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## ANKYLOSING SPONDYLITIS

### GET IN TOUCH

Questions and requests for information from members  
and non-members are welcome.

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This information leaflet is published by the  
Arthritis Foundation as part of its continuing education  
programme for all people with arthritis.

## INTRODUCTION

Ankylosing spondylitis (AS) is a rheumatic disease that affects the spine and may lead to some degree of stiffness of the back.

This booklet aims to tell you something about the condition and how it may affect your health and activity. It also deals with how to look after yourself, different forms of treatment, and gives advice about posture, exercise, occupation and inheritance.

## WHAT HAPPENS

Spondylitis means inflammation in the joints of the spine, and comes from the Greek word for vertebra (Spondylos). As the inflammation goes and healing takes place, bone grows out from both sides of the vertebrae and may join together; this stiffening is called ankylosis.

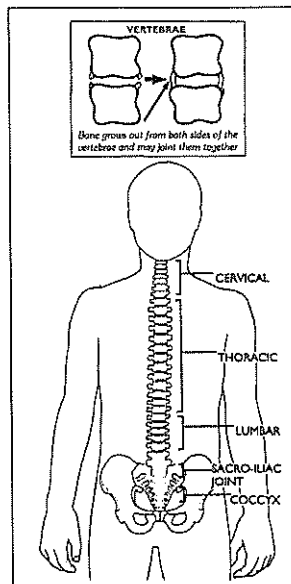
The cause is not yet known. Occasionally more than one member of a family may get it as there is a hereditary factor (see later). AS is neither infectious, contagious nor can it be caused by athletic activity or injury. However, symptoms sometimes follow unusual exertion or strain, which may be blamed at first. Typically, it attacks young men but can occur in women as well.

## THE BACKBONE

The backbone, or spine is made up of 24 bones (vertebrae) and 110 joints. The three main sections, cervical, thoracic and lumbar, differ in their shape and curve. The cervical (neck) section is most mobile. In the thoracic (chest) section, each vertebra has a rib attached by joints on each side. Below the lumbar section is the sacrum which sits like a keystone in the ring at the sacroiliac joints which lie between the sacrum and the pelvis.

## NOT JUST BACKACHE

Back troubles are some of the most common complaints seen in a GP's surgery. Two per cent of a doctor's patients consult him/her every year with backache. Most people with back pain do not have AS and the doctor must recognise the possible different nature of the backache in each patient.



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

The most common cause of backache is 'back strain', which can happen at any age. A 'slipped disc' is another example. In older patients, degenerative or wear-and-tear problems often affect the back. Diagnosis by your doctor is made by listening to your symptoms, and examining you. Your doctor may do certain blood tests and arrange for an X-ray. We will discuss these points separately.

## THE EFFECTS

### (Early Signs)

At the start, AS usually causes low backache and stiffness and may be diagnosed as lumbago. You may feel pain in the buttocks, possibly down the back of your thighs and in the lower part of your back. You may have first noticed these symptoms after some exertion or strain. Aches and pains in the neck, shoulders and hips, or in the thigh (like sciatica) may follow.

In a few cases the first complaint may not be in the back at all, but in the hip or knee, or in the leg - perhaps just a swollen knee. In the beginning, in spite of these complaints, even careful examination by a doctor may reveal nothing.

Some patients experience nothing more than a series of mild aches and pains coming and going over a period of months, never troubling them greatly. Others pass through a phase of active AS when symptoms are more troublesome; they become generally unwell, lose weight and tire easily. Gradually the ailment settles down and the worst pains disappear.

When AS has been present for several months the back may stiffen, usually lower down; and in some patients the disease then dies out, causing no further trouble. The stiff back is often painless and does not interfere with physical activity, because the upper part of the spine, the neck, hips and limbs can remain quite normal. If you feel stiff in the early morning this is a sign of inflammation and perhaps it may be an hour or so before you have properly limbered up - it may indicate the need for anti-inflammatory drugs.

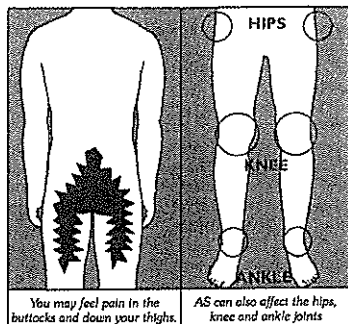
In its early stages AS causes considerable pain, but effective treatment is available to relieve this, even though the discomfort is not always banished. Later the disease becomes much less active, or even ceases completely. You will most probably be able to carry on with your work and lead a normal life.

## LIMB JOINTS

Sometimes, either earlier or later, AS may affect joints other than the spine. The hips, knees, ankles and shoulders may be involved. The smaller joints of the hands and feet can be attacked, but usually only in a few places. You may experience a period of aching in the joints in question, perhaps with some swelling. As a result some of them may not move fully but, with treatment and active exercises from the start, the disability is slight. In particular, your hip must not be allowed to stiffen in a bent position as this can lead to damage in the knees, and cause more backache.

## OTHER TROUBLE SPOTS

Tender places may sometimes develop in bones that are not part of the spine-the heel bone for example.



When this is affected it becomes uncomfortable to stand on a hard floor. The bone of your 'seat' (ischium) can be involved and make sitting on chairs uncomfortable.

Some patients experience chest pain. This does not come from the heart, but from the joints between the ribs and the breast bone. You may notice a strapped-in feeling as the ribs become less easy to move. However, your lungs are working well because the diaphragm is not affected. Breathing exercises (see *daily exercise programme*) will help you maintain ribcage mobility.

Iritis (inflammation of the iris which forms the pupil) occasionally occurs, so if you suddenly develop a red eye go to your doctor immediately.

Other rare complications, affecting less than one patient in a hundred, may occur. These include the heart, lung and nervous system, but treatment is available for all of them. Patients with AS are not any more at risk from getting heart attacks, strokes, or cancer, than the general population. Colitis, or inflammation of the bowel, is associated with AS in some patients, as is a skin condition called psoriasis.

## TESTS

AS is often not diagnosed until a patient has had backache for two or three years or even longer. A blood test may show an abnormal result in the early stages and so help your doctor to distinguish it from more common forms of backache. X-rays may also confirm it. However, in the early stages these may be normal, even when the symptoms are severe.

A special test (HLA-B27 antigen) can be used.

This is like testing for a blood group but concerns the white and not the red blood cells. If it is positive, it shows that you have a tendency to AS but does not prove the diagnosis (this is covered in more detail later).

## ASSOCIATED PROBLEMS

It is now clear that AS is one of a group of diseases ('spondarthritides'). Other examples are psoriatic arthritis, colitic arthritis and reactive arthritis (see

Arthritis Foundation booklets 'Psoriatic Arthritis', 'Reactive Arthritis'). Each of these can occur with AS or even before it. Some children can develop arthritis which later develops into AS. In some cases reactive arthritis, which may be associated with an infection of the bowel or the urethra (the tube from the urinary bladder), can develop into AS. The link between these and other diseases has revealed some of the genetic factors that are involved. Having certain genes will predispose you to AS, but without one of the 'triggers' the disease will not appear.

## THE OUTLOOK

AS takes a different course in different people, and no two cases are exactly the same. The symptoms may come and go over long periods, but in the end it almost always settles down. Your lower back will probably become stiff, but the same can happen to the upper part of your back and neck as well. Therefore it is most important to maintain a good posture.

Not every patient suffering from AS will return to normal, even when the exercises are followed, but serious deformities can usually be prevented. Sufferers with a bent back can often be acutely self-conscious and concerned about how others see them. But even though this may be difficult most patients can come to terms with the problem.

### SUMMING UP ANKYLOSING SPONDYLITIS

- It is a form of inflammation which affects the spine, usually beginning lower down.
- After a period of inflammation which causes aching and stiffness in the back it may settle down, but may also persist for many years.
- It may leave some pain and stiffness in the spine. It may interfere with your work and physical activity.

## TREATMENT

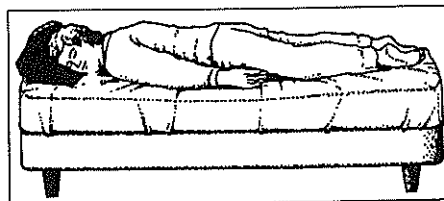
Do your best to keep fit. Eat anything, especially protein such as meat and fish, but don't get overweight. Take plenty of exercise. **The motto for treatment which all patients should remember is:**

**It is the doctor's job to relieve pain, and the patient's job to keep exercising and maintain a good posture.**

## REST

If the AS is very active and the stiffness very troublesome, a spell off work or in hospital may be necessary. This does not mean keeping still in bed, because this can hasten the stiffening of the spine. So even a spell of rest from work means that you will be encouraged to do exercises for your back, chest and limbs to keep them supple.

When you are in bed it is important that you should lie quite flat on your back; some of the time you should practise lying on your front. 'Prone lying', as it is called, is best done for twenty minutes before rising in the mornings, and twenty minutes before going to bed at night.



*Lie on your face for 20 minutes every morning and night.*

At first you may not be able to tolerate more than five minutes at a time, or may even need a pillow under your chest. But with practice, as the spine relaxes, it will become easier. If you make a habit of this, it will help prevent your back and hips becoming bent. It may, of course, not be practical every day but it is better to devote some time to it than nothing at all.

## YOUR BED

Your bed should be firm. If you have any internally sprung mattress, get a suitable board put between the mattress and the bed frame. A sheet of plywood 70 x 150 x 1cm is ideal. A hardboard door panel is satisfactory but not so durable. You will find this more comfortable to lie on than a bed which is too yielding. Even when the painful active phase of AS is passed, it is important to keep a firm bed in order to prevent any tendency for spinal curvature.

## MEDICAL APPROACH

There is no cure at present for AS. The doctor aims to relieve the symptoms, improve spinal mobility where this has been lost, and to allow the patient to hold down a normal job and social life.

Although AS will tend to become less active as you get older, treatment must continue. In particular you must pay close attention to keeping good posture, mobility and exercise.

Although the disease cannot be cured, much can be done to help. The doctor will prescribe tablets that relieve pain (analgesic) and inflammation. There are several drugs which will reduce or kill the pain, give you a good night's sleep and sufficient freedom from pain to do exercises.

You will probably need tablets during bad patches and some people need a small maintenance dose of their drug over a longer period. Some of the newer tablets are manufactured to remain effective throughout a 24 hour period, thus helping relieve night pain and morning stiffness.

Some drugs are called 'disease-modifying': they never make an immediate impact on the disease but rather take some time to start working, but ultimately they may make a big difference to the disease. Sulfasalazine and methotrexate are two such drugs. Both these drugs, commonly used in other forms of arthritis, are more likely to benefit the arthritis in the limb joints rather than the arthritis in the spine.

Some of the newer drugs are given by injection. These fall broadly into two groups:

- **Bisphosphonates** are given in short bursts over a period of a few weeks. You may feel pain relief in the spine soon after receiving this drug.
- **Biological Therapies** are drugs which are also given by injection - either as an infusion over a few hours or as a twice-weekly injection. You may also feel early benefit with these drugs. eg. Infliximab, Etanercept and Adalimumab

Heat in its various forms will help to relieve pain and stiffness. A hot bath before going to bed, a hot water bottle or electric blanket may be quite enough. It is seldom necessary to use special lamps.

Surgery has only a small place in treatment. An operation can be used to help restore movement to damage hip joints, and rarely, to straighten the back or neck of someone who has become so bent they cannot look forward (and find it dangerous to cross the road). The risk of postoperative complications is known to be greater in AS patients.

## POSTURE

Since untreated AS causes increased bending of the spine (the patient becomes progressively more stooped), you must keep as straight and erect as possible. Hardback, upright chairs or straightback rocking chairs are far better for your back posture than low, soft, upholstered chairs.

Pay special attention to the position of your back when at work, so that you do not have to stoop. If you sit at a desk or bench, see that your seat is at the proper height and do not sit in one position for too long without moving your back.

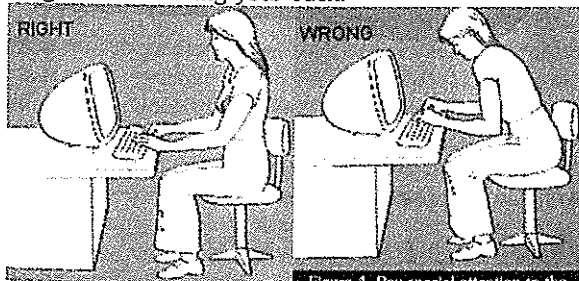


Figure 4. Pay special attention to the position of your back when at work.

A job which allows sitting, standing, and walking is ideal. The most unsuitable work is one in which you have to stoop over a bench for hours at a time. If you have a heavy or tiring job do not tackle other activities at home or elsewhere until you have had a break. If necessary, rest flat for a time. It may also help if you can rest flat for twenty minutes at midday. At such

times try to lie for part of the time face downward. If your job involves a lot of stooping or back strain, talk this over with your doctor. Some AS sufferers have found it helpful to show this booklet to their employers or their doctors in explaining their needs.

Corsets and braces are hardly ever helpful, and indeed can make AS worse. It is better to develop your own muscles, and keep a straight back by natural means. Very occasionally some form of support may be necessary, for example, after a back injury. However, this decision should only be taken by a doctor who is experienced in treating patients with AS.

## **THE FAMILY**

AS is mostly found in families descended from populations of European origin, and is virtually confined to those who inherit the white cell group HLA-B27. This group also occurs in 7-10% of the healthy population. Nearly all sufferers from AS will have this particular blood group.

However, it is very important to note that there are far more people with this blood group who never get AS than those who do. Even in families where one member suffers, a brother or sister can share the same blood group and never get the disease. Parents with AS sometimes ask if their children should have the HLA-B27 test to see whether they may develop the disease in the future. The answer at present is 'no' there is no way of knowing which child with this blood group is likely to get the disease and it would only cause unnecessary worry.

## **SEX AND PREGNANCY**

AS usually starts in the most sexually active period of one's life. The disease can make the sufferer feel tired, which may reduce the desire for sexual intercourse. This may put a strain on a loving relationship which can also be aggravated by lack of understanding by the partner. You may experience pain during sexual intercourse because of inflammation in the sacroiliac joints and lumber spine. Lack of mobility of the hips, especially in women, would also cause difficulty. Patients may be helped in various ways. The inflammatory pain can be suppressed with drugs.

Poorly mobile hips can be treated with an artificial hip joint. And if surgery is not appropriate, there are alternative positions for sexual intercourse. There may be a need for sexual counselling for both partners.

Pregnancy in women with AS provides no special problem for mother or baby. However, in contrast with some other forms of arthritis the condition does not die down during pregnancy. The babies are usually born by the normal route, but occasionally a Caesarean operation is necessary if the hip joints become stiff.

Although tablets commonly used for treating AS have never been shown to damage the unborn baby (foetus), it is sensible to take as few as possible - especially during the first three months of pregnancy.

## **EMPLOYMENT**

AS sufferers are capable of doing a wide variety of jobs, from strictly sedentary to manual, such as carpenters and builders. Many have pursued very successful professional and business careers. AS is not a sentence to life-long unemployment.

## **DRIVING**

If you have to make a long car journey, stop from time to time for five minutes and get out of the car for a stretch as pain and stiffness can distract your attention.

Many people with stiffness of the neck and other parts of the spine have difficulty in seeing to back into parking spaces or a garage; special mirrors can be fitted onto your car to help you. If this is the case, it is worth practising this new backing technique in an open area with some light wooden obstacles (such as a broom handle stuck in the earth) to act as markers.

The stiff neck of a sufferer is more easily hurt than normal, so restraints are advised to avoid sudden deceleration injuries to the neck. Disabled driver's stickers may be used if you can't walk very far, but this is rare in AS.

## **SPORT AND EXERCISE**

Exercise is good for AS so you should keep active.

Swimming is the best form of sport as it uses all muscles and joints without jarring them. And regular swimming is something in which the whole family can join.

Some young sufferers enjoy cross-country running, tennis or riding. Rough team games are not ideal, because the joints can get injured. Cricket holds no particular hazards unless you play as wicket keeper. It would be difficult to be very successful at golf, but it can certainly be taken up.

Regular daily exercise is important. It is best to choose activities you enjoy doing for their own sake. For those who prefer to carry out an exercise routine some suggestions are listed below. It is wise to do at least some each day. Contact sports (such as rugby or basketball) are best avoided as the joints and spine can be injured.

### GENERAL ADVICE

- Lie on your front on a firm surface for about 20 minutes every morning or evening.
- Repeat your deep-breathing exercises at frequent intervals during the day.
- Be aware of your posture - correct it constantly, not only during your exercise periods but also during the day while standing, sitting and walking.
- Do some of your exercises every day.

### SOME QUESTIONS ANSWERED

#### How should I take my tablets?

Pain-relieving tablets are usually best taken during a meal or just before; they irritate the stomach lining less when mixed with food. This is not of vital importance, so don't worry if you cannot.

#### Why do I feel tired?

Tiredness is sometimes due to the activity of the disease and this is detected by a blood test for

information. Occasionally anaemia causes tiredness, although some people remain anaemic for long periods and keep perfectly fit. Tiredness is commonly due to frustration and depression rather than to the disease.

#### Would manipulation help the spine?

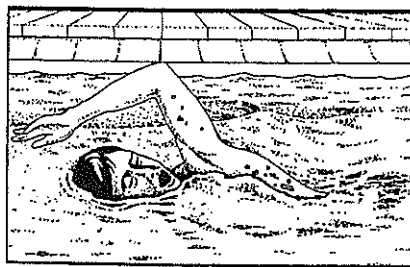
Unfortunately no. In fact manipulation of the spine, especially the neck, can be positively dangerous.

#### Would acupuncture help?

Acupuncture may relieve pain, but it does not affect the disease outcome.

#### Does treatment in a pool help?

The advantage of exercise in water is that the buoyancy of water helps movement. There is no special benefit from brine or other types of baths. Some hospitals have a pool in the physiotherapy department but ordinary public swimming pools are usually just as satisfactory for patients with AS.



*Swimming is the best form of exercise.*

#### Can I do anything to stop stiffness in the morning?

Some find a hot bath helps; others prefer doing exercises. Anti-inflammatory tablets that work overnight also help.

#### Will I have any trouble in taking out a life-insurance policy?

Life-insurance or medical aid companies often do not understand this disease, so they may want to load the premiums. But it should be possible to get normal terms. Patients should shop around if a loading factor is included. You might hand this pamphlet to the

insurance company or medical aid.

## Is it all right to be on the birth-control pill?

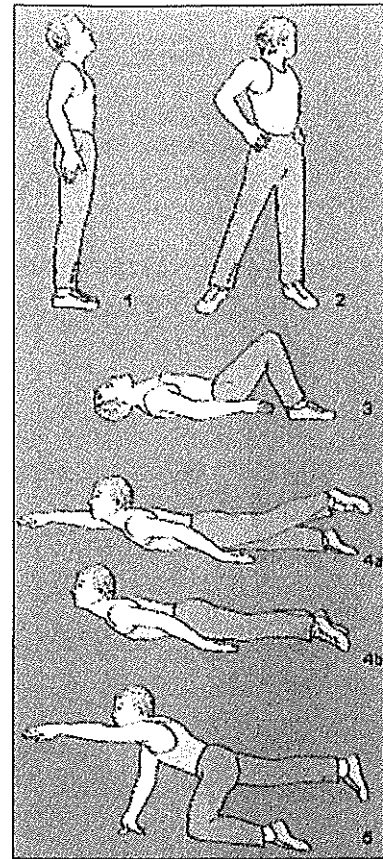
Yes, but always mention this to your doctor.

## What is the chance that my children will get AS?

The chance of your children developing it is small not more than 1 in 50, compared with 49 out of 50 chances of producing a normal, healthy child. No doctor would discourage a patient with AS from having a family.

## Daily exercise programme (to maintain flexibility and strength)

1. Standing with your heels and backside against a wall, push your head back towards the wall and hold for the count of 5, 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. 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 (about 10 times). Remember, it is 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 far as you can through your mouth. Push your ribs up against your hands as you breathe in - again about 10 times.



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 the count of 10. Lower and then repeat with other arm and leg, 5 times each side.