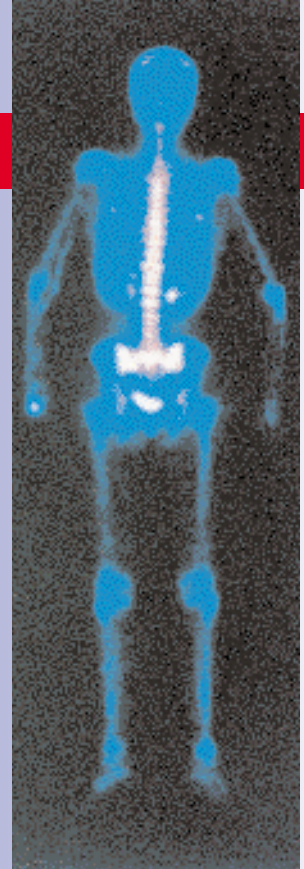


GUIDEBOOK FOR PATIENTS

A POSITIVE RESPONSE TO ANKYLOSING SPONDYLITIS

ANSWERS AND PRACTICAL ADVICE



ANKYLOSING SPONDYLITIS AND YOU

If you are suffering from ankylosing spondylitis, which we'll call AS for short, you may well have various questions about the disease. At the National

Ankylosing Spondylitis Society (NASS) we have produced this booklet to answer the questions patients most frequently ask. It also contains practical advice on things you can do to make the condition more bearable. Your family, friends, work colleagues, and even your GP, may also be interested to read it. Further copies are available from NASS free of charge if you need them.

As sufferers ourselves, we know what you are going through. As well as the inevitable pain of the disease, AS often generates feelings of frustration and fear. Some people do their best to ignore the condition and even deny that they have it. Our experience, however, shows that people who take an active interest in their condition can positively influence its outcome.

Moreover, there are certain exercises that will help reduce the deterioration in your posture and mobility. We have included some of these in this booklet.

Thousands of our members have benefited from them and we hope you will, too.

To keep fully up-to-date on treatment and issues related to AS, you will certainly find it worthwhile joining NASS. There are full details about the Society and its services at the back of this booklet.

We hope you find this publication useful. Above all, we wish you well.

Fergus J Rogers
Director of NASS

CONTENTS	PAGE
----------	------

- | | |
|--------------------------|----|
| • Questions you may have | 1 |
| • Leading a normal life | 4 |
| • Some practical advice | 5 |
| • Useful exercises | 6 |
| • Help from NASS | 10 |
| • Contact addresses | 11 |



QUESTIONS YOU MAY HAVE

What does ankylosing spondylitis mean?

Ankylosing means fusing together. Spondylitis indicates inflammation of the vertebrae. Both words come from the Greek. So, AS describes the condition by which some or all of the joints and bones of the spine fuse together. Entire fusing of the spine is unusual. Many people will only have partial fusion, sometimes limited to the pelvic bones.

What exactly is AS?

AS is a painful, progressive, rheumatic disease. It mainly affects the spine but it can also affect other joints, tendons and ligaments. Other areas, such as the eyes, lungs, bowel and heart can also be involved.

What actually happens?

Inflammation occurs at the site where certain ligaments or tendons attach to bone (entheses). This is followed by some erosion of bone at the site of the attachment (enthesopathy). As the inflammation subsides, a healing process takes place and new bone develops. Movement becomes restricted where bone replaces the elastic tissue of ligaments or tendons. Repetition of this inflammatory process leads to further bone formation and the individual bones which make up your backbone, the vertebrae, can fuse together. The pelvis is commonly affected first. The lower back, chest wall and neck may also become involved at different times.

Is ankylosing spondylitis the same as spondylosis?

No. They sound similar but they are different. Spondylosis is a term relating to "wear and tear" and is more common in older people. AS relates to an inflammatory condition which produces new bone and leads to fusion. The vigorous exercise therapy designed for people with AS might be harmful to those suffering from spondylosis.

Is AS common?

AS affects approximately 1 in 200 men and 1 in 500 women in Britain.

Who gets AS?

Men, women and children can all suffer from AS. It typically strikes people in their late teens and twenties, with the average age being 24. However, symptoms can start at other periods of life. AS is more common in men, with nearly three times as many men having it as women.

Is AS different in men, women and children?

Yes. AS tends to affect men, women and children in slightly different ways.

Men: The pelvis and spine are most commonly affected. Other joints which may be involved are the chest wall, hips, shoulders and feet.

Women: Involvement of the spine is generally less severe than in men. The pelvis, hips, knees, wrists and ankles are the most commonly involved.

Children: It is unusual for a child under the age of 11 to develop symptoms of AS. The joints which are typically affected first are the knees, ankles, feet, hips and buttocks. They rarely suffer from back pain. In youngsters, AS may lead to persistent hip disease ultimately requiring a hip replacement sometime in adult life.

What are the symptoms of AS?

Typical symptoms of AS include:

- Slow or gradual onset of back pain and stiffness over weeks or months, rather than hours or days.
- Early-morning stiffness and pain, wearing off or reducing during the day with exercise.
- Persistence for more than three months (as opposed to coming on in short attacks).
- Feeling better after exercise and feeling worse after rest.
- Weight loss, especially in the early stages.
- Fatigue.
- Feeling feverish and experiencing night sweats.

Does AS affect other joints?

Yes. AS sometimes causes aching, pain and swelling in the hips, knees and ankles. Indeed, any joint can be affected. In most cases the pain and swelling will settle down after treatment. It is particularly important to stretch the hip joint to prevent stiffening in a bent position making you lean forward. The heel bone can become particularly troublesome causing pain in two areas. Most common is the under surface, about three centimetres from the back of the foot. This is called plantar fasciitis and can last for many weeks. It may respond to an insole for the shoe designed to take weight off that part of the heel. The less common pain arises at the back of the heel where the Achilles tendon is attached to the heel bone. Pressure from the shoe may aggravate the pain.

Does AS affect other organs?

Yes. AS can sometimes affect the eyes, heart and lungs. These effects are not life-threatening and they can be treated with relative ease.

How does AS affect the eyes?

AS can cause inflammation of the iris and its attachment to the outer wall of the eye, the uvea. 40% of people will develop iritis or uveitis on one or more occasions. Usually the first symptom is a slight blurring of vision in one eye but the main symptom is a sharp pain together with a dramatically bloodshot eye. To avoid permanent damage you should receive prompt treatment. It is a good idea to go straight to a casualty department, rather than to your GP, where you can be treated by an ophthalmology team. Tell them that you have AS. They will give you eye-drops which will reduce the inflammation in a matter of hours. Continue treating yourself with the eye-drops for as long as the inflammation persists.

How does AS affect the heart?

Very occasionally AS can have a mild effect on the heart. In most cases this is so mild that it is difficult to detect. AS may cause the aortic valve to leak. More commonly, though, it affects the conduction of electrical activity within the heart. Usually any such problems are unnoticed by the person with the condition.

How does AS affect the lungs?

AS should not make you any more susceptible to lung or chest infections. However, it may affect the rib joints and the muscles between the ribs making breathing, sneezing, coughing or yawning painful. As a result, the lungs fail to become fully ventilated. You will find some advice in the exercise section of this booklet to help you maintain normal chest wall movement. Sometimes the lungs may get scarred, a condition known as apical pulmonary fibrosis. This will show up on an X-ray but does not usually cause any symptoms.

In the late stages of AS the chest wall may become quite fixed and affect air entry in and out of the lungs. This does not mean you stop breathing! The diaphragm muscle continues to work and your stomach moves in and out as you breathe. Large meals and tight clothing will increase the effort of breathing so you may find it more comfortable to avoid these. It is also vital to avoid smoking since this will not only make breathing more difficult but it could cause potentially serious lung and chest infections.

Does AS affect everybody the same way?

No. AS is a very variable disease. Some people have virtually no symptoms whereas others suffer more severely. However, at NASS we know that those patients who follow an appropriate course of exercises tend to do better than those who don't.

Will I need surgery ?

It is unlikely. Surgery plays a very small part in the management of this condition. About 6% of people with AS need to have a hip replaced. This will successfully restore mobility and eliminate pain of the damaged joint. In rare cases surgery is used to restore a straighter posture of the spine and neck to people who have become severely stooped.

What medication will I need?

Over 80% of people with AS take non-steroidal anti-inflammatory drugs (NSAID) to reduce inflammation and relieve pain and stiffness. However, some people may experience side-effects with NSAIDs and prefer to take simple pain killers such as paracetamol. For others, especially those who suffer from inflammatory bowel disease (Crohn's disease and ulcerative colitis) or peripheral joint arthritis, a disease-modifying antirheumatic drug like sulphasalazine may be required.

Is AS life-threatening?

Virtually never.

What causes AS?

We're not entirely sure. So far medical research has shown that 96% of people with AS in Britain all share the same genetic cell marker - Human Leucocyte Antigen B27 (HLA-B27). It is possible that some normally harmless micro-organism, which on this occasion the immune system cannot fight, comes into contact with HLA-B27 and sets up an adverse reaction. Sometimes bowel infections appear to spark off AS. Symptoms may also become apparent after a period of enforced bed rest, for example following a car accident, accelerating a previously existing mild condition.

A group of symptoms known as Reiter's Syndrome may also lead to AS. These include iritis (or uveitis) which is inflammation of part of the iris; and conjunctivitis which causes red, gritty and painful eyes. People with Reiter's Syndrome also suffer from urethritis. This is inflammation of the urethra, the tube that conveys urine from the bladder out of the body. This results in pain on passing urine, discharge on the end of the penis (especially on waking up in the morning) and an increased frequency of passing urine. Women may get the pain but won't notice a discharge from the urethra. Reiter's Syndrome also results in arthritis, affecting the large joints, especially in the legs, together with pain in the joints of the lower back particularly at night or on waking.

What is the risk of passing it on to my children?

If a parent has AS there is a 50% chance that the B27 gene will be passed on to a child. However, not everyone with the B27 gene will go on to develop AS. Overall, the likelihood of your child developing AS will be less than 1 in 10 (or 1 in 5 if B27 positive). The chance of a child inheriting the condition from a grandparent will be less than 1 in 20. Should your child develop early symptoms of AS, it is advisable to ask your GP for a referral to a rheumatologist.

Are any other diseases associated with AS?

A skin condition called psoriasis is associated with AS. Psoriasis causes scaly patches on the skin and scalp. It can also lead to a slightly different form of arthritis. A sexually acquired infection known as Non-Specific Urethritis (NSU) can be caused by an organism called chlamydia. This leads to urethritis and sometimes other features of Reiter's Syndrome. Ulcerative colitis or Crohn's disease are also related to AS but are not caused by it. The symptoms are bouts of bloody diarrhoea, often with fever, weight loss, and an associated peripheral arthritis in some cases.

How can I be sure I have AS?

If you have the classic symptoms of AS, your GP will look at your posture to see if the lumbar spine is losing the forward curve and beginning to flatten out. If so, the GP will probably refer you to a rheumatologist who will study X-rays of your spine and look for characteristic changes to the joints in the lower back. Unlike other rheumatic conditions, blood tests are not very helpful for diagnosing AS.

Is there a cure for AS?

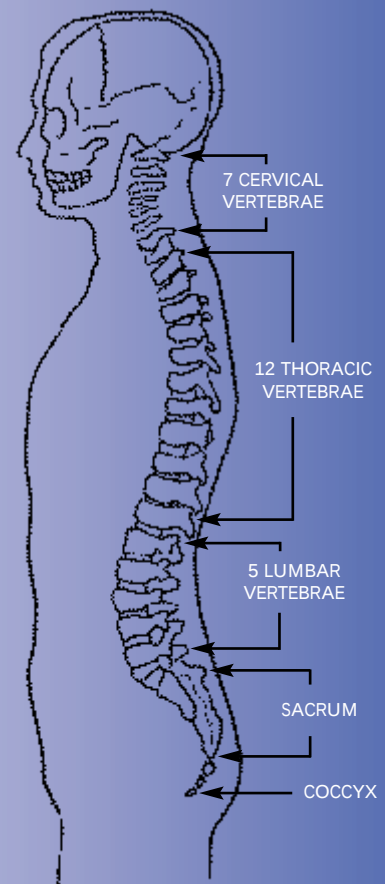
Alas, there is not! Anti-inflammatory drugs will help to reduce pain and improve your sleep and general well-being. But drugs are only half the answer. Appropriate exercise is crucial to managing your AS. The drugs should enable you to carry out these exercises with less pain. You will find some of these exercises later in this booklet.

What is the end result?

AS seems to affect everybody slightly differently. In general, though, you will probably find that the symptoms come and go over many years. In the classic case, the lumbar spine can become stiff, caused by the growth of additional bone, as can the upper spine and neck. If you pay attention to your posture, exercise regularly and avoid the stoop associated with the condition, you can prevent this from becoming too serious.

The Spine

The spine is made up of 24 vertebrae and 110 joints. There are 3 sections: 7 cervical, 12 dorsal or thoracic and 5 lumbar vertebrae. The cervical, or neck section, is the most mobile. In the thoracic section each vertebrae has a rib attached to it on each side. Below the lumbar section is the diamond-shaped sacrum which locks like a keystone into the pelvis. The joints between the sides of the sacrum and the rest of the pelvis are called the sacroiliac joints. This is usually the starting-point of the condition where the low back pain and AS begin.





LEADING A NORMAL LIFE

If you manage your AS carefully, you should be able to carry out most of your usual activities.

Carry on working

Most people with AS are highly motivated and are reported to have less time off work than average. Indeed, the vast majority remain in full-time employment. When you are at work, pay special attention to the position of your spine both when sitting and standing. If you sit at a desk or table maintain a correct posture by adjusting your chair to avoid having to bend forwards. Do not sit or stand in one position for too long. If you are required to stay in one position, wriggle, move or stretch as many joints as possible, as often as possible.

Play sport

If you have AS it is important to remain physically active. Aim to get out of breath at least once a day as this is the best form of breathing exercise. Swimming is very beneficial since all of the muscles and joints are exercised in a gravity free environment in the horizontal position. Use as many swimming strokes as possible. If it helps, use a snorkel when swimming on your front. It is best to avoid contact sports such as rugby and wrestling, and high impact sports like netball, basketball, tennis and step aerobics. Whatever the activity, wearing trainers with an impact absorbing insole will help lessen the jarring on your joints.

Take extra care when driving

You may well find an increase in pain and stiffness during prolonged car driving. So, on long journeys it is important to make frequent stops to limber up. Use a small cushion behind your back and/or under your buttocks to help maintain a good position. Also, make sure your car is fitted with correctly adjusted head-restraints as even a relatively small impact can be serious for people with neck problems. If your neck is stiff or rigid, you may have difficulties at junctions. Try attaching additional mirrors to your windscreen and dashboard. You can find these at most car accessory shops. If you have a rigid neck or severe peripheral joint involvement, it may be advisable to inform DVLC in Swansea and your motor insurance company.

Don't let AS ruin your sex-life

AS should not normally interfere with lovemaking. If, however, you are having problems with your hips, your AS is in a flaring stage or you have lost a considerable amount of spinal posture, you may need to use your ingenuity to find comfortable and satisfying positions. If fatigue is a problem you will need to pace yourself and plan your activities. It is important to discuss these issues with your partner to make sure they understand your feelings. Good communication and a sense of humour will help you maintain a fulfilling sex life.

Don't let AS put you off pregnancy

Generally speaking, pregnancy in AS is not a problem since it is unlikely to have reached a stage where it could cause a difficult birth. However, if you have serious problems with your hips you may need a caesarean section. During pregnancy the growing baby can create a tendency to pull the spine forward and increase pain when standing up. Use of a maternity support will help to spread the weight of the pregnancy higher up the spine. It is usually advisable to stop taking anti-inflammatory drugs during the first 12 weeks and last 4 weeks of pregnancy. You will not be able to restart your drug regime until you have finished breast-feeding. To compensate for not taking anti-inflammatory medication try to increase your exercise programme. After the first three months, and provided your pregnancy is normal, hydrotherapy in a warm pool can help take the place of your drugs.

Don't let AS affect an application for life insurance

Many life insurance companies do not understand AS and may try to add a loading to your policy. At NASS we feel this is grossly unfair and so we suggest you shop around and always appeal against any loading.

Get other people involved

It is quite natural for people with AS to feel isolated, particularly just after diagnosis. To help you adjust to having AS it is important that you enlist the support and encouragement of your family and friends. Involve other people by helping them to understand about AS and how it affects you. They may even like to improve their own fitness and join you in your exercise and sports activities.



SOME PRACTICAL ADVICE

There are certain things you can do that will help you manage AS more easily. There are also some things you should avoid.

Posture

This relates to the position of your body at any time during the day or night. The position you adopt affects the position of your spine. Poor posture will be detrimental to the ultimate position of your spine.

Get a suitable chair

The ideal chair either at home or at work has a firm seat and an upright, firm back, preferably extending to the head. A chair with arms will also help to relieve weight from the spine. The seat should not be too long, as you may have difficulty in placing your lower spine into the back of the chair. The chair should be of a height which will allow you to keep a right angle with the knee and hip joints. Whatever you do, avoid low, soft chairs and sofas as they will encourage bad posture and increase pain.

Watch how you sit

Try to move your spine regularly, straighten it out and stretch it by sitting tall and pulling your shoulders back. Try not to sit for too long. Stand up, walk about and limber up.

Take care with your bed, mattress and pillow

The ideal bed should be firm, without sag, but not too hard. If you have an interior sprung mattress with a sprung base which is not very firm, place a sheet of chipboard or plywood between the mattress and the base. Try to use as few pillows as possible, preferably only one. A feather pillow can be moulded to suit any position and still give your neck good support. If you decide to buy a new bed it does not need to be the most expensive. You should choose an ordinary interior sprung mattress with a firm edge. If possible, lie on the mattress for 20 minutes before purchasing to see if it is comfortable.

Lie flat on your back or your front for 20 minutes a day

It is beneficial to take the weight off your spine by lying horizontal for 15 - 20 minutes a day. Some of this time should be spent lying on your bed on your back with your legs dangling towards the floor.

Try heat or cold

In its various forms heat will help to relieve pain and stiffness. Many people find a hot bath or shower first thing in the morning and/or before bed reduces pain and stiffness, especially if some stretching exercises are done at the same time. You may also find hot water bottles or electric blankets useful in bed. If you have a particularly inflamed area, an ice-pack or bag of frozen peas wrapped in a damp tea towel may help. But do

take care as ice can burn.

Don't wear a corset or a brace

Some doctors who are not familiar with the modern management of AS prescribe corsets and braces. These often make matters worse, as they hold the spine rigid. And, with AS, not moving leads to not being able to move!

Eat well

You will need to eat a good nourishing diet with plenty of protein found in meat, fish and pulses. Eat fruit and vegetables for vitamins and drink milk for calcium. However, avoid becoming overweight.

Alcohol

Alcohol in moderation is not bad for AS. However, anti-inflammatory drugs and alcohol can both affect the stomach lining and should therefore not be taken together.

Don't smoke

AS can reduce the capacity of the lungs. Smoking can make this even worse, making you more prone to lung infections and shortness of breath. If you are a smoker, it is therefore important that you stop.

Avoid osteopathy, chiropractic and manipulation

Although osteopathy and chiropractic are useful for some conditions, we do not recommend them for AS as the manipulation can be inappropriate.

Consider alternative remedies carefully

We encourage people to do whatever they find helps, provided it is not expensive or dangerous. NASS members have tried alternative remedies such as acupuncture, aromatherapy, reflexology and homeopathy. So far none has been shown to have any advantage over conventional medical treatment, although there is evidence to suggest that massage and relaxation techniques provide some benefit. If you do want to try alternative remedies, please make sure that the practitioner fully understands the nature of AS.

Physiotherapy

This can greatly influence the outcome of your AS. A physiotherapist will teach you an exercise routine for daily use and will remind you to be aware of your posture. You will also learn how to increase the range of movement of certain joints, particularly shoulders and hips. It is important to keep your muscles strong because lack of movement can weaken them and it may take a long time to build them up again. You also need to learn how to stretch the muscles that become shortened. NASS can supply you with both an audio cassette and an exercise video for you to follow at home. On joining the Society you can also attend supervised weekly group physiotherapy sessions organised by your nearest NASS branch.



USEFUL EXERCISES

In conjunction with anti-inflammatory drugs, these exercises will help you manage your AS more easily. You may find them a little difficult at first but it is certainly worth investing some time now in learning them properly. They should become part of your normal daily routine. Aim to do them once a day or, even better, twice. Also, try to do at least one activity each day which makes you out of breath.

Warm Up

1. Vigorous marching on the spot for one minute with high stepping and arms punching upward for 20 seconds, forwards for 20 seconds and sideways for 20 seconds.

Repeat each of the following exercises at least 5 times

Floor exercises

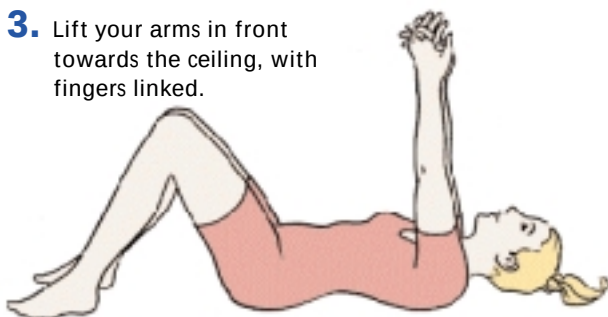
Lying on your back, both knees bent, feet on floor:



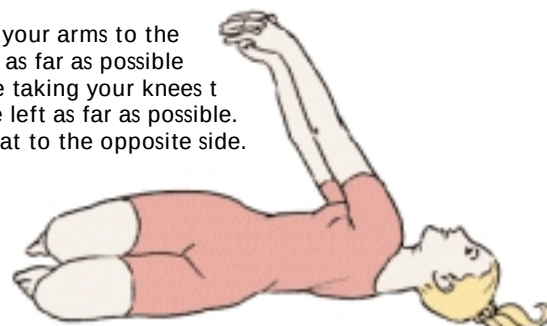
2. Lift your hips off the floor as high as possible, hold for 5 seconds and lower slowly.



3. Lift your arms in front towards the ceiling, with fingers linked.



Take your arms to the right as far as possible while taking your knees to the left as far as possible. Repeat to the opposite side.



4. Keeping your chin tucked in,

reach both hands towards your knees, lifting your head and shoulders off the floor. Relax.



- 5.** Keeping your chin tucked in, lift your head and shoulders off the floor, reach both hands towards the outside of your right knee. Relax.



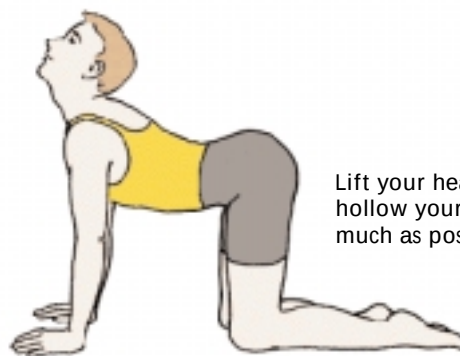
Repeat to the opposite side.



- 6.** Kneel on all fours. Keeping your elbows straight throughout, tuck your head between your arms and arch your back as high as possible.



Lift your head and hollow your back as much as possible.



- 7.** Keeping your head up, raise your right arm forwards as you raise your left leg backwards as high as possible. Hold for 5 seconds. Return to all fours and change to raising your left arm and right leg.



Chair exercises

Sit on a stable kitchen/dining room chair with your feet on the floor, hooked around the legs of the chair:

- 8.** Place your hands by your sides. Hold the chair with your left hand. Bend sideways as far as possible, without bending forwards, towards to the side.



9.



With your hands clasped on your forearms at shoulder level, turn your upper body to the right as far as possible. Repeat to the opposite side.



10.



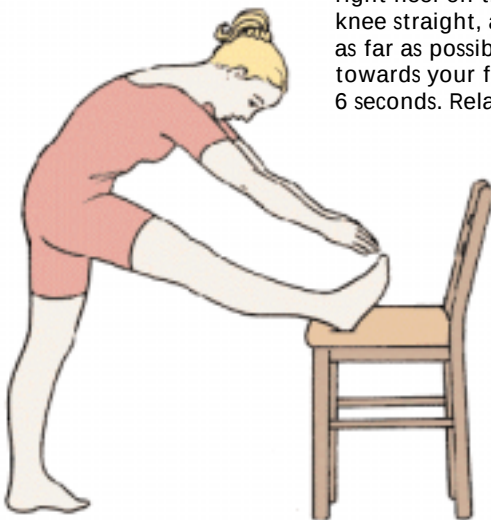
Hold the sides of the chair seat. Turn your head to the right as far as possible without letting your shoulders turn.

Repeat to the opposite side.



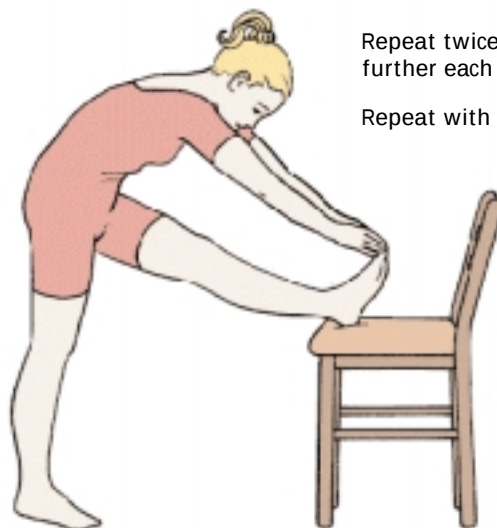
11. Stretches

Stand facing a kitchen chair, with a padded seat for comfort. Place your right heel on the seat, keeping the knee straight, and reach forwards as far as possible with both hands towards your foot. Hold for 6 seconds. Relax.



Repeat twice, stretching a little further each time. Relax.

Repeat with the opposite leg.



12.



Face the side of the chair and hold the chair back with your right hand.

Bend your right knee and place your right shin on the seat.



Left foot as far as

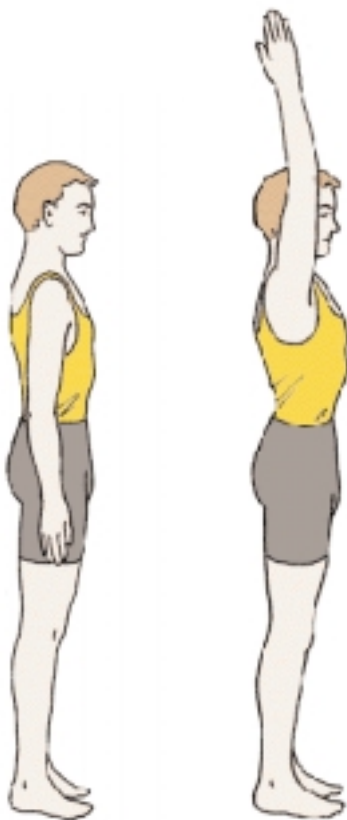
both hands reach back. Left knee as far as possible behind your head. Turn to face the other side of the chair. Repeat with the other leg.



Posture

Stand with your back to the wall, shoulders and buttocks against the wall and heels as close to the wall as you can. Tuck your chin in and push the back of your head towards the wall. Keep your shoulders down.

13. Stretch up as tall as possible without lifting your heels. Hold this position. Raise your right arm forwards and upwards while keeping your elbow straight, your upper arm close to your ear and your thumb towards the wall. Lower and repeat with opposite arm.



HELP FROM THE NATIONAL ANKYLOSING SPONDYLITIS SOCIETY

NASS was founded in 1975 at the Royal National Hospital for Rheumatic Diseases in Bath. Its members include people with AS, their families and friends together with physiotherapists, doctors and research scientists working on the problems of the disease.

The Society exists to:

- provide support, education and information about managing the social and medical aspects of AS;
- provide a forum to educate health professionals and the public in the problems of the disease;
- fund a small amount of research;
- influence governmental bodies and the National Health Service to provide improved treatment facilities;
- encourage and assist in the formation of similar societies in other countries.

Keep informed with AS News

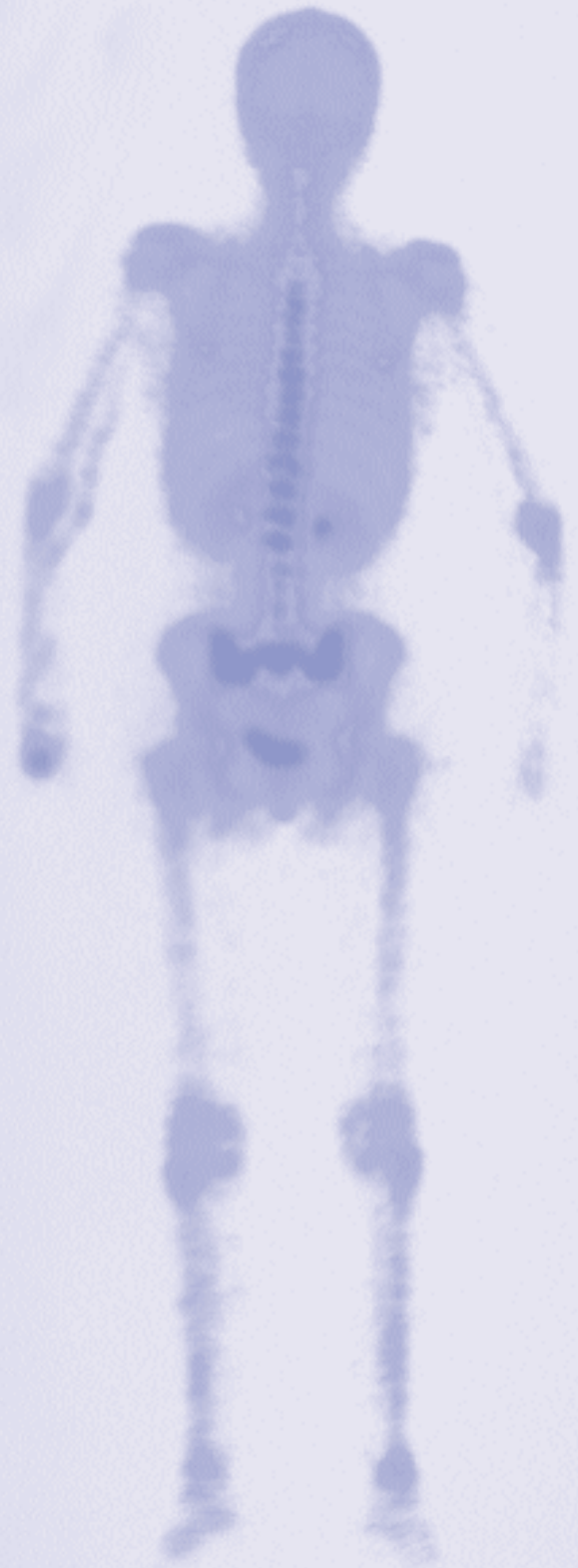
To keep you fully up-to-date, the Society publishes a twice-yearly membership journal called AS News. This publication contains articles by doctors, research scientists, physiotherapists and sufferers themselves on various aspects of AS. It also features news from our branch organisations, our foreign sister societies and a correspondence section from members of the Society. Information and prices of our other publications are also listed.

Keep mobile with NASS Exercise Programmes

The experience of NASS members shows that effective management of the condition relies on a combination of anti-inflammatory drugs with a programme of regular and vigorous exercises designed to stretch ligaments and strengthen muscles to maintain mobility and good posture. To help you learn this necessary programme, the Society is building up a network of branches around the country. All of these are supported by physiotherapists who supervise regular exercise sessions for members after working hours. An audio cassette and a home-exercise video are also available for purchase.

Joining is easy

To join simply complete the membership form and return it with a cheque/postal order made payable to NASS.



Contact Addresses

National Ankylosing Spondylitis Society
PO Box 179
Mayfield
East Sussex
TN20 6ZL
Tel: (01435) 873527
Fax: (01435) 873027

Arthritis and Rheumatism Council
Copeman House
St Mary's Court
St Mary's Gate
Chesterfield
Derbyshire
S41 7TD
(Raises and distributes money for research)

Arthritis Care
18-20 Stephenson Way
London
NW1 2HD
(Social and welfare assistance)

National Association for Colitis and Crohn's Disease
4 Beaumont House
Sutton Road
St Albans
Herts
AL1 5HH

Psoriasis Association
7 Milton Street
Northampton
Northants
NN2 7JG

The illustration on the front cover is of an isotope bone scan. This is a specialised form of X-ray showing areas of abnormal activity. The scan indicates areas of inflammation commonly found in ankylosing spondylitis.