

Ankylosing spondylitis and related conditions

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

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



What is ankylosing spondylitis?



Ankylosing spondylitis (AS) is a type of arthritis that mainly affects the back. It's one of a group of inflammatory conditions, referred to as spondyloarthritis, that all have similar symptoms. In this booklet, we'll explain how these conditions might affect you, 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.

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At a glance

Ankylosing spondylitis and related 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.

Ankylosing spondylitis affects people in different ways – some people can almost forget they have the condition, while for others it can have a big impact on their quality of life. Sometimes joints other than those in the spine can be affected too. Occasionally, other parts of the body may also be affected.

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 related conditions in this booklet.

🗨️ What are the symptoms?

Typical symptoms of ankylosing spondylitis include:

- lower back or neck pain and stiffness in the morning which wears off during the day or with activity
- pain in your sacroiliac joints (the joints where the base of your spine meets your pelvis), your buttocks or the backs of your thighs
- tiredness (fatigue).



Spondylitis means inflammation of the spine.

Other possible symptoms include:

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

🗨️ Who gets ankylosing spondylitis?

Ankylosing spondylitis can affect anyone, although it's more common in young men and most likely to start in your late teens and 20s. It's linked to the genes we inherit, but having ankylosing spondylitis doesn't mean you'll definitely pass it on to your children.

🗨️ 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 so magnetic resonance imaging (MRI) scans are often used instead.

🗨️ What treatments are there?

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

- **drug treatments** – These are given as tablets or injections to relieve pain, reduce inflammation or, if other treatments haven't helped, to modify the condition itself
- **physiotherapy and exercise** – These are very important to keep your spine strong and flexible.

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



What is a spondyloarthritis and ankylosing spondylitis?

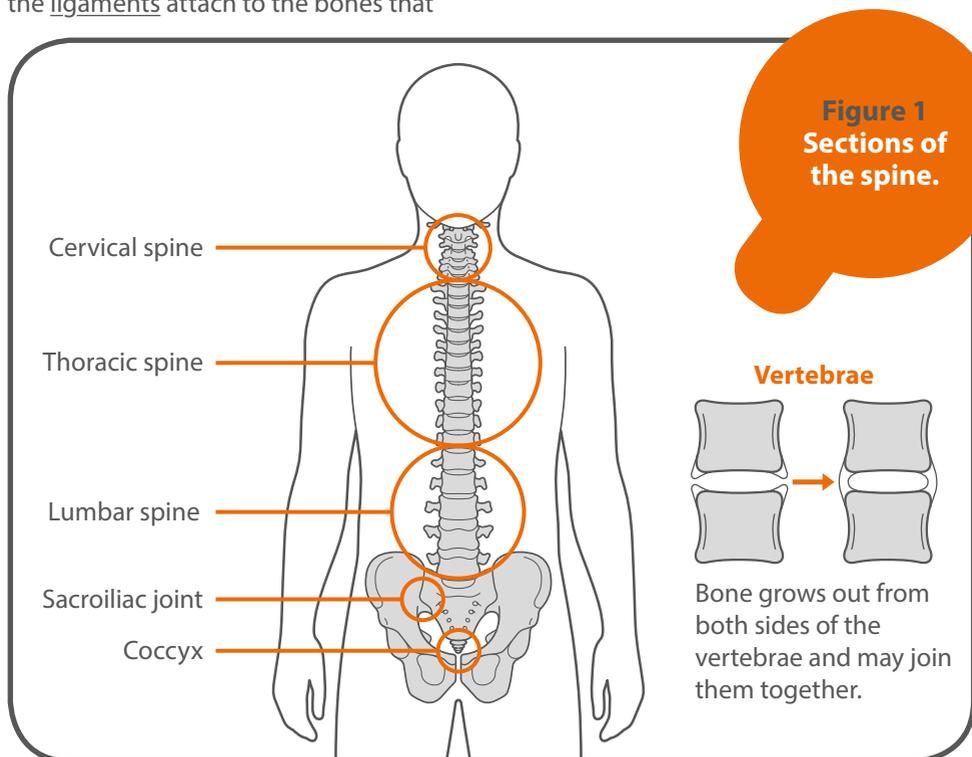
Your doctor may have told you that you have a spondyloarthritis (SpA), which is pronounced spond-ee-lo-arth-ritis. This is the name of a group of inflammatory conditions that all have similar symptoms.

Ankylosing spondylitis (AS) is the most well-known type of spondyloarthritis and it mainly affects the joints of your spine. Spondylitis simply means inflammation of the spine. As part of the body's reaction to inflammation, 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 and causes bone to grow from the sides of the vertebrae. Eventually the individual bones of your spine may link up (fuse). This is called ankylosis and can be seen on x-rays.

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

It often starts in your late teens or 20s.



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Ankylosing spondylitis and related conditions

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

What are the related conditions?

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

Non-radiographic ankylosing spondylitis and undifferentiated spondyloarthritis (uSpA) have similar symptoms to ankylosing spondylitis but don't have the signs of damage to your joints on an x-ray. Inflammation of the spine or sacroiliac joint may be seen on MRI scanning. Sometimes people with these conditions are diagnosed later on with ankylosing spondylitis.

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

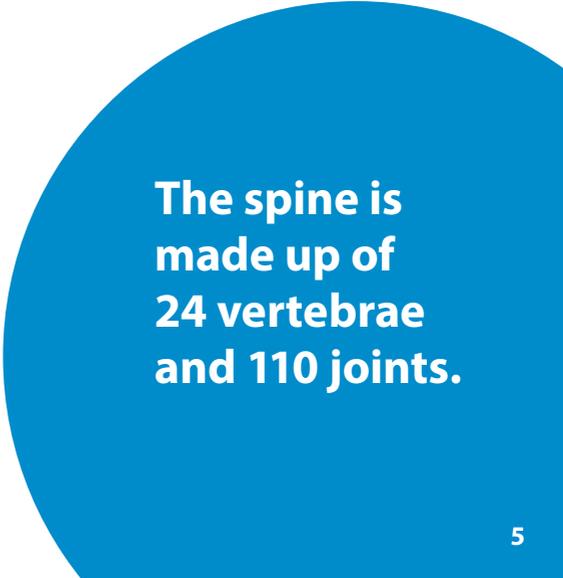
Spondyloarthritis associated with inflammatory bowel disease (IBD) (or enteropathic arthritis) occurs when your arthritis is related to bowel conditions such as Crohn's disease or ulcerative colitis.

Reactive spondyloarthritis (which used to be known as 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.

i See Arthritis Research UK booklets
Psoriatic arthritis; Reactive arthritis.

! Some doctors use the terms **spondarthritis, spondyloarthropathy, spondyloarthritis or seronegative spondyloarthritis** rather than just **spondyloarthritis**. These terms all describe types of arthritis belonging to the same group 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 your lower back in the early morning which eases through the day or with activity
- pain in your sacroiliac joints (the joints where the base of your spine meets your pelvis), your buttocks or the backs of your thighs.

The related conditions share these symptoms.

Some people first notice problems after a muscle strain, so the condition can sometimes 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, or it may wake you in the night. The stiffness can be eased by exercise or movement.

You may also have neck, shoulder, hip or thigh pain, which is often worse when you've been inactive for a time, for example if you work at a computer. Some people have pain, stiffness and swelling in their knees or ankles. In psoriatic spondyloarthritis, the smaller joints of the hands and feet (fingers, toes) may be affected. For some people, especially children and teenagers, the first signs may be in their hip or knee rather than in their back. Inflammation can occur at any point in the body where tendons attach to bone (enthesitis), for example at the elbow and heel.

The inflammation that causes these symptoms usually comes and goes, so the degree of pain and stiffness can vary over time. Some people may also find their symptoms are worse than other people's – if the condition is mild and only affects the sacroiliac joints, it may go almost unnoticed, but if the spine is affected, it can cause difficulty with activities that involve bending, twisting or turning. 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 your heel where your Achilles tendon meets your heel bone, or in the tendon in the arch of the foot, which causes 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 your spine is affected at chest level (the thoracic spine), it can affect movement at the joints between your ribs and 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 an eye casualty department but this might not be at your local hospital. Your GP surgery, local A+E or your optician will know where the nearest eye casualty department 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 two weeks or begin to pass

bloody or slimy stools. You might be referred to a bowel specialist (a gastroenterologist). Symptoms of IBD can vary, 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.

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, this gene isn't the only cause of ankylosing spondylitis and having this gene doesn't mean you'll definitely get ankylosing spondylitis. Only about 1 in 15 people with the gene will actually develop the condition.



What is the outlook?

Ankylosing spondylitis and the related conditions are quite variable and the longer-term outlook can be difficult to predict. They can cause a lot of pain, although treatment will help to ease 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 sometimes make you feel generally unwell, lose weight and tire easily.

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

Very rarely, there may be complications affecting the heart, lungs and nervous system. The valves in the heart may leak, which can put it under more strain. And long-term inflammation and tissue scarring in 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. Fewer than 1 in 100 people with ankylosing spondylitis have these problems, and they are even less common in the other types of spondyloarthritis. Even so, if you smoke, it's extremely important to try to stop because smoking is likely to add to any heart or lung problems.

People with ankylosing spondylitis, especially those who've had the condition for a long time and whose vertebrae have fused, are at increased risk of spinal fractures following a fall or car accident, for example. Spinal fractures can cause nerve damage, so it's important to tell any doctor treating you following an accident that you have ankylosing spondylitis, especially if you have new unexplained pain in your spine or new weakness, numbness or tingling in your arms or legs. The fracture may not show easily on x-rays, so you may need an MRI or computerised tomography (CT) scan.

Some people with ankylosing spondylitis develop osteoporosis (thinning of the bones), and it's important that this is treated. Your doctor may suggest you have a bone density (DEXA) scan to check for this.

i See Arthritis Research UK booklet *Osteoporosis*.

How is ankylosing spondylitis diagnosed?

Most back pain isn't caused by ankylosing spondylitis. However, the symptoms, especially in the 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. Usually, ankylosing spondylitis is diagnosed by a rheumatologist rather than a GP.

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

- the history of your condition (including whether pain and discomfort is waking you up during the second half of the night)
- a physical examination
- blood tests, which may show inflammation
- x-rays or an MRI scan.

What tests are there?

A blood test can sometimes show if there's inflammation in your body. You'll probably have one or more of these blood tests:

- C-reactive protein (CRP)
- erythrocyte sedimentation rate (ESR)
- plasma viscosity (PV).

These are all different tests for inflammation, so they give similar information. Different laboratories use particular tests. Only 30–40% of people with ankylosing spondylitis have inflammation that can be picked up in a blood test, so in many cases these blood tests will be normal.

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 many people who don't have the condition. A positive test may point to ankylosing spondylitis but it won't confirm the diagnosis.

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.

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X-rays can sometimes help to confirm the diagnosis, though they generally don't show anything unusual in the early stages. As the condition progresses new bone forms between the vertebrae, which will be shown in x-ray images. However, it may be several years before these changes show up in x-rays. MRI scans may show the typical changes in your spine and at the sacroiliac joints at an earlier stage of the disease and before x-ray changes can be identified.

What treatments are there for ankylosing spondylitis?

i A number of treatments are available that can ease pain and stiffness, but exercise and close attention to your posture are just as important to keep your spine mobile and help you to live a normal life.

Drug treatments

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.

i See Arthritis Research UK drug leaflet *Painkillers*.

Non-steroidal anti-inflammatory drugs (NSAIDs)

There's a wide range of NSAIDs that can reduce pain so you can get on with your daily 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 as gels, which you can rub 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.

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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 if you smoke or have circulation problems, high blood pressure, high cholesterol or diabetes.

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

Disease-modifying anti-rheumatic drugs (DMARDs)

Drugs such as sulfasalazine and methotrexate can be helpful for arthritis in the joints of your arms and legs, although they're not usually effective for spinal symptoms. These disease-modifying anti-rheumatic drugs (DMARDs) are given to prevent or reduce joint damage rather than just controlling pain. They 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.

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

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

Biological therapies (anti-TNF)

Biological therapies (anti-TNF drugs) are newer treatments that can be very effective for ankylosing spondylitis and for non-radiographic axial spondyloarthritis. A number of anti-TNF drugs are currently available for these conditions – including etanercept, adalimumab, certolizumab pegol and golimumab. 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 can only be prescribed if your condition can't be controlled with anti-inflammatory drugs and physiotherapy.

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

i See Arthritis Research UK drug leaflets *Adalimumab; Certolizumab pegol; Etanercept; Golimumab.*

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 tendon 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.

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

Bisphosphonates

Bisphosphonates are usually used for the treatment of osteoporosis. It's been suggested that they may also help the pain and stiffness of ankylosing spondylitis. However, research so far hasn't confirmed this.

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 and neck to avoid them stiffening into a bent position.

A physiotherapist will advise you on how to maintain good posture and may be able to offer you hydrotherapy. This involves specific exercises for the spine, hips and shoulders which you do 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.

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

Surgery

Most people with ankylosing spondylitis don't need surgery, although 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 your rheumatologist about a referral to an experienced spinal surgeon if you want advice on this.

i See Arthritis Research UK booklets

Hip replacement surgery; Knee replacement surgery.

Self-help and daily living

Medical treatments can help to control ankylosing spondylitis, and the condition may 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 your spine. However, if you're in intense pain and it's extremely difficult to exercise, then you may need to treat the pain first. You should start slowly and gradually build up the amount and intensity of exercise you do. Trying to do too much exercise too soon is likely to make your pain worse. There's a tear-off exercise section at the back of this booklet which includes some stretches to help improve strength and flexibility. Try to do them once a day.

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. You may find that stretching exercises after a hot shower or bath are especially helpful in easing morning stiffness.

NASS groups offer regular exercise classes, run by physiotherapists, at various centres 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 gym-based exercise, an exercise DVD and mobile app. Any exercise that you enjoy, for example dancing, swimming or gardening, will help in maintaining your mobility.

! Exercises for your back, chest and limbs will help 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.

Contact sports (such as rugby, hockey or basketball) aren't generally recommended if you have advanced disease as your joints and spine may be more easily injured, but there are plenty of other activities that are suitable. If you enjoy competitive sports, volleyball and badminton are both low-impact. Pilates, yoga and t'ai chi may also be useful as both can help with posture and flexibility. NASS have detailed information on exercising when you have ankylosing spondylitis, and you can 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 make neck pain worse. Using a snorkel can be helpful. Speak to your physiotherapist for advice if you have discomfort when swimming, as a different stroke or modification to your technique can often help. As an alternative to swimming, ask for a programme of exercises you can do in the pool.

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

Aside from using drug treatments, 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, but you shouldn't apply them directly to your skin.



Diet and nutrition

No particular foods have 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.

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

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

can last from a few days up to a couple of weeks and can make you feel completely exhausted. Over time, you'll probably 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. Talking with other people who have ankylosing spondylitis can be a good way of picking up tips for coping with flare-ups.

Hot and cold treatments can be useful for pain relief. Try using a hot-water bottle or wheat pack, taking care to make sure that you don't apply them directly to your skin. Any form of heat treatment should be comfortably warm to prevent you from burning yourself. Cold packs (for example an ice pack or bag of frozen peas) wrapped in a damp cloth may also help if applied to a particularly inflamed area. Check your skin regularly to make sure the packs aren't causing irritation.

Some people find that using a TENS (transcutaneous electrical nerve stimulation) machine can help to ease pain. A TENS machine is a small electronic device that sends pulses to your nerve endings via pads placed on your skin. It produces a tingling sensation and is thought to alter pain messages sent to the brain. TENS machines are available from pharmacies and other major stores, but a physiotherapist may be able to loan you one to try, or suggest where you might be able to hire one, before you decide whether to buy.

Additional pain relief and anti-inflammatories will also help with pain relief, as should short-term rest and gentle stretches. Massage may be useful too.

Contact your GP or your rheumatology department for advice or to arrange an early review if you're struggling.

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

Complementary medicine

Generally speaking, complementary and alternative therapies are usually safe. However, you should always discuss their use with your doctor before starting treatment as there are some risks associated with specific therapies. It's important to go to a legally registered therapist, or one who has a set ethical code and is fully insured.

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



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

Manipulation isn't helpful for people with ankylosing spondylitis as 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.

i 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) can help. OTs offer advice on gadgets that may help you and explain how to adapt your technique in order to reduce strain and pain. They often work closely with employers and/or Disability Employment Advisors from your Jobcentre Plus team to suggest equipment to help you at work, for example a special chair.

Corsets and braces aren't generally recommended. 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.

i 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 particularly painful, it's important to make sure your mattress provides enough support to prevent any tendency for your 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. Some people find memory foam mattresses, mattress toppers and pillows helpful.

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.

i See Arthritis Research UK booklet
Sleep and arthritis.

Feet and footwear

People with ankylosing spondylitis are more likely to develop plantar fasciitis, a condition that causes pain in the arch of your foot. 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 your 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.

i See Arthritis Research UK booklet *Foot pain*.

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

Stopping smoking

If you smoke, the best thing you can do for your health is to try to stop. 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 support.

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. People with an inflammatory arthritis such as ankylosing spondylitis are also at greater risk of heart disease, and smoking further increases this risk.

Posture

Ankylosing spondylitis can cause your spine to become stuck in a bent position, so it's important to pay special attention to your posture. You can check it by standing up as straight as you can against a wall – seek advice from a specialist physiotherapist if you're concerned about your posture.

Hardback, upright chairs or straight-backed rocking chairs are better for your posture than low, soft, upholstered chairs or sofas. Try using a cushion behind your lower back to give extra support and help you keep good posture. 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.

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Ankylosing spondylitis and related conditions

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 and you're physically able to do this, lie on your back on the floor sometime during the day. This will help stretch out the front of your 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 – stretching your knees out fully helps to maintain flexibility.

Sex, pregnancy and children

Sex may be painful if you have inflammation in your 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. Good communication is the key to preserving an active sex life and 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.

Usually, pregnancy doesn't present any special problems for either the mother or baby, though the symptoms of ankylosing spondylitis may not ease during pregnancy, as they do in some other types of arthritis. If your spine is very stiff, it may not be possible to have an epidural during childbirth. If your condition makes it difficult to open your legs, it's a good idea to think ahead about the delivery and to discuss with the team at your antenatal appointments whether a Caesarean section might be better for you.



If you're thinking of starting a family, it's very important for both men and women to discuss any medications with your doctor beforehand so that your prescription can be changed if necessary. Some drugs such as methotrexate should normally be stopped several months before you try for a baby. 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 considered safe to use during pregnancy and while breastfeeding.

i 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 – while there's a 50% chance that the child will inherit the gene from a parent, there's only a 15% chance that they'll go on to



Figure 2
Keep a good upright posture when using a computer.

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Ankylosing spondylitis and related conditions

develop the condition. This goes down to 8% if the parent doesn't have the HLA-B27 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.

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 they have one, otherwise, your local Jobcentre Plus office can put you in touch with Disability Employment Advisors 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 (see Figure 2). You could ask for a display screen equipment (DSE) assessment to help you find the best workstation layout.

If your job involves sitting down most of the time, try to build short spells of exercise into your day. 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.

i See Arthritis Research UK booklet
Work and arthritis.

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.



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 five 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 & 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.

Your local council can give you information on the Blue Badge parking scheme. NASS can also provide guidance on this and about special mirrors.

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.



Rebecca's story

Rebecca is 27 years old and has non-radiographic ankylosing spondylitis.

'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 non-radiographic ankylosing spondylitis.

'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.

Caesarean section (or C-section) – a method of delivering a baby 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.

DEXA (dual-energy x-ray absorptiometry) – a scan to test the strength or density of the bones. It involves lying on a couch, fully clothed, for about 15 minutes while your bones are x-rayed. The dose of x-rays is tiny – about the same as spending a day out in the sun. The results will tell how much risk there is of the bones fracturing.

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 and sulfasalazine.

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.

Fatigue – a feeling of weariness that’s more extreme than simple tiredness. It can affect you physically, but it can also affect your concentration and motivation, and often comes on for no apparent reason and without warning.

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.

Inflammatory bowel disease (IBD) – a group of inflammatory conditions that affect the small and/or large intestine. The symptoms can include abdominal pain, bleeding, weight loss, fatigue and diarrhoea. The two main types of IBD are Crohn’s disease and ulcerative colitis.

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) 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.

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 trained specialist who uses a range of strategies and specialist equipment to help people to reach their goals and maintain their independence by giving practical advice on equipment, adaptations or by changing the way they do things.

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 given by a trained specialist that helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

Plantar fasciitis – pain in the arch of the foot caused by strain to a band of tough fibres that runs from the heel to the base of the toes (the plantar fascia). This term is often wrongly applied to any type of pain in the arch.

Plasma viscosity (PV) – a screening test that measures the thickness or stickiness of the fluid in which blood cells are suspended. It's used as an indicator of disease activity in a number of conditions including rheumatoid arthritis, psoriatic arthritis and lupus.

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 registered with the Health Professions Council (HPC). A 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.

Psoriatic arthritis – an inflammatory arthritis linked to the skin condition psoriasis.

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

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).

Tendon – a strong, fibrous band or cord that anchors muscle to bone.

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*

Self help and daily living

- *Everyday living and arthritis*
- *Fatigue and arthritis*
- *Foot pain*
- *Keep moving*
- *Looking after your joints when you have arthritis*
- *Pain and arthritis*
- *Pregnancy and arthritis*
- *Sex and arthritis*
- *Sleep and arthritis*
- *Work and arthritis*

Drug leaflets

- *Adalimumab*
- *Certolizumab pegol*
- *Etanercept*
- *Golimumab*
- *Methotrexate*
- *Non-steroidal anti-inflammatory drugs*
- *Local steroid injections*
- *Painkillers*
- *Steroid tablets*
- *Sulfasalazine*

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: 0207 380 6500

Helpline: 0808 800 4050

Email: info@arthritiscare.org.uk

www.arthritiscare.org.uk

Chartered Society of Physiotherapy

14 Bedford Row

London WC1R 4ED

Phone: 0207 306 6666

www.csp.org.uk

Disabled Living Foundation

380–384 Harrow Road

London W9 2HU

Phone: 0207 289 6111

Helpline: 0845 130 9177

Email: helpline@dlf.org.uk

www.dlf.org.uk

Disability Employment Advisors

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:

www.hse.gov.uk/forms/health/emasoffices.htm

National Ankylosing Spondylitis Society (NASS)

Unit 0.2, One Victoria Villas

Richmond

Surrey TW9 2GW

Phone: 0208 948 9117

Email: sallyd@nass.co.uk

www.nass.co.uk

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



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 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 Andrew Keat, who has expertise in the subject. It was assessed at draft stage by consultant rheumatologist Dr Lorraine Croot, rheumatology specialist registrar Dr Laura Connell, rheumatology nurse specialist Lyn Ryan and nurse practitioner Karina Blunn. 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 Neil Snowden is responsible for the overall content.

Keeping active with ankylosing spondylitis

It's important to stay active when you have ankylosing spondylitis – exercising will help ease stiffness and stop your muscles becoming weak. As well as the simple exercises in this pull-out, you should choose a form of exercise you enjoy and stick at it. Swimming and walking are great options if you have ankylosing spondylitis.

Try the exercises in this pull-out once a day, starting off slowly and building up the number of repetitions gradually. You can speak to your physiotherapist for further guidance and to check you're using the correct technique, or join your local National Ankylosing Spondylitis Society (NASS) group.

Daily exercise programme

1



This exercise will help you to focus on your posture. Stand with your back against a wall with your heels, bottom and shoulders touching it as much as possible. Push (but don't tilt) your head back towards the wall. Hold for five seconds then relax. Repeat about 10 times. This can also be done lying down if you find this easier.

2



This exercise will help you to focus on your ability to turn your upper body. Stand in an open space with your feet apart. Place your hands on your hips. Turn from the waist to look behind you, keeping your knees and feet facing the front. Hold for five seconds. Repeat to the other side, five times each side. You can do this sitting down if it feels more comfortable.

3



This exercise will help you focus on moving your ribs, which will help with your breathing. Lie on your back with your knees bent and feet flat on the floor:

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 five times. Remember, it's as important to breathe out fully as it is to breathe in deeply.

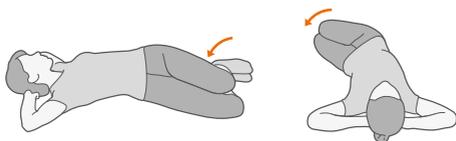
b) Put your hands on the upper part of the front of your chest. Breathe in deeply through your nose and then breathe out as much as you can through your mouth. Push your ribs up against your hands as you breathe. Repeat the exercise five times. You can do this exercise at any time in a lying or sitting position.

4



Lie on your back with your knees bent and feet flat on the floor. Lift your pelvis and lower back off the floor. Hold the position for five seconds and then lower down slowly.

5



This exercise will help you to stretch your lower back. Lie on your back, hands above your head. Bend your knees and roll them slowly to one side, keeping your feet on the floor

and your upper knee directly above your lower knee. Hold for five seconds. Repeat five times on each side.

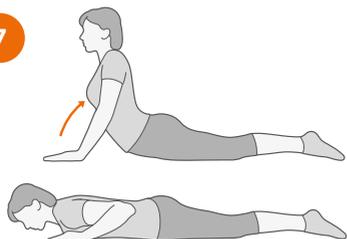
6



This exercise will help with your posture and strengthening your back muscles. Lie on your front, looking straight ahead, with your hands by your sides (you may put a pillow under your chest in order to get comfortable).

Raise one leg off the ground, keeping your knee straight. Repeat five times for each leg. It may help to have the opposite arm stretched out in front of you.

7



Lie on your front with your hands under your shoulders. Pushing up with your arms, lift your upper body, aiming to keep your hips and legs on the floor.

8



This exercise will help you to strengthen your upper and lower back and hips, which will help your posture. Kneel on the floor on all fours. Stretch your right arm and your left leg so they're in line with the floor. Hold for five seconds. Try not to twist your body or overstretch your neck. Lower and then repeat with the other arm and leg, five times each side.

Get involved

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

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

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



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