

Ankylosing spondylitis

This sheet has been written for people affected by ankylosing spondylitis. It provides general information to help you understand how you may be affected and what you can do to manage it. It also tells you where to find further information and advice.

What is ankylosing spondylitis (AS)?

Ankylosing spondylitis (AS) is a condition that mainly affects the spine. The joints of the neck, back and pelvis become inflamed, causing pain and stiffness. The sacroiliac joints are commonly affected in AS. These joints connect the base of your spine (sacrum) to your pelvis. Other joints, such as the hips and shoulders, can also be involved. AS can also affect other parts of the body, such as the eyes, skin, bowel and lungs. The symptoms of AS usually begin between the ages of 15 and 45 years.

What are the symptoms?

The symptoms of AS vary from person to person. The most common are:

- pain and stiffness in the back, buttocks or neck
- symptoms worse after rest (for example, in the early morning) and relieved with exercise
- pain in tendons (which connect muscles to bones) and ligaments (which connect bones to each other), often felt as pain at the front of the chest, back of the heel or underneath the foot.

What causes it?

It is not known what causes AS. Unlike other types of back pain, AS isn't caused by particular jobs, activities or injuries. You are more likely to get AS if you have a history of it in your family. There is a gene called HLA-B27 that is associated with AS. Almost nine out of ten people with AS test positive for this gene. However HLA-B27 is present in 8% of the general population, including healthy people without AS. Recently, two new genes (IL23R and ARTS1) have also been found to be associated with ankylosing spondylitis.

How is it diagnosed?

Many people in the early stages of AS think they have common back pain and do not seek help. However it

is important to have AS diagnosed as early as possible as there are many effective treatments available. Your doctor will diagnose AS from your symptoms, a physical examination and blood tests to measure levels of inflammation. Your doctor may also order x-rays of your spine, but these tests can all be normal in the early stages. If your doctor suspects you have AS you should be referred to a rheumatologist, a doctor who specialises in arthritis.

What will happen to me?

With the right treatment, most people with AS can lead full and active lives. Many people find there are times when their symptoms worsen (known as a 'flare'), and times when their symptoms get better. In most cases AS can be well controlled with treatment and the pain improves over time. However some people may have severe, long lasting pain. As a result of the inflammation in the spine, new bone may grow around the joints. This leads to permanent stiffness in the back or neck of some people with AS. In severe cases this extra bone can fuse the bones in the spine together, stopping the spine from moving. Fusion of the spine can lead to a bent or forward stooped posture. This used to be common but can now usually be prevented by starting proper treatment as early as possible.

Can AS be cured?

Currently there is no cure for AS. However treatment for AS has improved dramatically, with new medicines that are extremely helpful in controlling the condition. Be wary of any products or therapies that claim to cure AS.

What treatments are there for AS?

Your rheumatologist will tailor your treatment to your symptoms and the severity of your condition. There is no way of predicting exactly which treatment will work

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best for you. Each treatment has its own benefits and risks. Your doctor may need to trial several different treatments before finding the one that is right for you. Treatment for AS usually involves:

- physiotherapy exercises (such as hydrotherapy or exercises in water), to keep the spine flexible and improve posture
- medicines, such as:
 - analgesics (pain relievers, such as paracetamol)
 - non-steroidal anti-inflammatory drugs (NSAIDs)
 - corticosteroid medicines or injections
 - disease-modifying anti-rheumatic drugs (DMARDs)
 - biological DMARDs, such as tumour necrosis factor (TNF) medicines.

For more information about medicines see the Australian Rheumatology Association's Patient Medicine Information or the *Medicines and arthritis information* sheet.

What can I do?

See a rheumatologist. A rheumatologist can diagnose AS and make sure you get the right treatment. If you have AS and have not seen a rheumatologist, ask your doctor about a referral. See the *Working with your healthcare team* information sheet.

Learn about AS and play an active role in your treatment. Not all information you read or hear about is

trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying. Reliable sources of further information are also listed in the section below. Self management courses aim to help you develop skills to be actively involved in your healthcare. Contact your local Arthritis Office for details of these courses.

Learn ways to manage pain. See the *Dealing with pain* information sheet.

Live a healthy life. Eat a healthy diet, stop smoking and reduce stress to help your overall health and wellbeing. See the *Healthy eating* information sheet.

Stay active. It is important to do regular sports and activities for general fitness and wellbeing. See the *Physical activity* information sheet or ask your physiotherapist for advice.

Acknowledge your feelings and seek support. As there is no cure for AS and it can affect many parts of your life, it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the *Arthritis and emotions* information sheet.

CONTACT YOUR LOCAL ARTHRITIS OFFICE FOR MORE INFORMATION SHEETS ON ARTHRITIS.

Learn about AS and your treatment options.

See a rheumatologist as early as possible.

For more information:

Books Khan, Muhammad Asim 2002, *Ankylosing spondylitis: The facts*, Oxford University Press, Inc. Oxford; Melbourne.

Dougados, Maxime & van der Heijde, Desiree 2004, *Fast facts: Ankylosing spondylitis*, Health Press, Oxford.

Websites Australian Rheumatology Association - information about medicines and seeing a rheumatologist www.rheumatology.org.au

Arthritis Research UK www.arthritisresearchuk.org

American College of Rheumatology www.rheumatology.org

Arthritis Foundation (US) www.arthritis.org

AS Australia www.asaustralia.org

Spondylitis Association (US) www.spondylitis.org

National Ankylosing Spondylitis Association (UK) www.nass.co.uk

Australian Physiotherapy Association can help you 'find a physio' at www.physiotherapy.asn.au