

Ankylosing spondylitis



ARTHRITIS CARE

*Empowering
people with arthritis.*

What is ankylosing spondylitis?

Ankylosing spondylitis (AS for short) is a disease which affects the spine and other joints, and causes pain and stiffness.

AS starts with inflammation at a place where ligaments or tendons attach to a bone. The bone gets damaged, and new bone grows to heal the site. This usually happens first at the bottom of the back. This process repeats itself, and eventually the new bone growth makes the individual bones of the spine (vertebrae) fuse together. The spine becomes stiff and painful.

Real life story

“I was diagnosed with AS approximately four years ago. Although the condition has got progressively worse I have become progressively better at dealing with it. This is a combination of familiarity with the pain, improved medication and knowing my limits.

It can be difficult to adjust socially and with relationships as well. Don't stop being active. I'm rubbish at exercising but I am hoping to improve on this. Stretch often and try to achieve good posture. Know your physical limits but don't ever give up. ”

“I was diagnosed three years ago though I had had symptoms for five years – aches in my back and leg and a slight decrease in mobility. It was when I was knocked out by the pain in my hips, that I went to see my doctor for a diagnosis.

Now, I take anti-inflammatories so my condition is not too severe. But I am always aware that my hips don't feel quite right as there has been some loss of movement. Simple steps like stretching and making sure I exercise are excellent for making me feel better – and also give me a sense of control. ”

How will it affect me?

Ankylosing spondylitis comes in two stages. First, there is inflammation in the base of the spine. This can create pain in the lower back, hips, thighs or buttocks. In time, some people also get aching or swelling in other joints, including further up their back (lumbar spine), chest wall and neck, shoulders, knees and ankles. Children often feel pain in their knees, ankles, feet, hips and buttocks before they feel back problems.

The second stage of AS comes after bones begin to knit together, making the lower spine stiffen up. For some people, the pain gets less at this stage. Everyone is affected differently by the condition. Symptoms may come and go for many years.

The main things you would experience with AS are:

- back pain and stiffness, which comes on slowly over weeks or months and does not go away (rather than short attacks)
- early morning stiffness and pain, reducing during the day with exercise
- weight loss in the first stage of AS
- tiredness
- feeling feverish or getting night sweats, especially during a flare-up.



Other symptoms could include:

- pain in your heel – underneath your heel (plantar fasciitis) or in the Achilles tendon at the back
- pain in the eye, blurring vision and bloodshot eyes, called uveitis or iritis
- difficulty or pain when breathing or coughing. This happens because of stiffening where the ribs meet the breastbone
- problems with the heart – very occasionally AS causes the heart not to function completely perfectly, but these symptoms are usually so mild you won't know they are there.

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

Ankylosing spondylitis usually comes on in people's late teens or twenties, though not always. It affects nearly three times as many men as women. It is estimated that 200,000 people in the UK have ankylosing spondylitis.

Some people develop other conditions alongside AS. These include the skin condition psoriasis, and bowel disease called ulcerative colitis or Crohn's disease.

What is the treatment?

There is no cure for AS, but there are ways of managing it.

Exercise

Keeping physically active is crucial to stop your spine seizing up. Swimming is very good, as is other low-impact exercise like walking. Wear trainers with an impact-absorbing insole. Avoid high-impact or contact sports like rugby or step aerobics.

Keeping the range of movement in your hip joints and shoulders is vital to prevent stiffening into a bent position. Get advice on how to do this from a physiotherapist. Keep your muscles strong to stop them shortening, which they will do if you don't use them. Getting out of breath every day is also good for your lungs.



Medicines

- **painkillers** (like paracetamol) or **anti-inflammatories** (such as ibuprofen) can reduce pain so you can exercise and sleep well. You may need to take these during bad patches, or possibly over a longer period. Take them with or after food.
- **disease-modifying drugs** (like methotrexate) are very successful in treating some forms of arthritis, though the evidence is not so good for AS. These drugs may have side effects.
- **anti-TNFs** (also known as biologics) are new drugs given by injection or infusion (for example infliximab or etanercept), which are proving very good at controlling AS. However, they are expensive and as yet are only given to people with severe AS. They are powerful and can have side effects.

Getting pregnant

If you are trying for a baby, ask your doctor about your medicines, as some of them can affect your chances of getting pregnant, or can damage an unborn child. This is the case for men and women. For women, you may not be able to take them again until you finish breastfeeding. If you have serious hip problems, you might need to give birth by caesarean section. During the pregnancy, use a maternity support to help spread the weight of your bump.

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 more common back pain, so they may do some blood tests to help decide what is wrong. The doctor will probably then refer you to a specialist.

A specialist (or consultant) **rheumatologist** is based at a hospital, and is part of a rheumatology team including nurses and physiotherapists. They will x-ray your spine. You should also see a **physiotherapist**, who will teach you an exercise routine to suit you and help your posture.

If you get eye inflammation, go to your hospital's emergency department **straight away** so you can see an eye specialist (**ophthalmologist**). Otherwise, your eye could be permanently damaged. They will give you eye-drops which will reduce the inflammation in a few hours.

What can I do to help myself?

- 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. Physiotherapists and occupational therapists can advise further.
- Lie flat on your back or front for at least 20 minutes a day. It is helpful if you can spend some of this time lying on your front ('prone'), with your head turned to the side.
- Try heat or cold – hot baths or showers can help morning stiffness. Hot water bottles or electric blankets help at night. An ice pack (or a bag of frozen peas in a towel) can soothe an inflamed area (take care as ice can burn).
- Don't wear a corset or brace – 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. You can add extra mirrors to reduce twisting round. Your car's head-restraint must be adjusted correctly to protect you in an accident. Even a small impact could affect you badly.
- Eat a good balanced diet with plenty of protein (meat, fish, pulses), fruit and vegetables for vitamins and milk for calcium.
- Stop smoking – AS can affect your lungs, and smoking will make this far worse.
- If back or hip stiffness or pain are interfering with making love, talk to your partner to make sure they understand your feelings. You can explore more comfortable positions together. Sex can be just as rewarding if you plan in advance so you can rest. Arthritis Care has a helpful booklet on relationships.
- Help your family to understand how AS affects you, so they can support and encourage you. Show them this or another factsheet, or refer them to Arthritis Care's website or helpline. They might join in with your exercise regime.
- Join a group of people who share similar problems, or join an online discussion forum. Arthritis Care has groups around the UK who meet regularly.



- Avoid osteopathy, chiropractic or other manipulation of the spine, which can be bad for AS. Other complementary therapies such as acupuncture or aromatherapy may help reduce pain and to relax, but you may have to pay for them – ask your GP first. Choose a complementary therapist who is a member of a professional body. Beware of anyone asking you to give up your prescribed drugs.



Is it hereditary?

Yes, it can be. Most people who have AS have inherited a gene called HLA-B27. Just because you have this gene, it does not mean you will get AS, and there are other genes involved too. If you have AS, the likelihood of your child inheriting AS is less than one in 10.

Where can I get more information and support?

- Arthritis Care's helpline 0808 800 4050 (weekdays 10am-4pm) plus website (www.arthritiscare.org.uk) can give you information about adapting your life, treatments and care, or just give you someone to talk to. You can also contact other people with arthritis through the discussion forums on our website.
- The National Ankylosing Spondylitis Society (NASS) has information about AS, and also runs exercise programmes: NASS, PO Box 179, Mayfield, East Sussex, TN20 6ZL. Tel: 01435 873527 or visit www.nass.co.uk

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Arthritis Care

Arthritis Care is the UK's largest voluntary organisation working with and for all people with arthritis.



Our publications are just one of the many services Arthritis Care provides. These include a confidential helpline, self-management and awareness training, information for people with arthritis and health professionals, and local activity and support. We also campaign locally and nationally to help change attitudes and laws and to ensure people with arthritis have access to the treatments and services they need and deserve.

Contact us

For confidential information and support,
contact the Arthritis Care Helpline

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10am-4pm (weekdays)

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For information about Arthritis Care and the services we offer,
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