Sjögren’s syndrome

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

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What is Sjögren’s syndrome?

Sjögren’s syndrome is a condition that mainly causes a dry mouth and eyes, though it can also cause a range of other symptoms including joint pain and fatigue. In this booklet, we’ll look at the symptoms, the possible causes and the treatments available for Sjögren’s syndrome.

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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What is Sjögren’s syndrome?

Sjögren’s syndrome is a condition which mainly affects the glands that produce saliva and tears, causing a dry mouth and/or eyes. It’s estimated that up to half a million people in the UK may have Sjögren’s syndrome, and it most commonly affects women aged 40–60.

What are the symptoms of Sjögren’s syndrome?

The most common symptoms of Sjögren’s syndrome are:

- dry, sore, irritable or gritty eyes
- a dry mouth and/or throat, which may cause difficulty chewing or swallowing food
- fatigue (tiredness)
- joint pain or general achiness.

There may also be dryness of the skin, digestive tract, vagina or air passages.

Other possible symptoms include:

- headaches
- fever
- swollen lymph glands in the neck, armpits or groin
- swollen salivary glands over the face in front of the ears
- aggravated menopausal symptoms
- fingers or toes turning blue in the cold (Raynaud’s phenomenon).

Sjögren’s syndrome can sometimes cause problems with the nervous system, liver and kidneys, inflammation of the blood vessels, skin rashes and chest pain.

How is it diagnosed?

Your doctor will ask about your symptoms and carry out tests to assess how dry your eyes and mouth are. It’s likely you’ll also need to see an eye specialist (ophthalmologist), a dentist or oral surgeon, or a rheumatologist before you’re diagnosed.
What tests are there?
The main tests that can help with diagnosis are:
- tear production
- eye examinations
- saliva production
- ultrasound of the salivary glands
- other scans
- blood tests
- a lip biopsy.

How can I help myself?
Some of the following tips may help:
- Increase the humidity in rooms by introducing humidifiers, plants or bowls of water.
- Always have some water to hand.
- Follow a good dental routine and have regular check-ups.
- Increase the amount of fibre in your diet if you have bowel symptoms.
- Don’t have too many sugary foods and drinks.
- Don’t have too many caffeinated or alcoholic drinks.
- Use lubricating gels if sex is painful.

What treatments are there?
Although there’s no cure yet, there are many treatments available that can help with the various symptoms. These include eye drops and ointments, mouth gels and sprays, painkillers and anti-inflammatory drugs. Other drugs may be prescribed depending on the type and severity of your symptoms.

Occasionally, a minor surgical procedure may be used to reduce the drainage of fluid from the eyes.
What is Sjögren’s syndrome?

Sjögren’s (pronounced Shurgren’s) syndrome is an autoimmune disease. Your body’s immune system usually fights infections, but with Sjögren’s syndrome it attacks its own tissues instead – particularly the tear glands and the salivary glands – causing dryness of the eyes and mouth. Other parts of the body can also be affected, leading to dryness of the skin, nose, throat, breathing tubes, gut or vagina.

Sjögren’s syndrome can occur on its own (when it’s described as primary) but can also occur in association with another rheumatic disease such as rheumatoid arthritis, lupus or scleroderma (when it’s described as secondary).

It’s estimated that up to half a million people in the UK may be affected by Sjögren’s syndrome but the exact figures aren’t known because many people never see a doctor about their symptoms.

See Arthritis Research UK booklets
Lupus; Rheumatoid arthritis; Scleroderma.

What are the symptoms of Sjögren’s syndrome?

The most common symptoms of Sjögren’s are dry eyes and/or mouth, and feeling tired and achy. Many people don’t have any other symptoms. However, the range and severity of symptoms can vary a great deal from person to person.

Eye problems

Your eyes may be dry and feel sore, irritable or gritty. Some people find strong lights can be uncomfortable, while others find their eyes become sticky with mucus.

Mouth and throat problems

Your mouth may become dry and you may have mouth ulcers, which can sometimes cause a sticky feeling in the mouth or throat. Swallowing may be difficult and some people find their sense of taste is altered. Your voice may be hoarse or weak, and some people have a dry cough.

Occasionally a very dry mouth can lead to other problems such as fungal infections (e.g. thrush), an unpleasant taste in the mouth and increased dental decay. The salivary glands may also become painful and/or swollen.

Extreme fatigue

Fatigue (extreme tiredness) is one of the most common symptoms and it’s not the sort of tiredness that’s cured by a good night’s sleep. Some people may also feel down or depressed.

See Arthritis Research UK booklet
Fatigue and arthritis.
Aches and pains
The joints may be painful and swollen due to inflammation, while some people have a general achy feeling or tenderness at various points around the body. However, joint problems are usually less severe than in conditions such as rheumatoid arthritis.

Other symptoms
Other parts of the body may also be drier than normal, for example:
- the digestive passage, making it difficult to swallow food
- the bowel, causing symptoms similar to irritable bowel syndrome (e.g. abdominal pain)
- the vagina, making sex uncomfortable
- the skin, which may also be itchy or unusually sensitive to strong sunlight
- the air passages, making you more sensitive to irritants such as smoke or dust.

Other problems and complications that can sometimes be associated with Sjögren’s syndrome include:
- fever
- cold, blue fingers (Raynaud’s phenomenon)
- migraine-like headaches
- swollen lymph glands in your neck, armpits or groin
- aggravated menopausal symptoms
- problems with your nervous system, such as weakness or numbness
- inflamed blood vessels (known as vasculitis)
- purple spots on the lower legs (purpura)
- chest pain (caused by pleurisy) or breathlessness
- liver or kidney problems.

See Arthritis Research UK booklet Raynaud’s phenomenon.

Who gets Sjögren’s syndrome
Women aged between 40 and 60 are most likely to be diagnosed with Sjögren’s syndrome. Only about 1 in 13 Sjögren’s syndrome patients are men, and the condition only rarely occurs in childhood.

It’s possible that some people are more likely to get Sjögren’s syndrome because something in their genes makes it difficult for them to get rid of certain infections. However, it’s unusual for children to inherit the condition from their mother or father.

Sjögren’s syndrome is an autoimmune disease, which means the immune system attacks the body’s own tissues.
What causes Sjögren’s syndrome?
Sjögren’s syndrome is an autoimmune disease in which the immune system attacks the body’s own tissues – mainly the tear-producing glands, such as the lacrimal glands behind the eyelids (see Figure 1), and the salivary glands in the mouth (see Figure 2). The body produces antibodies that react with and damage the tissues and nerve signals to the glands, reducing the amount of saliva and tears produced.

We don’t yet know what causes the immune system to behave this way in Sjögren’s syndrome. It’s been suggested that viruses could trigger it, although there’s no strong evidence for this.
What is the outlook?
You’re unlikely to be disabled by Sjögren’s syndrome, although the symptoms can be uncomfortable and long lasting. In a few people, the joints may become inflamed or the liver or kidneys may be affected. But usually the condition only damages the tear- and saliva-producing glands.

Some people with Sjögren’s syndrome might have an increased risk of developing cancers of the lymphatic tissues, known as lymphoma. Lymphoma only affects a small number of people with Sjögren’s syndrome – most people won’t be affected – but you and your doctor should look out for any early signs such as enlarged lymph glands (in your neck, armpits or groin) or salivary glands that are persistently swollen. The good news is that the treatment for lymphoma is generally very effective.

How is Sjögren’s syndrome diagnosed?
Dryness of the eyes and mouth can have other causes, which include:

- sicca syndrome, which means the glands are less able to make tears and saliva – this can occur as people get older
diseases other than Sjögren’s syndrome, such as sarcoidosis, which can also damage the tear- or saliva-producing glands

• certain medications such as antihistamines and antidepressants

• inflammation of the oil-producing glands in the eyelids (blepharitis), which causes excessive evaporation of the tear film.

It’s important to see your doctor to get an accurate diagnosis. Your doctor will ask about your symptoms and carry out tests to assess how dry your eyes and mouth are.

Because there are a number of possible symptoms and complications with Sjögren’s syndrome, it’s likely you’ll also need to see an eye specialist (ophthalmologist), a dentist or oral surgeon, or a rheumatologist before you’re diagnosed.

**What tests are there?**

The main tests that can help with diagnosis are:

- **Tear production** – A small piece of sterilised, pre-packaged blotting paper is used to measure your tear production. This is called Schirmer’s test (see Figure 3). The paper is placed in the corner of your eye and folded over your lower eyelid. This is a little uncomfortable and causes your eyes to water, making the paper wet. The amount of water that soaks into the blotting paper within five minutes is measured, and this tells the doctor how good your tear production is.

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**Figure 3**

Schirmer’s test

Blotting paper is placed under the eyelid to measure your tear production

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There’s no cure as yet for Sjögren’s syndrome, but there are many treatments that can help with the different symptoms. These can include eye drops for dry eyes and artificial saliva for a dry mouth.

Regular exercise can help with joint pain and is also good for your general health.
**Eye examination** – An eye specialist will put a dye (fluorescein and sometimes lissamine green dye) into your eyes and use an instrument called a slit lamp to examine them. The lamp shines a beam of light through a narrow slot (the slit-beam) and magnification allows the surface of the eye to be examined more effectively. This makes it possible to see the film of liquid over the surface of each eye. If you don’t have enough of this liquid, it could be a sign that you have Sjögren’s syndrome.

**Saliva production** – You may be asked to spit or dribble into a container over a period of five minutes or so. The amount of saliva that you can produce in that time is measured.

**Ultrasound scans** – These are commonly performed now to help diagnose Sjögren’s syndrome. The salivary glands usually have a uniform grey appearance on ultrasound images. In Sjögren’s syndrome, round black areas can be seen in the scans.

**X-rays of the salivary glands and ducts (sialography)** – A contrast dye is injected so that the glands and ducts show up clearly in the images. This is rarely performed for diagnosis now and is mainly used to identify blockages of the ducts in people who have repeated salivary gland infections.

**Other scans** – Occasionally magnetic resonance imaging (MRI) scans are used if there is uncertainty over the diagnosis or if lymphoma or another abnormality is suspected.

**Blood tests** – People with Sjögren’s syndrome often have high levels of antibodies in their blood. These can be measured with blood tests. The high antibody levels can make the blood thicker than usual, and this is measured by an erythrocyte sedimentation rate (ESR) test. The ESR measures how fast the cells in a tube of blood settle. The thicker the blood, the faster the cells settle and the higher the ESR. People with Sjögren’s syndrome often have very high ESR levels regardless of whether they feel well or ill. In Sjögren’s syndrome, the ESR or other measurements such as C-reactive protein (CRP) aren’t very useful in assessing how active the condition is – unlike in lupus or rheumatoid arthritis.

Two particularly important antibodies are called anti-Ro and anti-La antibodies. They’re found in 75% (anti-Ro) and 40–50% (anti-La) of people with primary Sjögren’s syndrome and can also be seen in patients with lupus. The presence of anti-Ro and/or anti-La antibodies in a person with dry eyes and/or dry mouth strongly suggests they have Sjögren’s syndrome.

**Lip biopsy** – Several tiny glands may be taken from your lower lip under a local anaesthetic and examined under a microscope. This is increasingly being done to assess the future risk of lymphoma, which may need further monitoring. If there are no early signs then the possibility of developing lymphoma in the future can almost be ruled out.

Further specialised tests may be needed if you develop swelling in the lymph glands (in the neck, armpits or groin) or if you have complications involving the chest, kidney, liver or nervous system.
What treatments are there for Sjögren’s syndrome?

There’s no cure yet for Sjögren’s syndrome, but the most common symptoms can usually be treated with a combination of specific medications and self-help measures.

Eye symptoms

For dry, sore or irritable eyes:

- Lubricant eye drops such as hypromellose, Sno Tears or Viscotears can be used several times a day.
- If you need eye drops more than six times a day, you should use a preservative-free formulation because frequent use of drops containing preservative can increase dryness and sensitivity. Formulations such as artelac, hypromellose preservative-free, Viscotears single-dose units, Celluvisc and Optive can be used up to hourly if you need to.
- For very dry eyes you may need to use ointments (e.g. Lacri-Lube) at night, or pseudoplastic drops such as Celluvisc or hyaluronate preparations.

If mucous and debris are causing stickiness:

- Mucolytic agents such as acetylcysteine eye drops may be helpful.
- Paraffin-based ointments such as Lacrilube can be used at night if your eyes are dry and crusty on waking.

If you have corneal ulcers or infections, you should NOT use any of these treatments and should seek advice from an eye specialist.

In some cases, an eye specialist may suggest punctal occlusion. This is where tiny plugs are inserted into the ducts (puncta) at the inner corners of the eyelids to reduce the drainage of tears (or eye drops) from the surface of the eye (see Figure 4). Usually, temporary plugs are tried first and if these are helpful more permanent plugs can be inserted. If the eyes remain very dry, the puncta may be sealed by cauterisation.

Figure 4
Puncta
Mouth and throat symptoms

**For a dry mouth:**

- Artificial saliva such as Biotene OralBalance or BioXtra gels can be helpful.
- Mouth sprays such as Luborant or AS Saliva Orthona are recommended if you have your own teeth because they contain fluoride. It’s best to avoid Glandosane mouth spray because it’s more acidic and may increase the risk of dental decay.
- If you’re able to produce some saliva, pilocarpine can be taken as a tablet (Salagen). This works by stimulating glandular tissue. Some people may notice side-effects such as sweating, flushing, a change of bowel habit or a more frequent need to urinate. These effects usually ease after a time, and it may help to start on a low dose, such as 5 mg a day, and gradually increase it as the side-effects decrease.
- If your mouth is severely dry and is causing other problems such as fungal infections or dry coughs, your doctor may recommend an antifungal treatment such as nystatin.
- Chlorhexidine mouth rinses such as Corsodyl may help with dental hygiene, and fluoride mouthwashes or high concentration fluoride toothpastes (Duraphat) can be used to help reduce dental decay. They should be alcohol-free so as to avoid worsening evaporation from the mouth. Non-sugar chewing gum or other dental care products or lozenges such as anhydrous crystalline maltose can also help.
If you have Raynaud’s phenomenon, try wearing an extra pair of socks to keep your feet warm.

### For mouth ulcers:

- **Adcortyl** in Orabase ointment is no longer available but Orabase ointment alone can be applied to mouth ulcers. If this doesn’t help, your doctor may prescribe betamethasone (Betnesol) tablets to dissolve in 20 ml warm water and use as a mouthwash a few times a day.
- **Difflam** oral rinse or spray can help relieve discomfort from mouth ulcers.
- If the ulcers are causing stickiness in your mouth or throat, a diluted chlorhexidine mouthwash such as Corsodyl will help. Alternatively you could try rinsing and gargling with a mouthwash made from a mixture of a teaspoon of salt, a teaspoon of baking powder and a litre of water.

If your salivary glands are painful, ask your doctor for further assessment and advice – they’ll check whether you have an infection. If your salivary glands aren’t infected, they may prescribe a short course of a corticosteroid called prednisolone.

### Other symptoms

#### Joint pain, aching or tender spots:

- Painkillers such as paracetamol and/or non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen may help.
- If joints are inflamed, an intramuscular steroid injection (Depomedrone) or short course of steroid tablets may be suggested for short-term relief.
- **Hydroxychloroquine** can be used for longer-term treatment (from 6 months to many years).

#### Extreme tiredness, lethargy, difficulty in concentrating:

- Your doctor may suggest blood tests to check the thyroid gland and screening for coeliac disease.
- Hydroxychloroquine may help with fatigue and joint pain.
- Lifestyle changes such as taking sensible exercise and pacing yourself in your daily activities can also be helpful.

#### Fever:

- Your doctor will want to rule out more serious problems such as infection, thyroid problem or lymphoma.

#### Raynaud’s phenomenon:

- Self-help measures will often improve the symptoms but drugs such as nifedipine, which open up the blood vessels, may be prescribed if necessary.

#### Migraine-like headaches:

- Painkillers or specific anti-migraine medications are usually effective.

#### Abdominal pain, irritable bowel syndrome:

- Antispasmodic drugs, such as mebeverine (Colofac) can be helpful for disrupted bowel habits.

#### Aggravated menopausal symptoms:

- Hormone replacement therapy (HRT) can be used if necessary, but it’s important to discuss the risk of side-effects with your doctor.

Other medications may sometimes be needed if you have a more severe form of the disease or if the peripheral nervous system is affected.
Patients with severe progressive disease may need high-dose corticosteroids and immunosuppressive drugs such as cyclophosphamide. Painkillers including gabapentin or pregabalin can be used for nerve pain.

Rituximab, which targets the B-cells of the immune system, and azathioprine or mycophenolate, which are immunosuppressant drugs, have been helpful in some people with Sjögren’s syndrome. However, the majority of people don’t need these drugs because their symptoms are confined primarily to the eyes and mouth.

Mild liver abnormalities aren’t common and probably won’t require treatment, but you should have regular checks. Specialist treatment may be needed if a condition called primary biliary cirrhosis develops.

People with primary Sjögren’s syndrome are more likely to develop coeliac disease (gluten intolerance) and an underactive thyroid gland (hypothyroidism) so these need to be checked for.

The lungs can occasionally be affected by fibrosis, which can cause breathlessness, a dry cough and chest pain. Fibrosis requires specialist advice but steroids can be prescribed.

### Self-help and daily living

Some symptoms of Sjögren’s syndrome can be eased by simple self-help measures:

- Wear wraparound sunglasses or glasses with side shields to help retain moisture in the eyes.
- Keep your eyelids and the surrounding areas clean to maximise oil secretion from glands in the eyelids.
- Avoid contact lenses because they’ll be uncomfortable if your eyes are dry.
- Consider wearing tinted glasses if you find strong lights uncomfortable.
- Increase the humidity in your home. This can help eye symptoms and a dry cough. Humidifiers, large-leaved houseplants or bowls of water all help to increase humidity in a room.
- Avoid strong soaps if you have dry, itchy skin. Water-based creams and emollients may be helpful.
- Wear sunscreen (factor 15 or higher) if your skin is sensitive to the sun or comes out in a rash.
- Wear warm gloves if you experience Raynaud’s phenomenon. Exercise will help by improving your circulation, and smoking should be avoided because it’s bad for the circulation.
- Good dental hygiene is recommended for any oral symptoms.

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**See Arthritis Research UK drug leaflets**

Azathioprine; Cyclophosphamide; Hydroxychloroquine; Mycophenolate; Non-steroidal anti-inflammatory drugs; Rituximab; Steroid tablets.

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**It’s important to have a good dental care routine and regular check-ups if you have oral symptoms of Sjögren’s syndrome.**
Exercise
Exercise is recommended to maintain mobility, particularly if you have symptoms in your joints. You’ll need to find the right balance between rest and exercise, especially if you also suffer from extreme tiredness. A physiotherapist will be able to advise on suitable exercises and on how to increase your activity level gradually.

See Arthritis Research UK booklets
Keep moving; Looking after your joints when you have arthritis; Physiotherapy and arthritis.

Diet and nutrition
No special diet is recommended for Sjögren’s syndrome. However, if you have abdominal pain or bowel problems, increasing the amount of fibre in your diet should help. Cutting down on sweet food and drinks will help to minimise dental problems.

Remember that alcohol, tea, coffee and other caffeinated drinks can be dehydrating. Sipping water or sucking ice cubes regularly can help to relieve the discomfort of a dry mouth.

See Arthritis Research UK booklet
Diet and arthritis.

Complementary medicine
There isn’t scientific evidence that suggests any specific complementary medicine can ease the symptoms of Sjögren’s syndrome. Generally speaking, though, complementary and alternative therapies are relatively well tolerated, 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 medicine 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.

Taking vitamins can help to control the symptoms in some people with Raynaud’s phenomenon. The use of high dose vitamins E and C, evening primrose oil, fish oils and ginger or Ginkgo Biloba can also help. If the vitamin regime doesn’t help within 3 months you should stop taking them, but always consult your doctor before you try anything.

Sex and pregnancy
One less common symptom of Sjögren’s syndrome may be that you have a dry vagina, which can make sex painful. Lubricants such as KY Jelly or Astroglide should help and so can oestrogen creams. Treatments for infections such as thrush are readily available from chemists.

There aren’t usually any increased problems during or after pregnancy.
with Sjögren’s syndrome. In about 2% of women who have anti-Ro and/or anti-La antibodies, these antibodies are passed on to the baby during pregnancy and cause symptoms in the baby after birth. These symptoms can include rashes and abnormal blood tests, but both settle within a few weeks to a few months as the mother’s antibodies are gradually lost from the baby’s blood. In some cases the antibodies affect the baby’s heart, causing it to beat slowly. Remember that 98% of mothers with anti-Ro and anti-La have no problems with pregnancy, but if you know you have these antibodies you should mention this to your obstetrician as additional monitoring of the baby’s heartbeat in the womb is required.

See Arthritis Research UK booklets *Pregnancy and arthritis; Sex and arthritis.*
**Glossary**

**Antibodies** – blood proteins that form in response to germs, viruses or any other substances that the body sees as foreign or dangerous. The role of antibodies is to attack these foreign substances and make them harmless.

**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.

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

**Cauterisation** – the controlled destruction of body tissues by the application of heat. In Sjögren’s syndrome it’s sometimes used to permanently seal the ducts that drain fluid away from the eye.

**Coeliac disease** – a lifelong autoimmune disease caused by intolerance to gluten, a protein present in cereal grains especially wheat.

**C-reactive protein (CRP)** – a protein found in the blood. The level of C-reactive protein in the blood rises in response to inflammation and a blood test for the protein can therefore be used as a measure of inflammation or disease activity.

**Erythrocyte sedimentation rate (ESR)** – a test that shows the level of inflammation in the body. Blood is separated in a machine with a rapidly rotating container (a centrifuge), then left to stand in a test tube. The ESR test measures the speed at which the red blood cells (erythrocytes) settle.

**Fibrosis** – the formation of scar tissue, sometimes caused by an exaggerated healing process. When it occurs in one of the body’s vital organs, fibrosis may impair the function of the affected organ.

**HTLV (human T-cell lymphotropic virus)** – a virus that infects a type of white cell called the T-cell or T-lymphocyte and is associated with adult T-cell leukaemia and lymphoma.

**Immunosuppressive drugs** – drugs that suppress the actions of the immune system. They’re often used in conditions such as rheumatoid arthritis where the immune system attacks the body’s own tissues.

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

**Lupus (systemic lupus erythematosus or SLE)** – an autoimmune disease in which the immune system attacks the body’s own tissues. It can affect the skin, the hair and joints and may also affect internal organs. It’s often linked to a condition called antiphospholipid syndrome (APS).

**Lymphoma** – cancer of the lymph nodes or glands.
Magnetic resonance imaging (MRI) – a type of scan that uses high-frequency radio waves in a strong magnetic field to build up pictures of the inside of the body. It works by detecting water molecules in the body’s tissue that give out a characteristic signal in the magnetic field. An MRI scan can show up soft-tissue structures as well as bones.

Non-steroidal anti-inflammatory drugs (NSAIDs) – a large family of drugs prescribed for different kinds of arthritis that reduce inflammation and control pain, swelling and stiffness. Common examples include ibuprofen, naproxen and diclofenac.

Oestrogen – one of a group of hormones in the body that control female sexual development and the reproductive cycle.

Physiotherapist – a therapist who helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

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

Primary biliary cirrhosis – an autoimmune disorder that gradually destroys the biliary system, which drains bile from the liver into the intestines. The bile ducts in the liver become inflamed and damaged, resulting in an accumulation of bile in the liver. Symptoms include yellowing of the skin (jaundice), itching and an enlarged liver.

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. Raynaud’s phenomenon can also occur with the condition scleroderma.

Retrovirus – a type of virus whose genetic material is ribonucleic acid (RNA) instead of deoxyribonucleic acid (DNA). The virus is able to change its genetic material into DNA so the virus becomes part of the genetic information of the host cell as the host cell replicates. Retroviruses include HIV and some forms of cancer.

Rheumatoid arthritis – an 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 wrists at once.

Sarcoidosis – a disorder that causes small fleshy nodules (granulomata) to form in tissues in the body. This can be in the lungs, liver, spleen, skin, salivary glands and other tissues, and the lymph glands are often swollen. The cause isn’t known.

Scleroderma – a medical condition characterised by hardening and tightening of the skin. It often affects other parts of the body as well, including the connective tissues that surround the joints, blood vessels and internal organs.
Ultrasound scan – a type of scan that uses high-frequency sound waves to examine and build up pictures of the inside of the body.

Vasculitis – inflammation of the walls of blood vessels. This can cause the blood flow to be reduced. Vasculitis can occur on its own (primary vasculitis) or in people who already have an established disease (secondary vasculitis). Secondary vasculitis can happen with a number of different rheumatic diseases, including Sjögren’s syndrome, rheumatoid arthritis and lupus.
Where can I find out more?
If you’ve found this information useful you might be interested in these other titles from our range:

Conditions
- Lupus (SLE)
- Rheumatoid arthritis
- Raynaud’s phenomenon
- Scleroderma

Therapies
- Physiotherapy and arthritis

Self-help and daily living
- Complementary medicine and arthritis
- Diet and arthritis
- Fatigue and arthritis
- Pregnancy and arthritis
- Sex and arthritis

Drug leaflets
- Azathioprine
- Cyclophosphamide
- Hydroxychloroquine
- Mycophenolate
- Non-steroidal anti-inflammatory drugs
- Rituximab
- Steroid tablets

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

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
www.arthritiscare.org.uk

British Sjögren’s Syndrome Association (BSSA)
PO Box 15040
Birmingham B31 3DP
Phone: 0121 478 0222
Helpline: 0121 478 1133
www.bssa.uk.net
National Rheumatoid Arthritis Society (NRAS)
Unit B4, Westacott Business Centre
Westacott Way
Littlewick Green
Maidenhead SL6 3RT
Phone: 0845 458 3969 or 01628 823524
Helpline: 0800 298 7650
www.nras.org.uk

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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’re the UK’s fourth largest medical research charity and 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 our quarterly 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: feedback@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. Simon Bowman, who has expertise in the subject. It was assessed at draft stage by specialist nurses Vicky Chamberlain, Sharon Petford and Debbie Bond, and GP Dr Giles Hazan. 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, Kate Gadsby is responsible for the content overall.
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