

## Behçet's syndrome

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



# What is Behçet's syndrome?



Behçet's syndrome is very rare in the UK – only about 2,000 people have it. In this booklet we'll explain the main facts about Behçet's syndrome, including the symptoms and who gets it. We'll also look at what you can do to manage and treat it, from simple self-help measures to the range of drug treatments that are available.

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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# At a glance

## Behçet's syndrome

**Behçet's syndrome or Behçet's disease is a condition that can cause a wide range of symptoms.**

### What is Behçet's syndrome?

Behçet's syndrome is a condition that can cause a number of symptoms. It's quite rare in the UK but can be controlled with the right treatment.

### What are the symptoms?

There are a number of possible symptoms. Some people have many symptoms whereas others have only a few. People can have different symptoms at different times, including:

- mouth ulcers
- genital ulcers around the penis or the vagina
- skin problems
- eye inflammation
- fatigue
- joint problems
- problems with the nervous system and bowels
- blood clots (thrombosis)
- headaches.

### What treatments are there?

At present, there's no cure for Behçet's syndrome. However, treatment can control the severity of your symptoms and improve your general well-being.

### Drugs

The following drugs might be used, depending on your symptoms:

- mouth washes with steroids and antibiotics, steroid paste and steroid sprays (applied directly to ulcers)
- steroids to apply to the eye, and to genital and skin ulcers
- colchicine tablets, pentoxifylline tablets or dapsone for mouth or genital ulcers
- painkillers or anti-inflammatory drugs for joint pain
- immunosuppressive drugs, for example azathioprine, mycophenolate, ciclosporin
- steroids, for example prednisolone, although use is limited due to the increased risk of osteoporosis
- anti-TNF drugs if other treatments don't help
- thalidomide is very occasionally used for severe ulceration – but not for women who may become pregnant.

## How is it diagnosed?

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A definite diagnosis isn't always possible, but you might have Behçet's if you have recurrent mouth ulcers (more than three in a 12-month period) plus any two of the following:

- genital ulcers
- skin problems
- inflammation in the eye
- a positive pathergy test.

## What tests are there?

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Although there's no test to confirm the diagnosis of Behçet's, you may have blood tests to:

- rule out other diseases
- measure the level of inflammation – for example:
  - erythrocyte sedimentation rate (ESR)
  - C-reactive protein (CRP)
- monitor the effect of drug treatments and to check they're not causing side-effects, for example:
  - full blood count
  - kidney function tests
  - liver function tests

- test for a genetic marker (HLA-B51) – it's thought that people with a positive result are more likely to develop Behçet's.

Other tests may include:

- a chest x-ray
- telescopic examination of the bowel or stomach (endoscopy)
- computer tomographic (CT) scan
- magnetic resonance imaging (MRI) scan.

## How can I help myself?

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To help with your symptoms, try the following:

- Exercise your joints and keep fit, but rest when you need to – exercise such as yoga or Pilates may also help to reduce stress.
- Stress can trigger a flare-up of symptoms in some people, so trying to reduce stress levels is important.
- To improve your overall health, eat a healthy, low-fat, balanced and nutritious diet, and drink plenty of water.



## What is Behçet's syndrome?

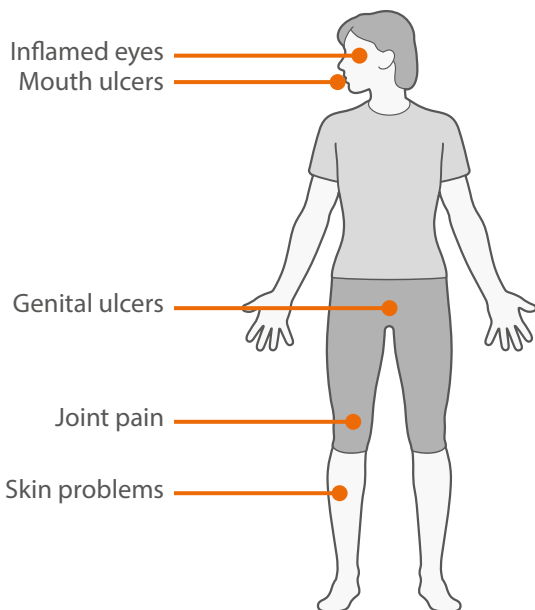
Behçet's syndrome or Behçet's disease (pronounced betchets) is a condition that causes a number of symptoms, including mouth ulcers, genital ulcers and eye inflammation. It's named after Professor Hulusi Behçet, a Turkish skin specialist, who first suggested these symptoms might all be linked to a single disease. Since then it has become clear that the syndrome may be associated with many other symptoms.

- ! A syndrome is a group of symptoms (what you experience) and signs (what the doctor finds by examining you). Doctors tend to talk of a syndrome

rather than a disease when the cause linking the different features isn't known. Although many doctors now refer to Behçet's disease, others believe that it may not be a single disease with a single cause. For this reason we'll use the term syndrome throughout this booklet, but you'll often hear the term Behçet's disease used instead.

## What are the symptoms of Behçet's syndrome?

Behçet's has a wide range of possible symptoms (see Figure 1) but most people only have a few of these.



**Figure 1**  
Some of the  
symptoms  
of Behçet's  
syndrome



### Mouth ulcers

About 98% of people with Behçet's syndrome have frequent mouth ulcers. They can affect the mouth, tongue and throat, and are often painful. Sometimes there are many tiny ulcers clustered together. If you only have occasional mouth ulcers, it's very unlikely that you have Behçet's. This is true even if you have a relative who has the condition.

### Genital ulcers

Women and girls may get ulcers on the vulva, in the vagina or on the cervix. Men and boys may get ulcers on the scrotum and the penis. Some men and boys also have pain or swelling in the testicles. Ulcers and boils may appear

around the anus and in the groin. Neither mouth nor genital ulcers in Behçet's syndrome are caused by the herpes virus. They're not sexually transmitted or contagious, so you can't catch them from someone else.

### Skin problems

Skin problems can include acne-like spots, boils, red patches, ulcers, spots that look like insect-bites and lumps under the skin. The skin may become inflamed, ulcerated or appear to be infected.

### Eye inflammation

Inflammation within the eye is one of the most serious symptoms of Behçet's syndrome. The inflammation may be at the front or back of the eye, around the iris or next to the retina (see Figure 2). It must be treated as soon as possible to avoid possible loss of sight. Symptoms include floaters (dots or specks that appear to float across the field of vision), haziness or loss of sight, and pain and redness in the eye.

### Tiredness (fatigue)

Extreme tiredness is a very common symptom.

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

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### Joint problems

You may have aches, pains and swelling in various joints. These problems may come and go or they may be longer lasting. This sort of joint problem isn't the same

**If you have Behçet's syndrome and develop new eye symptoms go straight to the emergency department of an eye hospital, or a general Accident & Emergency department.**



as rheumatoid arthritis or osteoarthritis and doesn't usually damage the joints.

**i See Arthritis Research UK booklets**

*Osteoarthritis; Pain and arthritis;  
Rheumatoid arthritis.*

### Problems with the nervous system

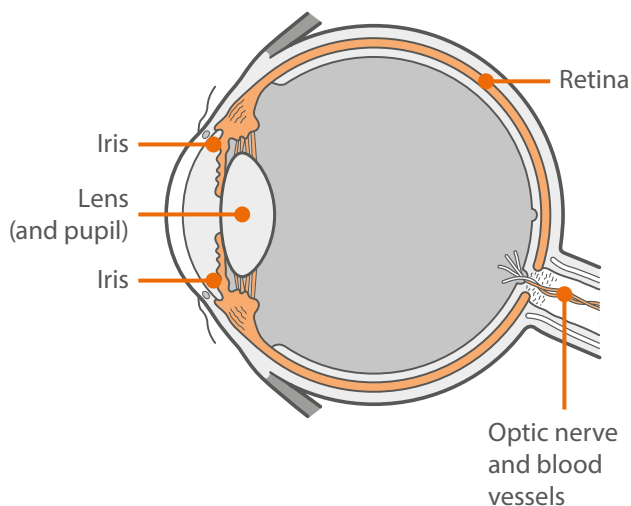
Many people have bad headaches. These may be caused by inflammation and you may need tests, but the headaches by themselves aren't usually a sign of anything serious. The headaches often respond to the same treatments that doctors give to people with migraine.

Occasionally Behçet's causes other symptoms such as double vision, difficulty hearing, dizziness, loss of balance, fainting, and weakness or numbness in the arms or legs. Some people with Behçet's experience depression.


### Bowel problems

Many people with Behçet's syndrome have bloating, excessive wind and abdominal pain. Behçet's sometimes causes inflammation of the bowel, leading to diarrhoea, with blood and mucus in the stools.

**Figure 2**  
Areas of the  
eye that can  
be inflamed  
in Behçet's  
syndrome



A side cross-section of the eye showing the inside structure and the areas that can be inflamed in Behçet's syndrome (marked in orange)



**Behçet's syndrome can't be passed on to other people. It's not associated with any other condition, a specific diet or any particular lifestyle.**

**Behçet's can occur in most ethnic groups and is most likely to develop in your 20s and 30s.**

### Blood clots (thrombosis)

Inflamed blood vessels can increase the risk of blood clots (thrombosis), but these aren't the type which cause heart attacks. Veins near the skin's surface become painful, hot and red when they're affected, and thrombosis in deeper veins leads to pain and swelling in the affected limb. The legs are affected more often than the arms. Thrombosis can occur in the blood vessels of the head, lungs or other internal organs, but this is rare.

### Who gets Behçet's syndrome?

Behçet's is rare in the UK – there are probably only about 2,000 people who have it. It's more common in Mediterranean countries, Turkey, the Middle East, Japan and south-east Asia, and it's sometimes called the Silk Route Disease after the ancient trade routes that ran through these areas.

Behçet's syndrome can occur in most ethnic groups, and we still don't know how much ethnic background increases or reduces the chances of getting it. It affects men and women of all ages, though it's most likely to develop in your 20s or 30s. It's a long-term (chronic) condition.

- ! Although there are families in which more than one person has Behçet's syndrome, overall most people who have this condition don't have relatives who also have it. Behçet's syndrome isn't passed directly from parent to child, but genetic factors may increase the likelihood of a person developing the condition.

### What causes Behçet's syndrome?

The symptoms of Behçet's syndrome are caused by inflammation, though it's not yet clear why this happens. It's possible that a viral or bacterial infection may trigger the condition, but no specific infection has been identified. It's also possible that Behçet's may be an autoimmune disease, where the immune system attacks the body's own tissues, but this isn't yet certain.

Behçet's syndrome can't be passed on to other people. It's not associated with any other condition, a specific diet or any particular lifestyle.

### What is the outlook?

Although Behçet's syndrome is a long-term problem, it doesn't usually affect how long you live. The condition tends to go through phases when sometimes it's better than others.

Treatment may prevent new symptoms from appearing and control the existing ones. Because of the many possible problems that can occur, people with Behçet's syndrome should see a rheumatologist or another doctor with an interest in the condition.

## How is Behçet's syndrome diagnosed?

Diagnosing Behçet's can take some time. There's no test to confirm the diagnosis, and the symptoms can be confused with those of other more common illnesses. Your doctor will need to rule out other possible causes of your symptoms.

### What tests are there?

#### Pathergy test

You may need to take a pathergy test. This measures the increased sensitivity of the skin that occurs in Behçet's syndrome.

Your doctor will give you a small pin-prick or injection – if a characteristic red spot appears on the skin around the pin-prick, then the result is positive.

This doesn't mean you definitely have Behçet's, but your doctor will take this result into account, along with your symptoms, when making the diagnosis.

A definite diagnosis isn't always possible, but you might have Behçet's if you have recurrent mouth ulcers (more than three in a 12-month period) plus any two of the following:

- genital ulcers
- skin problems
- eye inflammation
- a positive pathergy test.

#### Blood tests

Blood tests won't confirm a diagnosis of Behçet's, but they may be taken in order to:

- rule out other diseases
- measure the degree of inflammation, for example:
  - erythrocyte sedimentation rate (ESR)
  - C-reactive protein (CRP)
- monitor the effect of drug treatments and to check they're not causing side-effects, for example:
  - full blood count
  - kidney function tests
  - liver function tests
- test for a genetic marker (HLA-B51)
  - it's thought people with this genetic marker are more likely to develop Behçet's. Its presence supports a diagnosis (although it may be found in people without Behçet's).

Parents with Behçet's syndrome sometimes ask if their children should have the HLA-B51 test to see whether they might develop the disease in the future. This isn't recommended because there's no way of knowing whether a child will develop Behçet's syndrome even if they do have this gene. If you think your child or another relative might have Behçet's syndrome, they should see their doctor and mention that there's a history of Behçet's syndrome in the family.

Additional symptoms (for example arthritis, thrombosis) may increase the likelihood that the diagnosis is correct.

### **Other tests**

Different people may need different tests, for example:

- You may have a chest x-ray to check there's no infection in your lungs, particularly if your doctor suggests treatment that might affect your immune system.
- If you have bowel problems you may need a telescopic examination of the bowel or stomach (endoscopy). In some specialist centres, examination of the small bowel can be carried out using a small, pill-sized camera which is swallowed (wireless capsule endoscopy).
- CT and MRI scans can give more detailed images than x-rays. These scans may be needed to look further into specific symptoms.

### **What treatments are there for Behçet's syndrome?**

While there's currently no cure for Behçet's syndrome, evidence shows that there is an improved prognosis with early diagnosis and prompt treatment.

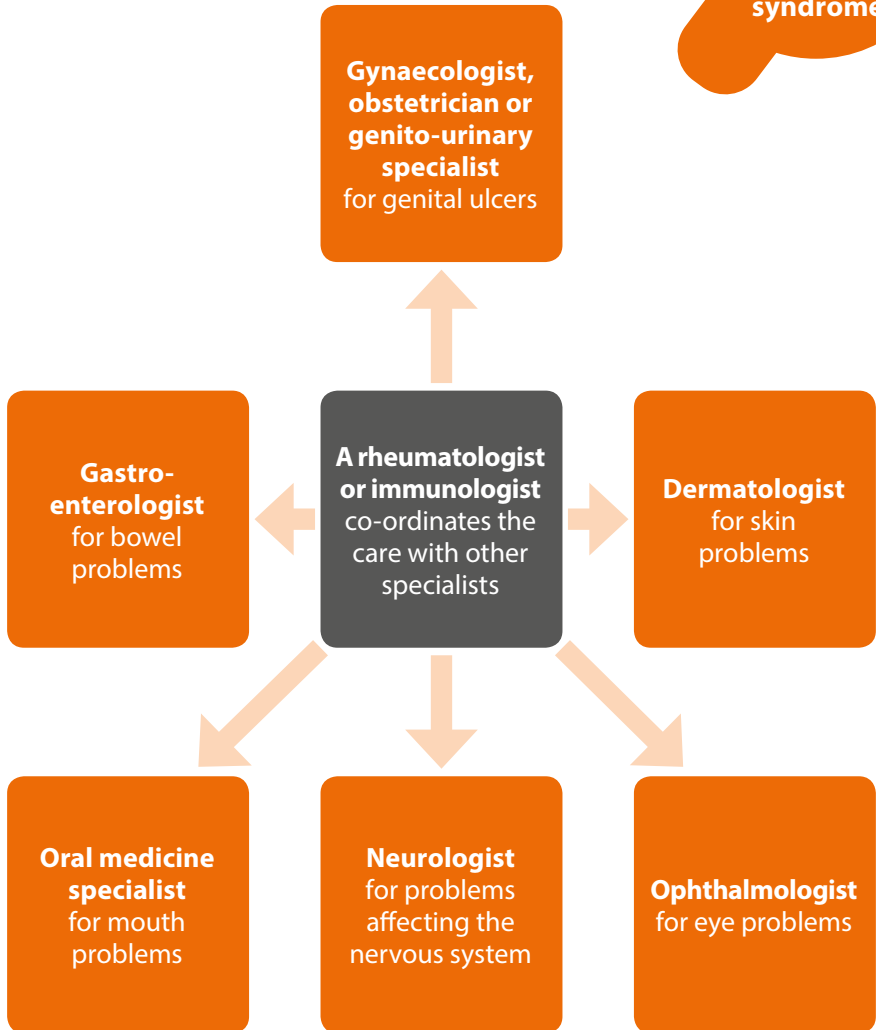
And treatment can control the severity of your symptoms and improve your general well-being.

Because Behçet's can affect many parts of the body, you may see and be treated by several different specialists. Usually one specialist will co-ordinate your treatment. This is often a rheumatologist or immunologist, who frequently works with an ophthalmologist (who specialises in eye problems).

Figure 3 outlines the other specialists that you may be referred to.



**Figure 3**  
Specialists  
who may treat  
you if you  
have Behçet's  
syndrome



## Drugs

Many drugs can be used to control Behçet's syndrome. Doctors aim to match the strength of the drug with the seriousness of the problem since the chances of side-effects are generally higher with more powerful drugs:

- There are treatments that can be applied directly to the ulcers. These include mouthwashes with steroids and antibiotics, steroid paste and steroid sprays. Most of these are only available on prescription. Steroids can also be prescribed to apply to the eye and to genital and skin ulcers.
- Colchicine tablets are often prescribed for mouth or genital ulcers. Pentoxifylline tablets, and dapsone may also be effective.
- The usual treatment for moderate to severe cases of Behçet's syndrome is a group of drugs that control inflammation by suppressing the body's overactive immune system. Azathioprine is most commonly prescribed but mycophenolate and ciclosporin are also used.
- Some people need additional treatment with steroids (usually prednisolone), although doctors try to limit the use of these because of their side-effects, particularly the increased risk of osteoporosis.

There's evidence that anti-TNF drugs, for example infliximab or adalimumab, may be effective if other treatments don't help. These have been highly successful

in other inflammatory illnesses (such as rheumatoid arthritis) and are becoming more widely used in Behçet's syndrome. However, these drugs are expensive and approval for use needs to be given within the NHS on an individual patient basis.

Thalidomide can also be useful for treating severe ulceration, although doctors are cautious about giving this to women who may become pregnant. This is because of the risk of severe birth defects. It can also cause damage to nerves and therefore its use is becoming less common. Special arrangements apply for its prescription, so it's not always approved.

A drug called interferon alpha is currently being tested. It works by suppressing the immune system and may be helpful for all symptoms of Behçet's.

You may need painkillers in addition to the drugs mentioned above, for example, to ease joint pain. Over-the-counter painkillers (like paracetamol, ibuprofen) may be enough, but your doctor may be able to prescribe something stronger if not.

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**i See Arthritis Research UK booklet and drug leaflets**

*Osteoporosis; Azathioprine; Ciclosporin; Drugs and arthritis; Local steroid injections; Mycophenolate; Painkillers and NSAIDs; Steroid tablets.*

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## Self-help and daily living

### Exercise

It's important to exercise your joints and to keep up your general level of fitness. Do as much as you can but make sure you rest when you feel you need to. Exercise such as yoga or Pilates may also help to reduce stress, which can trigger a flare-up of symptoms in some people.

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

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### Diet and nutrition

A poor diet won't cause Behçet's. But we recommend a healthy, nutritious and balanced diet, with plenty of fruit and vegetables and water, and not too many fats and sugars. This, alongside an active lifestyle, will improve your general health.

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

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**A poor diet won't  
cause Behçet's,  
but we recommend  
a balanced diet for  
your general health.**

### Complementary medicine

There's no evidence to suggest that any particular complementary medicine can help ease the symptoms of Behçet'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 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. If your therapist suggests that you should stop your prescribed treatment, you should consider the safety of this advice very carefully and discuss it with your rheumatologist or GP.

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

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### Sex and pregnancy

The genital ulcers associated with Behçet's can sometimes make sex uncomfortable or even painful. However, they're not sexually transmitted or contagious.



Some of the drugs used to treat Behçet's syndrome can affect sperm, eggs, fertility or even the baby – for example, thalidomide is known to be harmful to an unborn child. It's important to discuss your plans with your doctor if you're thinking of having a baby. This applies to both men and women with Behçet's. However, there's no reason why you shouldn't have a family, and the chances of your children inheriting the condition are tiny.

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

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## Living with Behçet's syndrome

Any long-term condition can affect your mood, emotions and confidence, and it can have an impact on your work, social life and relationships.

Talk things over with a friend, relative or your doctor if you do find your condition is getting you down. You can also contact support groups if you want to meet other people with Behçet's.

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**i See Arthritis Research UK booklets**  
*Everyday living and arthritis; Work and arthritis.*

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## Research and new developments

Fatigue is a common symptom of Behçet's syndrome. Arthritis Research UK is funding a number of research projects investigating the cause of fatigue in arthritic conditions. For example Dr Ben Seymour, at the University of Cambridge, is investigating the relationship between fatigue and inflammation. Although this research will mainly involve people with rheumatoid arthritis, the outcomes may also be relevant to people with other conditions, such as Behçet's.



## Glossary

**Anti-TNF** – drugs that block the action of a protein in the blood called tumour necrosis factor (TNF) which causes inflammation when present in excessive amounts. Adalimumab, etanercept and infliximab are examples of anti-TNF drugs.

**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.

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

**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.

**Full blood count** – a blood test used to measure haemoglobin (found in red blood cells), white blood cells and platelets. This test is frequently carried out to monitor drug treatment.

**Herpes virus** – a family of viruses. Different strains of the herpes virus can cause a number of conditions, including chickenpox, cold sores and herpes, symptoms of which can include blisters and ulcers.

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

**Immunologist** – a specialist who treats disorders of the immune system.

**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.

**Liver function tests** – blood tests used to check the healthy functioning of the liver. They're frequently performed to monitor drug treatment.

**Magnetic resonance imaging (MRI) scan** – 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.

**Osteoarthritis** – the most common form of arthritis (mainly affecting the joints in the fingers, knees, hips), causing cartilage thinning and bony overgrowths (osteophytes) and resulting in pain, swelling and stiffness.

**Osteoporosis** – a condition where bones become less dense and more fragile, which means they break or fracture more easily.

**Pathergy test** – a simple test that involves pricking the skin with a small needle in order to see if the skin reacts.

**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 both wrists at once.

**Rheumatologist** – a specialist with an interest in autoimmune diseases and diseases of joints, bones and muscles.

**Thrombosis** – a blood clot that occurs in an artery or a vein. A pulmonary embolism is when a blood clot reaches the lungs.

## 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

- *Osteoarthritis*
- *Osteoporosis*
- *Rheumatoid arthritis*
- *What is arthritis?*

### Self-help and daily living

- *Complementary and alternative medicine for arthritis*
- *Diet and arthritis*
- *Everyday living and arthritis*
- *Fatigue and arthritis*
- *Keep moving*
- *Looking after your joints when you have arthritis*
- *Pregnancy and arthritis*
- *Sex and arthritis*
- *Work and arthritis*

### Drug leaflets

- *Azathioprine*
- *Ciclosporin*
- *Local steroid injections*
- *Mycophenolate*
- *Painkillers and NSAIDs*
- *Steroid tablets*

## **Arthritis Research UK**

### **Behçet's syndrome**

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)

Links to sites and resources provided by third parties 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.

### **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: 0207 380 6500  
Helpline: 0808 800 4050  
Email: [info@arthritiscare.org.uk](mailto:info@arthritiscare.org.uk)  
[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

#### **Behçet's Syndrome Society**

Kemp House  
152-160 City Road  
London EC1V 2NX  
Helpline: 0845 130 7329  
Email: [info@behcetsdisease.org.uk](mailto:info@behcetsdisease.org.uk)  
[www.behcets.org.uk](http://www.behcets.org.uk)



## 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. Dorian Haskard and revised by Dr Nicola Ambrose, who have expertise in the subject. It was assessed at draft stage by GP Giles Hazan who has a specialist interest in musculoskeletal medicine, rheumatology nurse specialist Gail Melling and members of the board of trustees of the Behçet's Syndrome Society. An **Arthritis Research UK** editor revised the text to make it easy to read. An **Arthritis Research UK** medical advisor, Prof. Anisur Rahman, 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](mailto:enquiries@arthritisresearchuk.org)**  
or go to  
**[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)**



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calls charged at standard rate

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

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