



# Ankylosing Spondylitis

## The National Ankylosing Spondylitis Society (NASS)

The NASS has information about AS, and also runs exercise programmes.

Tel: 020 8948 9117 or visit [nass.co.uk](http://nass.co.uk)

### ► Is AS hereditary?

**It can be. Most people who have AS have inherited the gene HLA-B27. However, having this gene does not mean you will definitely get AS, as there are many other genes involved in the process.**

► AS can be present for up to 10 years before being identified by an X-ray.

## What is ankylosing spondylitis?

Ankylosing spondylitis (AS) is a condition that affects the spine and other joints, causing pain and stiffness.

AS causes inflammation at the entheses, which are the tissues where ligaments or tendons attach to a bone. The bone gets damaged, and new bone grows to heal the area affected. The spine, which also has entheses, becomes stiff and painful.

This usually happens first in the lower back, in the sacroiliac joints. Eventually the new bone growth makes the individual bones of the spine (vertebrae) fuse together, causing the spine to be 'ankylosed'. Ankylosing spondylitis refers to the later stage of the condition, axial spondyloarthritis (axSpA), which affects the spine. Only a portion of this group will go on to develop AS.

AS usually becomes apparent during a person's teenage years or in early adulthood. It affects nearly three times the number of men as women.

## How will AS affect me?

AS comes in two stages. First, there is inflammation in the base of the spine, affecting the sacroiliac joints. This can cause pain in the lower back, hips, thighs or buttocks. Some people also experience aching or swelling in other joints, including in the lower back (lumbar spine), chest wall and neck, shoulders, knees and ankles. During this time, AS may be difficult to diagnose, as it may not be visible on radiographs or X-rays during the early stages. This stage is known as 'the non-radiographic axSpA'.

The second stage of AS comes after bones begin to knit together, making the spine less flexible. Some people find that their pain lessens at this stage, but symptoms vary. Many people with non-radiographic axSpA may never progress to this second stage.

## Symptoms

The main symptoms associated with AS are:

- pain in your buttocks, hips and thighs
- back pain and stiffness, which comes on slowly over weeks or months and does not go away (compared to short bursts)
- early morning stiffness and pain, which may lessen during the day with exercise
- fatigue
- weight loss in the first stage of AS
- feeling feverish or getting night sweats, especially during a flare-up.

Other symptoms can include:

- pain in your foot – underneath the heel (plantar fasciitis) or in the Achilles tendon at the back of the foot
- pain in the eye, blurred vision and bloodshot eyes – called uveitis or iritis
- difficulty or pain when breathing or coughing
- heart problems – very occasionally, AS causes the heart not to function properly.

► **Some people develop other conditions alongside AS. These include psoriasis, ulcerative colitis or Crohn's disease.**

In time, AS can make the spine bend forward, into a stoop. Working on your posture (the way you stand and sit) and exercising can stop this happening.

## What are the drug treatments for people with AS?

► **Keeping the range of movement in your hip joints and shoulders is important. For more information on how to keep mobile, see Arthritis Care's *Exercise and Arthritis* booklet.**

- Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, can reduce pain so you can exercise and sleep well. You may need to take these when you experience more pain or flare-ups, although they may need to be taken over a longer period. Take them with or after food. Have regular check ups with your GP to monitor your risk of having a cardiovascular event, such as a heart attack or stroke.
- Painkillers, such as paracetamol.
- Disease-modifying anti-rheumatic drugs (DMARDs), such as methotrexate or sulfasalazine. These are very successful in treating some forms of arthritis, though evidence suggests they are not as effective in managing AS.
- Anti-tumour necrosis factor drugs (anti-TNFs, also known as biologics). These are given by injection and infusion. Examples include adalimumab, certolizumab, etanercept, secukinumab and golimumab. They are generally effective at controlling AS. However, they are expensive and are currently only given to people with severe AS under guidelines by the National Institute for Health and Care Excellence, British Society of Rheumatology or the Scottish Medicines Consortium. Not all drugs in this family are licensed for use in treating AS. Anti-TNFs are powerful drugs that can have side effects as well as benefits, so you should discuss these with your GP.

If you have inflamed eyes, go to your hospital's A&E department straight away, so you can see an eye specialist (ophthalmologist). They will give you eye drops, which will reduce the inflammation in a few hours.

## Who will I see?

Your GP will look at your posture to see if your lower spine is beginning to flatten out, instead of curving in. In the early stages, it can be hard to tell AS from general back pain, so blood tests may be used to help decide if you have AS or not. If you do have AS, you may then be referred to a specialist.

► **A rheumatologist is a doctor who specialises in diagnosing and treating arthritis, and other musculoskeletal conditions. They are part of a hospital-based rheumatology team.**

It is likely that you will be seen by a consultant rheumatologist, who may arrange for an X-ray or CT scan of your spine. You may then be seen by a physiotherapist, who can give you an exercise programme and advise on your posture. You may also see an occupational therapist.

## What can I do to help myself?

Keeping physically active is crucial, as it will help stop your spine from seizing up. Low-impact exercises, such as swimming and walking, are the most effective types of activity. If doing outdoor activities, wear trainers with an impact-absorbing sole. Avoid high-impact or contact sports, such as tennis or rugby.

### Other useful tips

- Watch your posture (how you sit, stand and lie). Get a good chair for work and home; avoid squashy, low sofas. Sit tall and pull up your shoulders, and move your spine regularly. Your bed should be firm and not sag.
- Spending time lying on your front, with your head turned to the side, can be helpful.
- Hot baths or showers can help morning stiffness, while hot water bottles or electric blankets can help night-time stiffness. An ice pack or a bag of frozen peas can soothe an inflamed area. Put some oil on your skin beforehand, as this helps to avoid ice burn, and make sure to put a layer between the ice pack or frozen peas, such as a tea towel or a hand towel.
- Avoid corsets or braces – these will just make the spine rigid.
- When driving, take frequent stops to stretch. Use a small cushion behind your back or under your bottom. Extra mirrors can reduce the amount you need to twist round. Your car's head restraint must be adjusted correctly to protect you.
- Eat a balanced diet with plenty of protein, fruit and vegetables. Make sure you get enough calcium and vitamin D, as AS makes you more likely to develop osteoporosis.
- Stop smoking. Smoking can make your AS progress faster and more difficult to treat.
- If back or hip stiffness or pain are interfering with intimacy, be open and honest with your partner.
- Help your family to understand how AS affects you, so they can offer support and encouragement. Show them this factsheet, or refer them to Arthritis Care's website or Helpline.
- Join Arthritis Care's Online Community ([arthritiscare.org.uk/forums](http://arthritiscare.org.uk/forums))
- Osteopathy, chiropractic or other manipulation of the spine can be bad for AS. Other complementary therapies, such as acupuncture or aromatherapy, may help reduce pain and relax you, but you may have to pay for them (ask your GP). Always choose a member of a professional body and beware of anyone asking you to stop taking your prescribed medication.



## ARTHRITIS CARE

### How Arthritis Care can help you

Want to talk to someone about your arthritis?  
Or read more about the condition?

Call our free, confidential Helpline on 0808 800 4050  
for information and support. We're open weekdays from  
09:30 to 17:00 – we'd really like to hear from you.

We have over 40 free booklets and factsheets on  
various aspects of arthritis, from diet and surgery, to  
managing pain and fatigue. These can be sent to you  
in the post – just ask our Helpline staff for details.

### Go online

You can download all our booklets and factsheets  
as PDFs from [arthritiscare.org.uk/information](http://arthritiscare.org.uk/information)

We also have an Online Community, where you can  
chat to others with arthritis, and can be reached at  
[arthritiscareforum.org.uk](http://arthritiscareforum.org.uk)



Arthritis Care and Arthritis Research UK have joined together  
to help more people live well with arthritis. Read how at  
[arthritiscare.org.uk/merger](http://arthritiscare.org.uk/merger). All donations will now go to  
Arthritis Research UK and be used to help people with arthritis  
live full and active lives in communities across England and  
Wales, Scotland, and Northern Ireland.

## Thank you

### Contact us

#### Our Helpline:

0808 800 4050

#### Our website:

[arthritiscare.org.uk](http://arthritiscare.org.uk)

#### Our offices:

England:

020 7380 6540

Northern Ireland:

028 9078 2940

Scotland:

0141 954 7776

Wales:

029 2044 4155

#### Social media:



@arthritis\_care



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Arthritis Care, Floor 4, Linen Court, London N1 6AD Registered Charity Nos. 207711 and SC041156.

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Please check our website for up-to-date information and reference sources or call 020 7380 6577.



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and trustworthy source of health and social care information.