are now many more successful pregnancies in women who have these antibodies.

There's conflicting evidence about whether pregnancy is likely to cause a flare-up of lupus. If the disease is well controlled at the time the baby is conceived, and you don't have kidney disease, then you're unlikely to have any problems.

If you do have kidney disease then you may well have increased protein in your urine during the later stages of pregnancy. It is important, but sometimes difficult, to distinguish between protein in the urine due to kidney disease which is associated with lupus, or to a more common complication of pregnancy, known as pre-eclampsia. The doctors looking after your pregnancy will check for this and consult your rheumatologist if necessary.

In pregnant women who have anti-Ro antibodies there's a small risk (about 1 in 50) that their babies will have neonatal (newborn) lupus syndrome. This means the baby may have a rash and/or a slow heartbeat. There's a slightly greater risk in following pregnancies, so make sure you discuss this in detail with your rheumatology and obstetric team before considering another pregnancy. Most babies born to mothers with anti-Ro antibodies will be fine, but it's important to have regular scans of the baby's heart during the pregnancy.

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**i See Arthritis Research UK booklet  
*Pregnancy and arthritis.***

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## Research and new developments

We are the UK's biggest funder of research into lupus and are supporting a wide range of projects which aim to prevent the onset of lupus, transform its treatment and ultimately find a cure.

New therapeutic approaches which target cells and molecules believed to be part of the cause of lupus are being used to help many patients and further research studies should allow us to find out how these and other drugs can be used to the best effect.

We're currently funding research into many aspects of lupus, for example:

- Investigating the genetics of people with lupus in different parts of the world to identify genes which increase an individual's risk of developing lupus
- Testing whether rituximab, a drug that removes a type of immune cell called B cells from the circulation, is effective in patients with lupus who have not responded to previous treatment
- Investigating why common genetic changes in the gene IKZF2 seem to increase an individual's risk of developing lupus
- Our experimental Arthritis Treatment Centre for Children is trialling new and existing treatments in children with different forms of childhood arthritis and lupus.



## Glossary

**Acupuncture** – a method of pain relief that originated in China. Fine needles are inserted, virtually painlessly, at sites (called meridians) but not necessarily at the painful area. Pain relief is obtained by interfering with pain signals to the brain and by releasing natural painkillers (called endorphins).

**Anaemia** – a shortage of haemoglobin (an oxygen-carrying pigment) in the blood, which makes it more difficult for the blood to carry oxygen around the body. Anaemia can be caused by some rheumatic diseases such as rheumatoid arthritis or lupus, or by a shortage of iron in the diet. It can also be a side-effect of some drugs used to treat arthritis.

**Antibodies** – blood proteins that form in response to germs, viruses or other substances your body sees as foreign or dangerous. Antibodies attack these foreign substances to make them harmless.

**Antiphospholipid antibody** – an antibody that attacks phospholipids (a type of fat) which often make up the surface of cells. Because the antibody attacks the body's own cells, rather than bacteria, it's called an autoantibody.

**Antiphospholipid syndrome (APS)** – a disorder in which the blood can clot too quickly ('sticky blood' syndrome). The clotting can affect any vein or artery in the body, resulting in a wide range of symptoms. It's caused by an antibody that attacks phospholipids found particularly in the outer coating of white blood cells.

**Autoantibodies** – antibodies that, instead of reacting with germs or viruses, react with the body's own tissues. They're present in a number of rheumatic conditions.

**Autoimmune disease** – a disorder of the body's defence mechanism (immune system) in which antibodies and other components of the immune system attack the body's own tissue rather than germs, viruses and other foreign substances.

**Biological therapies** – drugs that reduce joint inflammation in people with rheumatoid arthritis and some other inflammatory diseases. They work by targeting specific molecules involved in the inflammatory process and include anti-TNF drugs (adalimumab, etanercept and infliximab) and rituximab.

**Biopsy** – the removal of a small amount of living tissue from the body. The sample can help diagnose illness when examined under a microscope.

**Bisphosphonates** – drugs used to prevent the loss of bone mass and treat bone disorders such as osteoporosis and Paget's disease. They work by reducing high levels of calcium in the blood and by slowing down bone metabolism.

**Bone marrow** – soft tissue inside long bones which makes blood cells.

**Computerised tomography (CT) scan** – a type of scan that records images of sections or 'slices' of the body using x-rays. These images are transformed into cross-sectional pictures.

**Dialysis** – a method of separating particles in a liquid by passing them through a membrane. In kidney dialysis the blood is circulated through a special machine to remove waste materials or poisons from the blood.

**Disease-modifying anti-rheumatic drugs (DMARDs)** – drugs used in rheumatoid arthritis and some other rheumatic diseases to suppress the disease and reduce inflammation. DMARDs treat the disease itself rather than just reducing the pain and stiffness caused by the disease. Examples of DMARDs are methotrexate, sulfasalazine, infliximab, etanercept and adalimumab.

**Flare-up** – a period where your joints become inflamed and painful.

**Haemoglobin** – a protein in red blood cells which contains the pigment that gives blood its colour. It can combine with, and release, oxygen, allowing blood to carry oxygen around the body.

**Heparin** – a daily injection to slow blood clotting.

**Immune system** – tissues that enable the body to resist infection. They include the thymus (a gland behind the breastbone), bone marrow and lymph nodes.

**Inflammation** – a normal reaction to injury or infection of living tissues. Blood flow increases, resulting in heat and redness in affected tissues. Fluid and cells leak into the tissue, causing swelling.

**Jaccoud's arthropathy** – a rare form of arthritis that alters the shape of the joints of the fingers.

**Joint hypermobility** – also known as double-jointedness, hypermobility means that some or all of your joints have an unusually large range of movement.

**Lymph glands** – small organs found in clusters around the body, including in the armpit, behind the ear and in the groin. Lymph nodes act as filters to help prevent infections or foreign particles getting in the blood. They release white blood cells called lymphocytes, which are important to the immune system.

**Magnetic resonance imaging (MRI) scan** – a type of scan using high-frequency radio waves in a strong magnetic field to build up pictures of the inside of the body. It detects water molecules in the body's tissue that give out a signal in the magnetic field. An MRI scan can show up soft-tissue structures, such as organs, as well as bones.

**Non-steroidal anti-inflammatory drugs (NSAIDs)** – a large family of drugs used for different kinds of arthritis to reduce inflammation and control pain, swelling and stiffness. They're best used for relatively short periods, to minimise side-effects. Common examples are ibuprofen, naproxen and diclofenac.

**Obstetrician** – a doctor who specialises in pregnancy and labour. They provide prenatal and postnatal care.

**Oestrogen** – one of a group of hormones in the body that control female sexual development and the reproductive cycle. It can be a factor in causing flare-ups of lupus symptoms.

**Osteoporosis** – a condition where bones become less dense and more fragile, which means they break or fracture more easily. Osteoporosis can be a side-effect of long-term steroid use.

**Pericarditis** – inflammation of the membranes around the heart. The more acute (short-lasting) form causes fever and chest pain, and fluid may build up in between the membranes, causing shortness of breath.

**Physiotherapist** – a specialist who helps keep your joints and muscles moving, ease pain and keep you mobile.

**Placenta** – an organ within the womb that provides food and oxygen to the developing baby. The placenta is delivered after the baby is born and is sometimes known as the afterbirth.

**Pleurisy** – inflammation of the lining of the lungs and of the inside surface of the chest wall (the pleura), causing pain on deep breathing.

**Pre-eclampsia** – a condition which can affect some pregnant women, usually in the second half of pregnancy or soon after the baby is born. Women with pre-eclampsia might have protein in their urine and high blood pressure (hypertension). Other symptoms can include swelling in the feet, ankles, face and hands, and headaches. If you notice any symptoms seek urgent medical attention.

**Progesterone** – one of a group of hormones in the body. In women it prepares the lining of the uterus for

pregnancy. Synthetic progesterone is used in the oral contraceptive pill (both in the combined pill, which contains oestrogen and progesterone, and in the progesterone-only pill).

**Proton pump inhibitor (PPI)** – a drug that acts on an enzyme in the cells of the stomach to reduce the secretion of gastric acid. They're often prescribed along with non-steroidal anti-inflammatory drugs (NSAIDs) to reduce side-effects.

**Raynaud's phenomenon** – a circulatory problem that causes the blood supply to certain parts of the body to be greatly reduced. It can make the fingers and toes go temporarily cold and numb and they turn white, then blue, then red.

**Rheumatoid arthritis** – a common inflammatory disease affecting the joints, particularly the lining of the joint. It most commonly starts in the smaller joints in a symmetrical pattern – that is, for example, in both hands or both wrists at once.

**Sjögren's syndrome** – an autoimmune disorder that's characterised by dry eyes and/or a dry mouth, aching and fatigue. This can occur on its own or may be secondary to a disease like lupus.

**Thyroid gland** – part of the endocrine system found at the base of the neck. The gland makes hormones that help to control the body's metabolism.

**Ultrasound scan** – a type of scan that uses high-frequency sound waves to examine and build up pictures of the inside of the body.

## **Where can I find out more?**

You can download all of our booklets and leaflets from our website or order them by contacting:

### **Arthritis Research UK**

Copeman House  
St Mary's Court  
St Mary's Gate, Chesterfield  
Derbyshire S41 7TD  
Phone: 0300 790 0400  
[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

### **Related organisations**

The following organisations may be able to provide additional advice and information:

#### **Arthritis Care**

Floor 4, Linen Court  
10 East Road  
London N1 6AD  
Phone: 020 7380 6500  
Helpline: 0808 800 4050  
Email: [info@arthritiscare.org.uk](mailto:info@arthritiscare.org.uk)  
[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

#### **British Sjögren's Syndrome Association**

PO Box 15040  
Birmingham B31 3DP  
Phone: 0121 478 0222  
Helpline: 0121 478 1133  
[www.bssa.uk.net](http://www.bssa.uk.net)

#### **LUPUS UK**

St James House  
Eastern Road  
Romford  
Essex RM1 3NH  
Phone: 01708 731251

Email: [headoffice@lupusuk.org.uk](mailto:headoffice@lupusuk.org.uk)

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

#### **NHS smokefree – stop smoking service**

Phone: 0800 022 4332  
[www.smokefree.nhs.uk](http://www.smokefree.nhs.uk)

#### **Raynaud's & Scleroderma Association**

112 Crewe Road  
Alsager  
Cheshire ST7 2JA  
Phone: 01270 872776 (for enquiries) or  
0800 917 2494 (for information orders)  
[www.raynauds.org.uk](http://www.raynauds.org.uk)

#### **St Thomas' Lupus Trust**

Ground Floor  
Conybeare House  
Great Maze Pond  
Guys Hospital  
London SE1 9RT  
Tel: 020 7188 3562  
[www.lupus.org.uk](http://www.lupus.org.uk)  
[www.lupus.org.uk/online-help/online-nurse](http://www.lupus.org.uk/online-help/online-nurse) (for questions for the online nurse)

Links to third-party sites and resources are provided for your general information only. We have no control over the contents of those sites or resources and we give no warranty about their accuracy or suitability. You should always consult with your GP or other medical professional.

**Please note:** We've made every effort to make sure that this content is correct at time of publication. If you would like further information, or if you have any concerns about your treatment, you should discuss this with your doctor, rheumatology nurse or pharmacist.



## We're here to help

Arthritis Research UK is the charity leading the fight against arthritis.

We fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

We're working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We'll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you'd like to receive an email alert about our quarterly online magazine, *Arthritis Today*, which keeps you up to date with current research and education news, highlighting key projects that we're funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers' hints and tips for managing arthritis.

### Tell us what you think

Please send your views to:

**bookletfeedback@  
arthritisresearchuk.org**

or write to us at:

Arthritis Research UK, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD

A team of people contributed to this booklet. The original text was written by Prof. David Isenberg, who has expertise in the subject. It was assessed at draft stage by senior lecturer/consultant physician Prof. Munther Khamashta, lead nurse inflammatory and connective tissue disease Louise Parker and special registrar in rheumatology Dr Veena Patel. An **Arthritis Research UK** editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An **Arthritis Research UK** medical advisor, Dr Ben Thompson, is responsible for the content overall.

Thank you to Monique for sharing her story, and to other members of the Enfield Lupus Support Group for their help with this booklet.

## Get involved

**You can help to take the pain away  
from millions of people in the UK by:**

- volunteering
- supporting our campaigns
- taking part in a fundraising event
- making a donation
- asking your company to support us
- buying products from our online and high-street shops.

To get more **actively involved**, please call us on **0300 790 0400**, email us at **enquiries@arthritisresearchuk.org** or go to **www.arthritisresearchuk.org**



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calls charged at standard rate

**[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)**

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