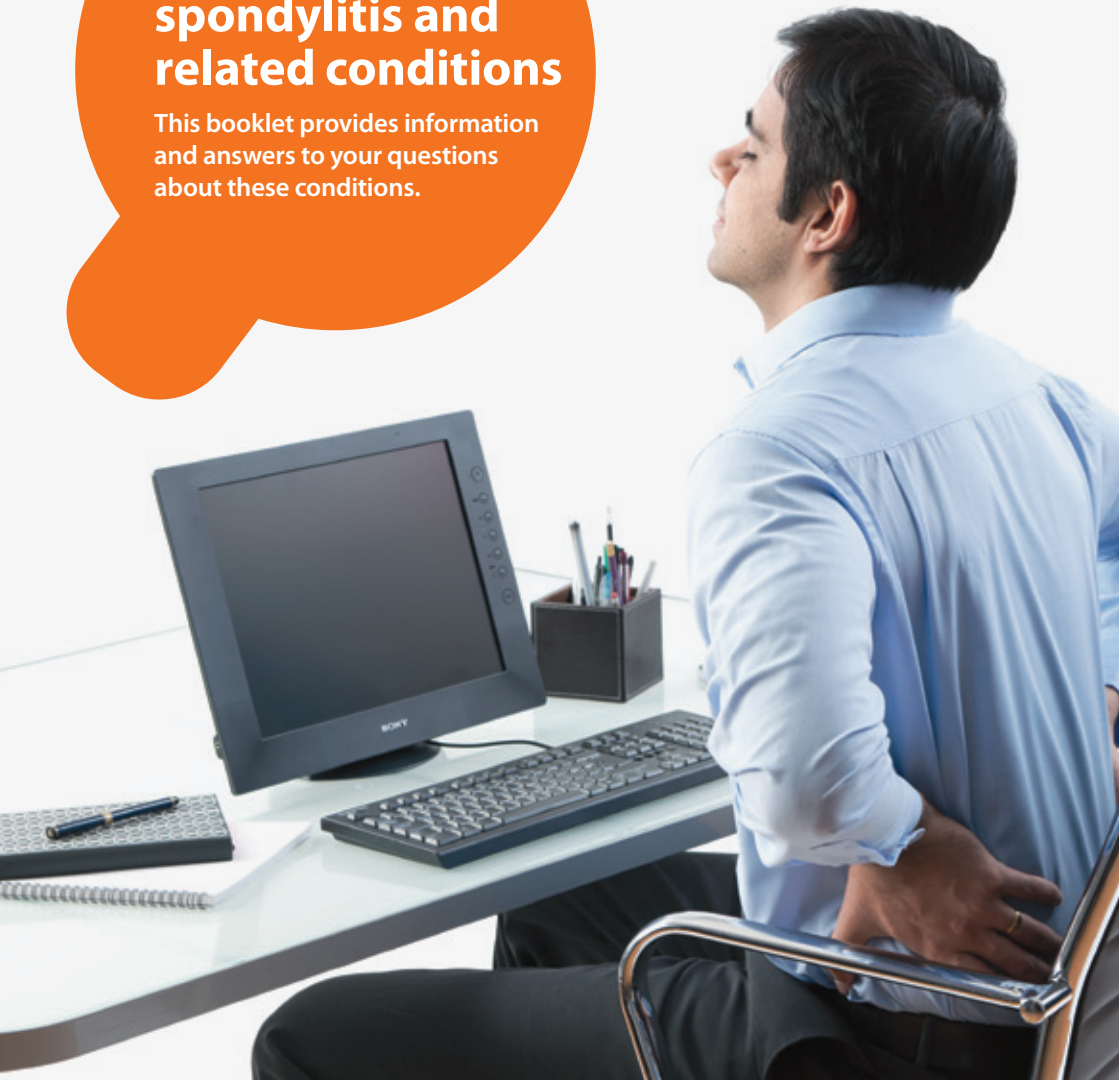
Arthritis Research UK

Condition
Ankylosing spondylitis

Ankylosing spondylitis and related conditions

This booklet provides information and answers to your questions about these conditions.



What is ankylosing spondylitis?

Ankylosing spondylitis (AS) is a type of arthritis that mainly affects the back. It causes inflammation in the joints of the spine, leading to pain and stiffness. In this booklet, we'll explain the symptoms of ankylosing spondylitis, what causes them, how they're diagnosed and the available treatments.

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

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What's inside?

At a glance
Ankylosing spondylitis and related conditions

Spondylitis means inflammation of the spine.

What is ankylosing spondylitis?

Ankylosing spondylitis (AS) is a type of arthritis that mainly affects the back. It causes inflammation in the joints of the spine, leading to pain and stiffness.

Ankylosing spondylitis is variable – some people can almost forget they have the condition, while for others it can have a big impact on their quality of life. Sometimes other joints and different parts of the body can be affected too.

Ankylosing spondylitis is a type of spondyloarthritis (pronounced as spond–ee–lo–arth–ritis), a group of conditions that share many of the same symptoms. There's more information about these conditions in this booklet.

What are the symptoms?

Typical symptoms of ankylosing spondylitis include:

- lower back or neck pain and stiffness
- pain in the sacroiliac joints (the joints where the base of the spine meets the pelvis), the buttocks or the back of the thighs
- tiredness (fatigue).

Other possible symptoms include:

- pain and swelling in other joints
- tenderness or discomfort around your heels
- swelling of the fingers or toes
- pain or tightness in the chest
- eye inflammation (painful, bloodshot eyes).

Who gets ankylosing spondylitis?

Ankylosing spondylitis can affect anyone, young or old, male or female, although it's more common in young men. It's most likely to start in your late teens and 20s. Ankylosing spondylitis is linked to the genes we inherit but it's not a certainty that a child will get it if a parent has it.

How is ankylosing spondylitis diagnosed?

There's no specific test for ankylosing spondylitis, so your doctor will base the diagnosis on:

- your symptoms and how they developed
- an examination
- blood tests, x-rays or scans.

X-rays can show changes in the spine as the condition develops but aren't always helpful in the early stages. Magnetic resonance imaging (MRI) scans may be useful when x-rays aren't.

What treatments are there?

There are many different treatments available, including exercises, tablets and injections.

The health professionals in your rheumatology department can help you find treatments that are best for you. These will often include:

- **drugs** – these are given as tablets, injections or infusions to relieve pain, reduce inflammation or to alter the condition itself
- **physiotherapy and exercise** – these are very important to maintain mobility and strength in the spine and affected joints.

Surgery is very rarely needed but may be very helpful when hip joints are badly affected. Surgery to the spine is even more uncommon and only used if the spine has become very bent.

What are spondyloarthritis and ankylosing spondylitis?

Your doctor may have told you that you have a spondyloarthritis (SpA), which is pronounced spond–ee–lo–arth–ritis. This is the name of a family of inflammatory conditions that all have similar symptoms.

Ankylosing spondylitis (AS) is the most well-known type of spondyloarthritis and it mainly affects the joints of the spine. Spondylitis simply means inflammation of the spine. As the inflammation settles, calcium is laid down where the ligaments attach to the bones that make up the spine (these bones are called the vertebrae). This reduces the flexibility of the back. Eventually the individual bones of the spine may link up (fuse). This is called ankylosis and can be seen on x-rays.

Ankylosing spondylitis typically starts in the joints between the spine and the pelvis, but it may spread up the spine to the neck (see Figure 1). It can sometimes affect other parts of the body, including joints, tendons or the eyes.

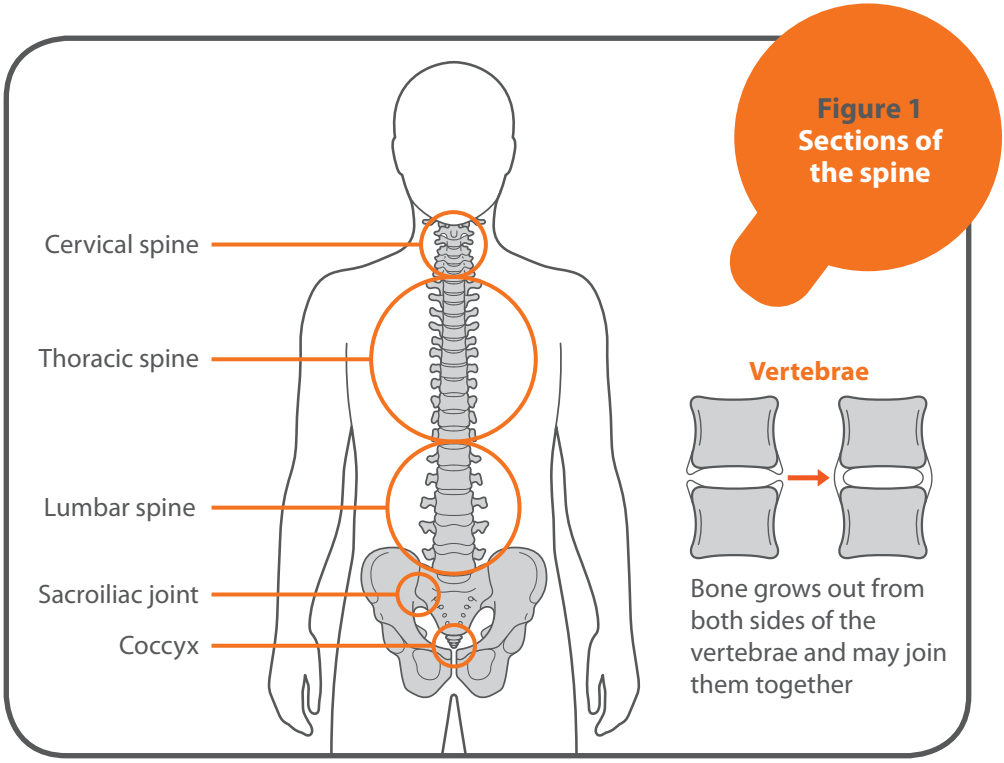


Figure 1 Sections of the spine

Ankylosing spondylitis affects 2–3 times as many men as women and often starts in your late teens or 20s. The average age of onset is 24.

Although we don't yet know the exact causes of ankylosing spondylitis, there are many different treatments and therapies that can help to minimise the impact the condition has on your life.

What are the related conditions?

There are a number of related conditions in the spondyloarthritis family and they have many linked symptoms. Unless stated otherwise, the information in this booklet will be useful for whichever type you have.

Undifferentiated spondyloarthritis (uSpA) has similar symptoms to ankylosing spondylitis but doesn't have the signs of damage to your joints on an x-ray. Some people with undifferentiated spondyloarthritis later develop ankylosing spondylitis.

Psoriatic spondyloarthritis (a form of psoriatic arthritis) occurs when your arthritis is related to the skin condition psoriasis.

Spondyloarthritis associated with inflammatory bowel disease (or enteropathic arthritis) occurs when your arthritis is related to bowel conditions such as Crohn's disease or ulcerative colitis.

Reactive spondyloarthritis (Reiter's syndrome) is diagnosed when your arthritis is a reaction to an infection.

Enthesitis-related arthritis is the name used when children and teenagers develop arthritis of the entheses, the sites where tendons and ligaments attach to bone.

See Arthritis Research UK booklets *Psoriatic arthritis; Reactive arthritis; When your child has arthritis.*

Some doctors use the terms spondarthritis, spondyloarthropathy, spondyloarthritides or seronegative spondyloarthritis rather than just spondyloarthritis. These terms are interchangeable and all describe types of arthritis belonging to the same family of conditions as ankylosing spondylitis.

The spine is made up of 24 vertebrae and 110 joints.

What are the symptoms of ankylosing spondylitis?

In the early stages, ankylosing spondylitis is likely to cause:

- stiffness and pain in the lower back
- pain in the sacroiliac joints (the joints where the base of the spine meets the pelvis), the buttocks or the back of the thighs.

The related conditions share these symptoms.

You may first notice problems after a muscle strain, so the condition can be mistaken for common backache. However, stiffness that lasts at least 30 minutes in the morning helps to distinguish ankylosing spondylitis from simple back pain. It may also occur after rest. The stiffness can be eased by exercise or movement.

Pain in the neck, shoulders, hips or thighs may follow. This is often worse after prolonged rest and immobility, and can be bad at night. Some people have pain, stiffness and swelling in the knees, ankles or in the smaller joints of the hands and feet. For some people, especially children and teenagers, the first signs may be in the hip or knee rather than in the back. Inflammation can occur at any point in the body where tendons attach to bone (enthesitis), for example in the jaw, shoulder or knee.

Other possible symptoms include:

Tenderness at the heel – This makes it uncomfortable to stand on a hard floor. Inflammation can occur at the back of the heel where the Achilles tendon meets the heel bone or in the tendon in the arch of the foot, causing pain known as plantar fasciitis.

Pain and swelling in a finger or toe – When the whole digit is swollen it's known as dactylitis.

Tenderness at the base of your pelvis (ischium) – This makes sitting uncomfortable.

Chest pain or a 'strapped-in' feeling that comes on gradually – If the spine is affected at chest level (the thoracic spine), it can affect movement at the joints between the ribs and the breastbone. This makes it difficult to take a deep breath. Your ribs may be very tender, and you may feel short of breath after even gentle activity. Coughing or sneezing may cause discomfort or pain.

Inflammation of the eye (uveitis or iritis) – The first signs of this are usually a red (bloodshot), watery and painful eye, and it may become uncomfortable to look at bright lights. If this happens to you or if you develop blurred vision, it's important to get medical help within 24–48 hours. The best place to go is Eye Casualty – there will be one in your region, but it might not be at your local hospital. Your GP surgery, local A+E or even your optician will know where the Eye Casualty is. Treatment is usually with steroid eye drops, which are generally very effective.

Some people get recurrent attacks, but they're extremely unlikely to cause permanent damage to your eyesight if they're treated quickly.

Inflammation of the bowel – People with ankylosing spondylitis can develop bowel problems known as inflammatory bowel disease (IBD) or colitis. It's a good idea to tell your doctor if you develop diarrhoea for more than 2 weeks or begin to pass bloody or slimy stools. You might be referred to a bowel specialist (a gastroenterologist). Inflammatory bowel disease is variable, but it can usually be treated successfully with medication. Sometimes treatments like non-steroidal anti-inflammatory drugs (NSAIDs) can make bowel problems worse, and you might be advised to stop taking them.

Tiredness (fatigue) – People with ankylosing spondylitis may experience tiredness caused by the activity of the condition, anaemia or sometimes depression and frustration associated with the condition.

The inflammation that causes these symptoms usually comes and goes, so the degree of pain and stiffness can vary over time. The severity of the disease can also vary between different people. If the condition is mild and only affects the sacroiliac joints, it may go almost unnoticed. If most of the spine is affected, it can cause difficulty with any activities that involve bending, twisting or turning.

What causes ankylosing spondylitis?

We don't yet know why some people develop ankylosing spondylitis. To some extent it's related to your genes, but the condition isn't passed directly from a parent to their children. Ankylosing spondylitis isn't contagious, so you can't catch it from anyone else.

Most people with ankylosing spondylitis have a gene called HLA-B27, which can be detected by a blood test. However, having this gene doesn't mean you'll definitely get ankylosing spondylitis, and the test isn't very useful in diagnosing the condition. Even in families where somebody has ankylosing spondylitis, a brother or sister may have the HLA-B27 gene and never get the condition.

What is the outlook?

Ankylosing spondylitis and the related conditions are quite variable and difficult to predict. They can cause considerable pain, although treatment will help to relieve this. You may have times when the symptoms become worse and other times when you find it easier to cope with the pain and stiffness and can get on with your life. Ankylosing spondylitis can make you feel generally unwell, lose weight and tire easily.

Most people with a spondyloarthritis have some stiffening in the spine, usually in the lower back. This can be painless and may not interfere with physical activity because the upper part of the spine, the neck, hips and limbs can remain quite mobile. However, if more of your spine stiffens up or your knees or hips are affected then you may have more difficulties with mobility.

Many of the treatments described in the rest of this booklet can help to prevent these mobility problems and improve the pain of arthritis. Other sections might help you cope better with the problems ankylosing spondylitis is causing.

Rarely, there may be complications affecting the heart, lungs and nervous system. These are less common in the other types of spondyloarthritis, and fewer than 1 in 100 people with ankylosing spondylitis have these problems.

The valves in the heart may leak, which can put more strain on the heart. And long-term inflammation and tissue scarring of the lungs can decrease rib movement, which means you can't take in a full breath. Very rarely, the top of the lungs may become scarred. If you smoke, it's extremely important to try to stop because it's likely to add to any problems with the heart or lungs.

How is ankylosing spondylitis diagnosed?

Most back pain isn't caused by ankylosing spondylitis. However, the symptoms of the condition, especially in its early stages, can be very similar to more common back problems.

Because of this, many people put up with the pain for some time before seeking help. When you first see your doctor, there may be little to show whether the problem is ankylosing spondylitis or some other, more common, back problem. Unfortunately, ankylosing spondylitis may even be misdiagnosed at first.

No specific test will confirm you have ankylosing spondylitis, so diagnosis involves piecing together information from different sources, including:

- the history of your condition
- a physical examination
- blood tests, which may show inflammation
- x-rays, a magnetic resonance imaging (MRI) scan or a computerised tomography (CT) scan.

Some people with ankylosing spondylitis have the HLA-B27 gene – having this gene won't confirm the diagnosis but it can point towards the condition.

What tests are there?

A blood test can show if there's inflammation in the body, but only if the condition is in an active phase. You'll probably have one or both of these blood tests:

- C-reactive protein (CRP)
- Erythrocyte sedimentation rate (ESR).

C-reactive protein and ESR are different tests for inflammation, so they give similar information. The laboratory that analyses the tests will decide which one you take.

Another blood test can confirm whether you have the HLA-B27 gene. Most people with ankylosing spondylitis test positive for HLA-B27, but so do some people without the condition. A positive test may point to ankylosing spondylitis but it won't confirm the diagnosis.

X-rays sometimes help to confirm the diagnosis, though they generally don't show anything unusual in the early stages of the disease. As the condition progresses new bone forms between the vertebrae, which will be visible in x-ray images. However, it may be several years before these changes show up.

Further tests may be needed, especially in the early stages of the condition. CT or MRI scans may show the typical changes in the spine and at the sacroiliac joints at an earlier stage of the disease and before x-ray changes can be identified.

A bone density scan may also be arranged as some people with ankylosing spondylitis develop osteoporosis (thinning of the bones), and it's important that this is treated.

See Arthritis Research UK booklet *Osteoporosis.*

What treatments are there for ankylosing spondylitis?

A number of treatments are available that can relieve the symptoms of pain and stiffness, keep the spine mobile and help you to live a normal life, but exercise and close attention to your posture are also important in reducing the impact of the condition.

Drugs

Several different kinds of drugs can be helpful. Painkillers and non-steroidal anti-inflammatory drugs (NSAIDs) are usually the first choice of treatment, and most people with ankylosing spondylitis will need to take these at times. For people who have more severe symptoms that can't be controlled by anti-inflammatories, a number of drugs are available which can help to reduce pain or limit the effects of the condition.

Painkillers (analgesics)

Simple pain-relieving tablets such as paracetamol or co-codamol are often very helpful. They can be taken regularly and are particularly useful if taken just before activity to keep your pain to a minimum. It's best not to wait until you're in severe pain before taking them. Simple painkillers don't need to be taken with a meal, though some water and a small snack are advised.

Non-steroidal anti-inflammatory drugs

There's a wide range of NSAIDs that can reduce pain so you can get on with your daily jobs and activities and your exercise routine. You'll probably need to take these during bad patches, and some people may need them over a longer period. Some tablets are made in a slow-release formulation, which can relieve night-time pain and morning stiffness. NSAIDs are also available in gels, which can be applied to the skin over the painful area.

There are a number of different treatments available for ankylosing spondylitis. Your doctor might prescribe you an NSAID to reduce pain and a DMARD to reduce the damage to your joints.

Steroids can be prescribed for short-term use if you have a flare-up.

Like all drugs, 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 NSAIDs will be prescribed along with a drug called a proton pump inhibitor (PPI), which will help to protect the stomach.

NSAIDs also carry an increased risk of heart attack or stroke. Although the increased risk is small, your doctor will be cautious about prescribing NSAIDs if there are other factors that may increase your overall risk – for example, smoking, circulation problems, high blood pressure, high cholesterol or diabetes.

See Arthritis Research UK drug leaflet *Non-steroidal anti-inflammatory drugs.*

Disease-modifying anti-rheumatic drugs (DMARDs)

Some drugs are designed to reduce damage to the joints rather than just ease the symptoms. DMARDs are slow-acting so you won't notice an immediate impact on your condition, but they can make a big difference to your symptoms over a period of time. Drugs such as sulfasalazine and methotrexate can be helpful for arthritis in the joints of the arms and legs, although they're not effective for spinal symptoms.

When taking DMARDs, you'll need regular check-ups and blood tests to monitor their effect.

See Arthritis Research UK drug leaflets *Methotrexate; Sulfasalazine.*

Biological therapies (anti-TNF)

Biological therapies are a group of relatively new treatments that can be very effective. There are currently two anti-TNF drugs for ankylosing spondylitis – etanercept and adalimumab – although others may become available. They can only be prescribed by a rheumatologist and are given as an injection under the skin, which you can learn to give yourself. Biological therapies aren't suitable for everyone and are currently only available to patients with more severe forms of the condition if it can't be controlled with anti-inflammatory drugs. Anti-TNF drugs aren't approved for people with undifferentiated spondyloarthritis.

The effect of anti-TNF drugs is monitored, and you'll need to complete questionnaires regularly to assess how active your disease is.

See Arthritis Research UK drug leaflets *Adalimumab; Etanercept.*

A course of physiotherapy can help you to keep your joints mobile and strengthen your muscles.

Steroids

Steroids can be used as a short-term treatment for flare-ups. They're usually given as an injection into a swollen joint or as a slow-release injection into a muscle. They can also be used for painful tendons, for example at the heel, although they won't be repeated too often as they may cause weakness. Occasionally, you may be given a course of steroid tablets (prednisolone). While these treatments can be very effective at improving pain and stiffness, you may develop side-effects if you use them for long periods (for example weight gain, bruising or thinning of the skin, high blood pressure, high blood sugar, infections and osteoporosis).

If you develop eye inflammation, it'll usually be treated with steroid eye drops. In more severe cases, steroids may be given as tablets or as an injection into the eye.

See Arthritis Research UK drug leaflets *Local steroid injections; Steroid tablets.*

Bisphosphonates

Bisphosphonates are more often used for the treatment or prevention of osteoporosis but are sometimes helpful for reducing the pain and stiffness of ankylosing spondylitis. The one that's most commonly used is called pamidronate, which is given by infusion every few weeks.

See Arthritis Research UK drug leaflet *Pamidronate.*

Physical therapies

Physiotherapy is a very important part of the treatment for ankylosing spondylitis. A physiotherapist can put together a programme of exercises that will increase your muscle strength and help you to maintain mobility in your spine and other joints. It's especially important to exercise your back to avoid it stiffening into a bent position.

A physiotherapist will advise you on how to maintain good posture and may be able to offer you hydrotherapy treatment. This involves specific exercises for the spine, hips and shoulders that are carried out in a special warm-water pool. Many people with ankylosing spondylitis find this therapy helpful and continue their programme at their local leisure pool or with their local National Ankylosing Spondylitis Society (NASS) group.

See Arthritis Research UK booklets *Hydrotherapy and arthritis; Physiotherapy and arthritis.*

Surgery

Most people with ankylosing spondylitis don't need surgery. Some people may need a hip or knee replacement if these joints are badly affected. This can get rid of pain and improve mobility. Surgery to straighten a bent spine is very rare and isn't usually recommended. You should speak to an experienced spinal surgeon if you want advice on this.

See Arthritis Research UK booklets
Hip replacement; Knee replacement.

Self-help and daily living

Medical treatments can help to control ankylosing spondylitis, and the condition can become less active as you get older. Paying attention to your posture, mobility and exercise will help you to minimise the long-term effects of ankylosing spondylitis. Making simple changes, for example not carrying heavy shopping, can help.

Exercise

Bed rest is certainly not recommended as this will speed up the stiffening of the spine. However, if you're in intense pain it's obviously going to be extremely difficult to exercise, so you may need to treat this first. Starting slowly and building up the amount and intensity of exercise is the best strategy, because too much exercise is likely to make your pain worse.

Your physiotherapist will be able to plan an exercise programme to suit your particular needs. Over time, you'll need to exercise regularly to get the best from it. Many people find that stretching exercises after a hot shower or bath are especially helpful in easing morning stiffness.

NASS groups offer regular exercise classes, which are run by physiotherapists at various venues around the country. The classes are a good opportunity to meet other people with ankylosing spondylitis and take part in specific exercises that will help your condition. NASS can also provide information about exercising in a gym and an exercise DVD. Taking part in other sorts of exercise that you enjoy, for example dancing, swimming or gardening, are excellent ways of keeping fit too.

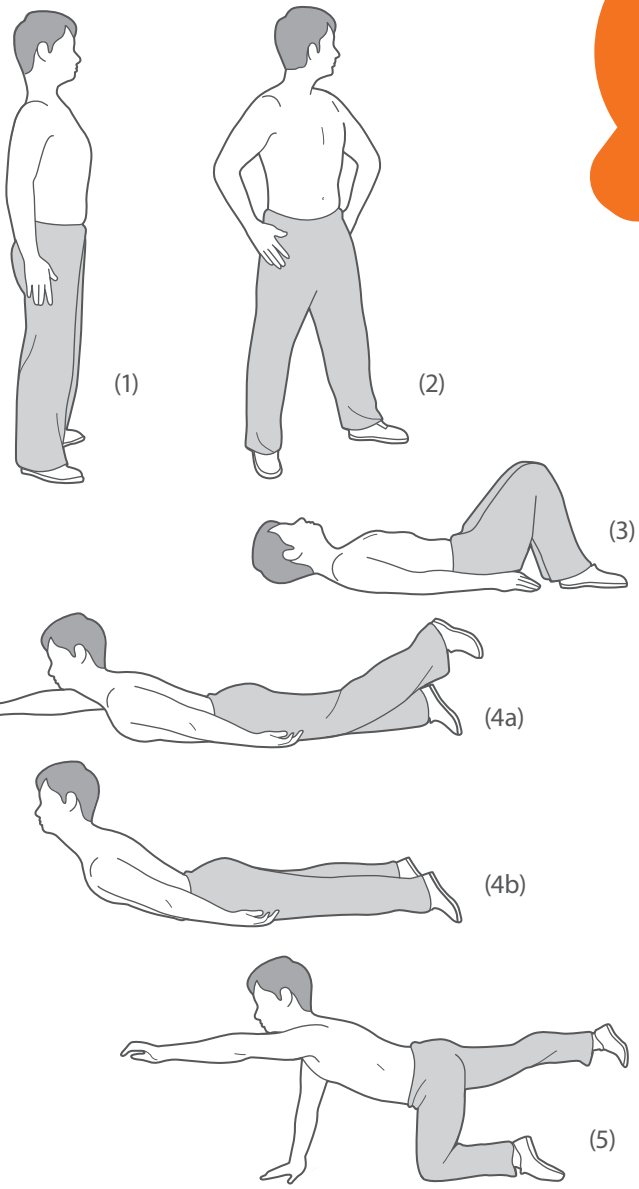
Exercises for your back, chest and limbs will keep them supple. Be careful not to overdo it as this may increase your pain, but try to do at least some exercises each day. Remember that you can take painkillers beforehand to allow you to exercise without pain.

Daily exercise programme (to maintain flexibility and strength)

Figure 2 shows a few exercises that you may find useful. Please speak to your physiotherapist for further guidance and to check you're using the correct technique, or join your local NASS group.

1. Standing with your heels and backside against a wall, push (but don't tilt) your head back towards the wall. Hold for 5 seconds then relax. Repeat about 10 times if possible.
2. Stand in an open space with your feet apart. Place your hands on your hips. Turn from the waist to look behind you. Keep your knees and feet facing the front. Hold for 5 seconds. Repeat to the other side, 5 times each side.
3. Lying on your back, knees bent, feet flat on the ground:
   (a) Put your hands on your ribs at the sides of your chest. Breathe in deeply through your nose and out through your mouth, pushing your ribs out against your hands as you breathe in. Repeat about 10 times. Remember, it's as important to breathe out fully as it's to breathe in deeply.
   (b) Put your hands on the upper part of the front of your chest. Breathe in deeply through your nose and then breathe out as far as you can through your mouth. Push your ribs up against your hands as you breathe in – again about 10 times. You can do this exercise at any time in a lying or sitting position.

Figure 2
Daily exercise programme



4. Lying on your front, looking straight ahead, hands by your sides (if necessary you may put a pillow under your chest in order to get comfortable):
   (a) Raise one leg off the ground keeping your knee straight, about 5 times for each leg. It helps to have the opposite arm stretched out in front of you.
   (b) Raise your head and shoulders off the ground as high as you can – about 10 times.
5. Kneeling on the floor on all fours, stretch alternate arms and legs out parallel with the floor and hold for 10 seconds. Lower and then repeat with the other arm and leg, 5 times each side.

You should avoid contact sports (such as rugby or basketball) as the joints and spine can be injured, but there are plenty of other activities that are suitable. Ask your physiotherapist for advice if you're in any doubt about a particular activity.

Swimming is one of the best forms of exercise because it uses all muscles and joints without jarring them. If you have limited neck movement, breaststroke and front crawl may become more difficult, and if you swim with your head up it can aggravate neck pain. Using a snorkel can be helpful. Breaststroke can also inflame the hips and pelvis, so back crawl may be better. Speak to your physiotherapist for advice. As an alternative to swimming, ask for a programme of exercises you can do in the pool.

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

Diet and nutrition

No particular diet has been found to make ankylosing spondylitis either better or worse. However, it's sensible to eat a balanced diet and to keep to a healthy weight. Being overweight will increase the strain on your back and other joints.

It's also a good idea to make sure you get enough calcium and vitamin D, which are important for the health of your bones, because people with ankylosing spondylitis have an increased risk of osteoporosis.

Many diets have been recommended for people with ankylosing spondylitis, including avoiding certain food types. There's no convincing evidence that these work, and there's a chance that you may make your health worse by missing out essential nutrients. If you're keen to try any of these diets it would be a good idea to discuss it with a dietitian or your doctor first.

See Arthritis Research UK booklet *Diet and arthritis.*

Aside from using drug treatment, there are a number of things you can try to ease your symptoms. Massage and acupuncture can help to relieve pain, and using specialist tools can help you protect your joints.

Hot or cold pads can be useful for pain relief as long as they're not applied directly to the skin.

Pain management

Most people will experience a flare-up of their arthritis at some time, when some or all of their joints become more painful and stiff. You may also feel tired and generally unwell. These flare-ups usually last from a few days up to a couple of weeks and can be completely debilitating.

Over time, you'll hopefully find treatments that prevent or limit the flare-ups you experience. You'll also become better at coping with them if and when they occur. Try talking to other people with ankylosing spondylitis or any spondyloarthritis about how they cope with flare-ups and whether they can offer any advice.

Additional pain relief and anti-inflammatories will help, as should short-term rest and gentle stretches. Massage, heat packs or ice packs may also be useful. Contact your GP or your rheumatology department for advice or to arrange an early review if you're struggling.

See Arthritis Research UK booklets *Fatigue and arthritis; Pain and arthritis.*

Complementary medicine

Generally speaking, complementary and alternative therapies are relatively well tolerated, although 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.

Acupuncture can help to relieve pain but won't have any effect on the way the disease progresses.

Manipulation isn't helpful for ankylosing spondylitis and manipulation of the spine, especially the neck, could result in permanent damage to your spine or spinal cord. We wouldn't recommend treatment by a chiropractor or osteopath.

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

Supports, aids and gadgets

If your condition causes difficulty with everyday tasks or your work, an occupational therapist (OT) should be able to help. They can advise on gadgets that may help you or explain how to adapt your technique in order to reduce strain and pain. They often work closely with disability employment advisers from the local Jobcentre Plus team to suggest equipment to help you at work, for example a special chair.

Taking a painkiller before going to bed can ease night-time pain so you can get to sleep more easily.

Corsets and braces should be avoided as they can make ankylosing spondylitis worse. It's better to strengthen your own muscles to maintain a good posture. Very occasionally, some form of support may be necessary, for example after a back injury. Discuss this with a doctor or specialist physiotherapist who's experienced in treating ankylosing spondylitis.

See Arthritis Research UK booklets *Everyday living and arthritis; Occupational therapy and arthritis.*

Sleep

Tiredness and night pain can be problems if you have ankylosing spondylitis. They're often caused by inflammation, but they may also be a result of anaemia or loss of sleep caused by night-time pain. Whatever the reason, it's important that you try to get a good night's sleep.

A medium-firm bed will be more comfortable than one that's too soft, although the mattress should have some give in it so that it moulds to the shape of your spine. Even when ankylosing spondylitis isn't in a particularly painful, active phase, it's important to make sure your mattress provides enough support to prevent any tendency for the spine to bend. When you lie on your side your spine should be straight, and when you're on your back it should keep its natural 'S' curve. Try to use as few pillows as possible so that your neck stays in a good position.

If pain is a problem at night, heat may help. Try a hot bath before going to bed, or use a hot-water bottle, wheat bag (which you can heat in a microwave) or electric blanket. A hot bath or shower helps to ease morning stiffness. You can also try the exercise shown in Figure 3.

See Arthritis Research UK booklet *Sleep and arthritis.*

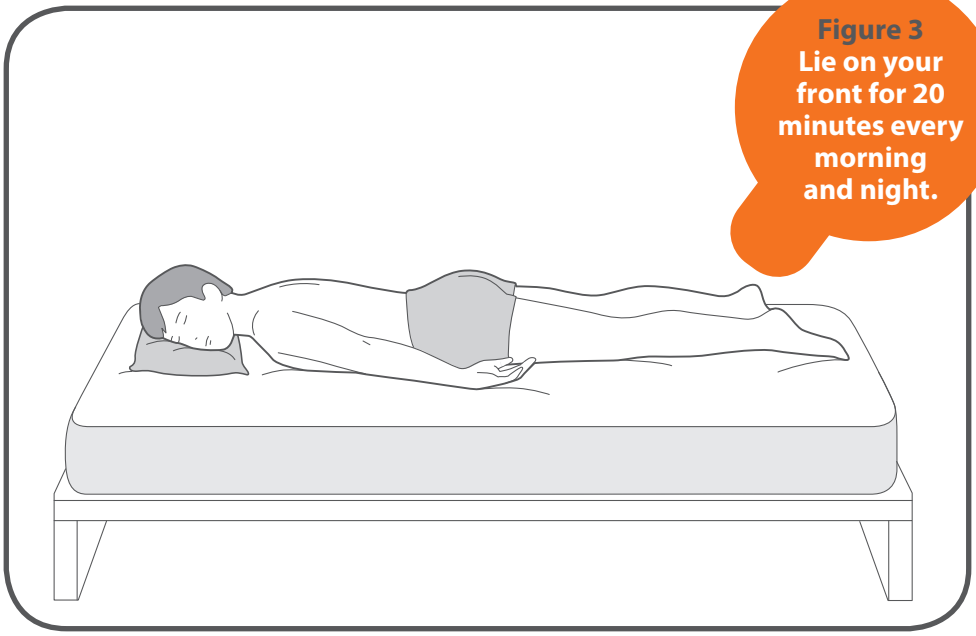


Figure 3
Lie on your front for 20 minutes every morning and night.

Feet and footwear

If your heels or feet are affected, you may benefit from custom-made insoles (orthotics) inside your shoes. Such insoles may also help with the alignment of your lower limbs and therefore relieve pain in the hips, pelvis or lower back. A podiatrist can assess and advise whether you need custom-made insoles, although sorbothane insoles or gel heel cushions, which can provide padding, may be enough to ease discomfort. These can be found in your local chemist or sports shop.

See Arthritis Research UK booklet *Feet, footwear and arthritis.*

Speak to your physiotherapist or occupational therapist if you need advice on seating, either at home or at work.

Stopping smoking

If you have a spondyloarthritis and smoke, the best thing you can do for your health is to try to stop. Of course this is easier said than done, but help is available that makes it more likely that you'll be successful. Your hospital or GP will be able to direct you to a local service that can offer advice and treatment.

Smoking can be particularly damaging because ankylosing spondylitis can reduce the movement of your rib cage when you breathe, making smoking-related lung damage more disabling and dangerous.

Posture

Ankylosing spondylitis can cause the spine to become stuck in a bent position, so it's important to pay special attention to your posture. Check it regularly by standing up as straight as you can against a wall.

Hardback, upright chairs or straight-backed rocking chairs are better for your posture than low, soft, upholstered chairs or sofas. Don't stoop or stretch across a desk or bench. Make sure your seat is at the correct height and don't sit in one position for too long without moving your back. A lumbar support and/or seat wedge may be useful.

A physiotherapist can provide ergonomic advice, for example on seating, and guidance on exercise to help you maintain a good upright posture.

If you get an opportunity, lie on your back on the floor sometime during the day. This will help stretch out the front of the hips and improve your posture. When lying on your back use pillows to support your head, but try to keep the number of pillows to a minimum. If your neck relaxes more as you rest, try removing one pillow at a time. Don't place a pillow under your knees because stretching them out fully helps to maintain flexibility.

Sex, pregnancy and children

Sex may be painful if you have inflammation in the sacroiliac joints or lumbar spine, and lack of mobility in the hips can be a problem. Try taking some painkillers beforehand and experimenting with different positions.

Ankylosing spondylitis can also make you feel tired, so it's important that your partner understands how your condition affects you. People with ankylosing spondylitis tell us that good communication is the key to preserving an active sex life and that counselling can sometimes be helpful for both partners.

It's fine to use the contraceptive pill if you have ankylosing spondylitis, but you should tell your doctor that you take it.

The symptoms of ankylosing spondylitis may not ease during pregnancy, as happens with other types of arthritis. If the mother's spine is very stiff, it may not be possible to have an epidural during childbirth, and occasionally a Caesarean birth may be necessary if the mother's hip joints have become stiff. If your condition makes it difficult to open your legs, it's a good idea to think ahead about the delivery and to discuss it with the team at your antenatal appointments. Usually, however, pregnancy doesn't present any special problems for either the mother or baby.

You may be concerned about taking your medication during pregnancy, and it's sensible to take as few tablets as possible, especially during the first 3 months. In particular, methotrexate and the anti-TNF drugs should normally be stopped several months before you try for a baby. NSAIDs may reduce the chance of becoming pregnant and sulfasalazine may temporarily reduce male fertility.

If you're thinking of starting a family, it's a good idea for both men and women to discuss any medications with your doctor beforehand so that the prescription can be changed if necessary. Your doctor will also be able to advise on how long you should continue to use contraception before trying for a baby and which medications are well tolerated during pregnancy and while breastfeeding.

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

Will my children develop AS?

If you have ankylosing spondylitis, there's a small chance that your children will also develop it. However, the way ankylosing spondylitis runs in families isn't straightforward, so if you're thinking of having a baby and are concerned about this it's a good idea to discuss it with your specialist.

Parents with ankylosing spondylitis sometimes ask if their children should have the HLA-B27 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 ankylosing spondylitis even if they do have this gene. If you think your child or another relative might have ankylosing spondylitis, they should see their doctor and mention that there's a history of ankylosing spondylitis in the family.

Having ankylosing spondylitis shouldn't stop you from having a baby, but talk to your doctor before you try for a family because some drugs can affect the baby's development.

Work

Most people with ankylosing spondylitis are able to continue in their jobs, though you may need some modifications to your working environment, especially if you have a physically demanding job.

Seek advice if your job involves a lot of stooping or back strain. Speak to your employer's occupational health service if there is one. Otherwise, your local Jobcentre Plus office can put you in touch with Disability Employment Advisers who can arrange work assessments. They can advise you on changing the way you work and on equipment that may help you to do your job more easily. If necessary, they can also help with retraining for more suitable work. If work or career planning is difficult, mention this to your doctor or ask to see an occupational therapist. The Citizens Advice Bureau can also be a useful contact.

If you use a computer at work or at home, make sure it's positioned correctly so you can maintain a good posture while using it. You could ask for a display screen equipment (DSE) assessment to help you find the best workstation layout. See Figure 4 for examples of the right and wrong ways to sit at a computer.

If you have a job where you're sitting down most of the time, try to incorporate some short spells of exercise into your work. Any movement will help to prevent or ease stiffness. Ask your physiotherapist for advice on simple exercises you can do at any time. When you finish for the day, have a break before tackling any jobs at home.

See Arthritis Research UK booklet *Work and arthritis*.

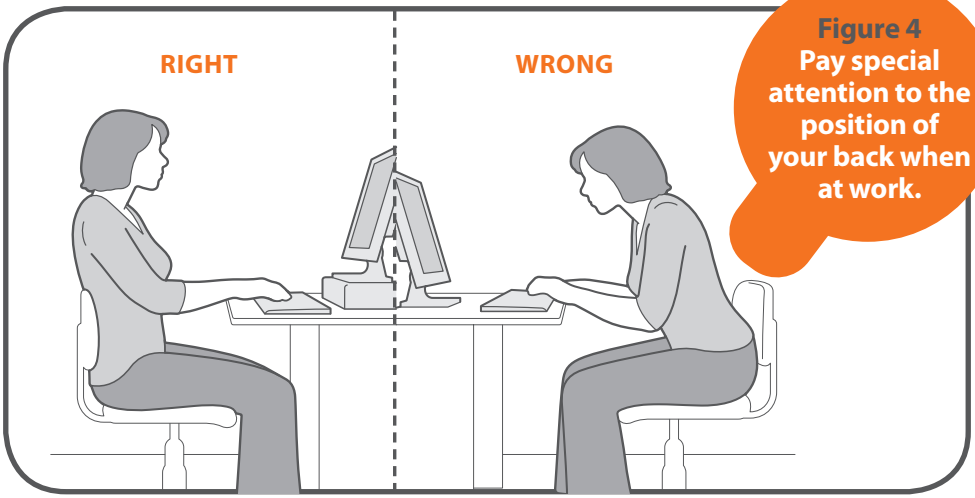


Figure 4
Pay special attention to the position of your back when at work.

Driving

Driving shouldn't be a problem if you have ankylosing spondylitis, but there are a few points to bear in mind:

- On a long journey, stop from time to time for 5 minutes and get out of the car for a stretch.
- If your neck or back is very stiff, reversing into parking spaces may be difficult. Special mirrors and parking sensors can be fitted to help with this. You should inform the Driver and Vehicle Licensing Agency (DVLA) of your condition if you use fitted adaptations.
- If your neck is stiff, it'll be more prone to injury. Make sure your headrest is correctly adjusted and that you keep your head back against it.
- If you can't walk very far you may be eligible for a Blue Badge, which entitles you to use disabled drivers' parking spaces.

NASS can provide guidance on special mirrors or the Blue Badge parking scheme. Your local council will also be able to give information on the Blue Badge.

Getting life insurance

Life insurance companies often don't understand this condition, so they may try to increase your premium. However, most people with ankylosing spondylitis should be able to get normal terms. We suggest you try other companies and appeal if you're being treated unfairly.

Research and new developments

Research continues into the genetic factors that contribute to ankylosing spondylitis and related conditions. Recently, research partly funded by Arthritis Research UK has identified two specific genes, ERAP1 (or ARTS1) and IL23R, with a particularly strong link to ankylosing spondylitis, as well as other genetic material that might be involved. As we learn more about the inflammatory processes that these genes are involved in, it should eventually become possible to develop drugs that specifically target them.

New drug treatments are in development. One treatment, golimumab, is another anti-TNF drug given by injection once a month. At the time of going to press, it's currently being considered for approval by the National Institute for Health and Clinical Excellence (NICE) and may become widely used if it's approved.

Patient stories

Arthur is in his mid-20s and his ankylosing spondylitis started in childhood.

When I was 11 my right knee became very swollen. My parents gave me aspirin but that didn't help. They took me to our local hospital, where they put my leg in a plaster-of-Paris splint for 6 weeks. The swelling went down but my knee was still very stiff afterwards. I then had some physiotherapy, and after 3 months my knee was back to normal. Then, when I was 14, the problem came back, but again it settled after a time.

At 21, I started to get pain in the buttocks and the tops of my legs, which they said was lumbago. Aspirin didn't help and the pain kept waking me at night. I was so stiff in the mornings that I had to set the alarm an hour early so I could loosen up to get to work on time.

I decided to go and see an osteopath, who manipulated my spine on three occasions. But that seemed to make the pain worse so I stopped going.

When I was 24 I was referred to the hospital, where they diagnosed ankylosing spondylitis. I'd been having attacks of pain low down in my back for about 4 months and it had been waking me at night. I'd changed my job from working in a warehouse doing heavy lifting to an office job, but that didn't help my back. The specialist explained the condition to me and I felt a bit less worried and depressed about it then. The drugs they gave me and the physiotherapy really helped.

Rebecca is 27 years old and has undifferentiated spondyloarthritis

I've always been fit and healthy, but I developed some pain in my lower back about two years ago. I thought I'd pulled a muscle and stopped going to the gym. Unfortunately, the pain got worse rather than better, and I began to struggle at work.

I found sitting for long periods was painful, and it was really difficult to get out of bed in the morning because my back was so sore and stiff.

I'd been to see the GP a few times, and I looked around on the internet a bit to try to find out what the problem could be. After a few months, and some time off work, I was referred to a rheumatologist at the hospital. There were no signs of damage to my back on the x-rays I had, but an MRI scan showed some inflammation. I was told I had undifferentiated spondyloarthritis.

I wasn't really sure what this meant, and it's taken me some time to get my head round it. I started some anti-inflammatory tablets, which have made a big difference. I've also started to do some stretching exercises each day and have gone back to the gym. Work have been helpful – I've made some changes to my desk space, and I get up every 30 minutes for a walk around. It's odd – some days I completely forget I've got this condition, but on others it comes back and reminds me! At the moment I can cope with things, but I'm still worried it'll get worse in the future. The doctors and physios have been really helpful, and I know I can phone them if I'm struggling.

Glossary

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

Anaemia – a shortage of haemoglobin (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.

Ankylosing spondylitis – an inflammatory arthritis affecting mainly the joints in the back, which can lead to stiffening of the spine. It can be associated with inflammation in tendons and ligaments.

Caesarean section (or C-section) – a method of delivering a child where a surgical incision is made in the mother's abdomen.

Chiropractor – a specialist who treats mechanical disorders of the musculoskeletal system, often through spine manipulation or adjustment. The General Chiropractic Council regulates the practice of chiropractic in the UK.

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.

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

Enthesitis – inflammation of the entheses, the sites where tendons and ligaments attach to bone.

Epidural – an injection given into the space around the spinal cord in the small of your back to anaesthetise the lower half of the body. The full name is epidural blockade.

Erythrocyte sedimentation rate (ESR) – a test that shows the level of inflammation in the body and can help in the diagnosis of some forms of arthritis and other conditions. 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.

Flare-ups – periods where your joints become inflamed and painful, sometimes known as flares.

HLA-B27 (human leukocyte antigen B27) – a gene that's often present in people who have conditions such as reactive arthritis, psoriatic arthritis or ankylosing spondylitis. It's also present in many healthy people.

Hydrotherapy – exercises that take place in water (usually a warm, shallow swimming pool or a special hydrotherapy bath) which can improve mobility, help relieve discomfort and promote recovery from injury.

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.

Infusion – an injection directly into a vein or tissue.

Ligaments – tough, fibrous bands anchoring the bones on either side of a joint and holding the joint together. In the spine they're attached to the vertebrae and restrict spinal movements, therefore giving stability to the back.

Lumbar spine – the lower part of the spine, made up of five vertebrae (bones) in the part of the back between the lowest ribs and the top of the pelvis.

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.

Manipulation – a type of manual therapy used to adjust parts of the body, joints and muscles to treat stiffness and deformity. It's commonly used in physiotherapy, chiropractic, osteopathy and orthopaedics.

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.

Occupational therapist – a therapist who helps you to get on with your daily activities (e.g. dressing, eating, bathing) by giving practical advice on aids, appliances and altering your technique.

Osteopath – a specialist who treats spinal and other joint problems by manipulating the muscles and joints in order to reduce tension and stiffness, and so helps the spine to move more freely. The General Osteopathic Council regulates the practice of osteopathy in the UK.

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

Physiotherapy – a therapy that helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

Podiatrist – a trained foot specialist. The terms podiatrist and chiropodist mean the same thing, although podiatrist tends to be preferred by the profession. NHS podiatrists are state-registered, having followed a 3-year university-based training programme. The podiatrist or chiropodist can deal with many of the foot problems caused by arthritis.

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 from the NSAIDs.

Psoriasis – a common skin condition characterised by patches of thickened, red and inflamed skin often with silvery scales. New skin cells are produced more quickly than normal, leading to a build-up of excess skin cells. The condition is sometimes associated with psoriatic arthritis.

Sacroiliac joints – a pair of rigid joints on either side of the pelvis, where the large triangular bone at the base of the spine (sacrum) meets the hip bones (ilia). Ankylosing spondylitis can lead to inflammation in the sacroiliac joints (sacroiliitis).

Vertebra (plural **vertebrae**) – one of the bones that make up the spinal column.

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

- *Osteoporosis*
- *Psoriatic arthritis*
- *Reactive arthritis*

Therapies

- *Hydrotherapy and arthritis*
- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis*

Surgery

- *Hip replacement*
- *Knee replacement*

Self help and daily living

- *Complementary and alternative medicine for arthritis*
- *Diet and arthritis*
- *Everyday living and arthritis*
- *Fatigue and arthritis*
- *Feet, footwear and arthritis*
- *Keep moving*
- *Looking after your joints when you have arthritis*
- *Pain and arthritis*
- *Pregnancy and arthritis*
- *Sex and arthritis*
- *Sleep and arthritis*
- *When your child has arthritis*
- *Work and arthritis*

Drug leaflets

- *Adalimumab*
- *Etanercept*
- *Methotrexate*
- *Non-steroidal anti-inflammatory drugs*
- *Pamidronate*
- *Local steroid injections*
- *Steroid tablets*
- *Sulfasalazine*

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

Arthritis Research UK
PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations

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

Arthritis Care
18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline: 0808 800 4050
www.arthritiscare.org.uk

Chartered Society of Physiotherapy
14 Bedford Row
London WC1R 4ED
Phone: 020 7306 6666
www.csp.org.uk

Disabled Living Foundation
380-384 Harrow Road
London W9 2HU
Phone: 0207 289 6111
Helpline: 0845 130 9177
www.dlf.org.uk

Disability Employment Advisers
Your Jobcentre or Jobcentre Plus office can put you in touch with your local Disability Employment Advisor.
www.direct.gov.uk/en/Employment/index.htm

Employment Medical Advisory Service (EMAS)
To find your local office, see the telephone directory under 'Health & Safety Executive'. The address and phone number should also be available in all workplaces. Alternatively, you can get this information from:
HSE Infoline: 0845 345 0055
www.hse.gov.uk/contact/index.htm

National Ankylosing Spondylitis Society (NASS)
Unit 0.2, One Victoria Villas
Richmond
Surrey TW9 2GW
Phone: 020 8948 9117
www.nass.co.uk

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 of our booklet

Please send your views to:
feedback@arthritisresearchuk.org
or write to us at:
Arthritis Research UK, PO Box 177,
Chesterfield, Derbyshire S41 7TQ.

A team of people contributed to this booklet. The original text was written by Andrew Keat, who has expertise in the subject. It was assessed at draft stage by Dr Clifford Eastmond, rheumatology occupational therapist Louise Hollister, physiotherapist Nigel Mann and Juliette O'Hea of AStretch. 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 overall content.

Arthritis Research UK

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

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- Supporting our campaigns
- Taking part in a fundraising event
- Making a donation
- Asking your company to support us
- Buying gifts from our catalogue

To get more **actively involved,** please call us **0300 790 0400** or e-mail us at enquiries@arthritisresearchuk.org

Or go to:
www.arthritisresearchuk.org

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