



Living with an inflammatory arthritis Ankylosing Spondylitis

Information for patients, families and carers



Table of contents

Chapter 1	What is Ankylosing Spondylitis	3
Chapter 2	Understanding the effects of AS	7
Chapter 3	Assemble your healthcare team	11
Chapter 4	Get to know your medicines	13
Chapter 5	Living with AS	17
Chapter 6	AS needs exercise	23
Chapter 7	Helpful contacts	34

This booklet has been designed to help people with AS, their families and carers. It deals with some of the key challenges for people who have AS.

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Mrs Margaret Lewington

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Mrs Diana Aspinall

All the people with AS who are featured in the photos in this booklet.

1

What is ankylosing spondylitis?

Ankylosing spondylitis (or AS for short) is a chronic rheumatic condition that mainly affects the back and neck. The term ankylosing spondylitis is derived from the Greek language and is pronounced 'Ank-ill-ose-ing Spon-dill-eye-tis'.

Ankylosing means stiffening or joining together and is used to describe the fusion of bones in the spine. Spondylitis means inflammation of the spine, a characteristic feature of AS.

Is ankylosing spondylitis the same as spondylosis?

No. The term spondylosis is used to describe degenerative changes of the spine and is more common in older people. This is unlike AS which is an inflammatory condition, without degenerative changes, which can produce overgrowth of bone and can lead to fusion (joining) of vertebrae (bones that make up the spine).

AS is an inflammatory condition

In AS, inflammation commonly occurs where ligaments or tendons attach to bone (this is called an enthesis). Ligaments are made of fibrous tissue that connects bone to bone while tendons connect muscles to bone.

In the early stages of AS most of the pain and stiffness is caused by inflammation. Over time, the process of spinal inflammation and associated tissue damage may lead to bony overgrowths (called syndesmophytes, pronounced 'sin-de-moe-fye-tees') which extend from the edge of one vertebra to the next. This process may lead to ankylosis or fusion of part of the spine and sometimes the pelvis. Over time, the elasticity of the ligaments and tendons may be replaced by rigid fused bone, and flexible movement of the spine may become increasingly restricted.

Related disorders

AS is part of a larger group of disorders called spondyloarthritis (pronounced 'spon-dill-oh' arthritis) which also includes:

- **Psoriatic arthritis** (pronounced 'sore-attic' arthritis) - this arthritis usually occurs with psoriasis (pronounced 'sore-eye-a-sis'). Psoriasis is a scaly skin disorder characterised by scattered red patches covered with white scales.

- **Reactive arthritis** - this is an acute arthritis that is triggered by certain bowel and genital infections such as Salmonella or Chlamydia.
- **Arthritis with inflammatory bowel disease** - arthritis can sometimes occur in inflammatory bowel disease such as Crohn's disease and ulcerative colitis.
- **Undifferentiated spondyloarthritis** - this usually presents with symptoms of AS without the characteristic X-ray changes in the sacroiliac joints. Over time, most individuals with undifferentiated spondyloarthritis will develop ankylosing spondylitis.

Who gets AS?

AS may affect as many as 1 in 300 people in the community. It is more common in men, with 3 times as many men having AS compared to women. Symptoms usually begin between the ages of 15 and 45 years.

AS may affect children in different ways to adults. When AS appears in children (usually adolescents), it commonly affects the ankles and feet rather than the spine.

What causes AS?

Approximately 90% of people with AS carry a gene called HLA-B27 (Human Leucocyte Antigen-B27). This is a normal genetic variant and occurs in approximately 8% of Caucasians. Only 10-15% of people with HLA-B27 will develop AS or another spondyloarthritis. The majority of people with HLA-B27 will therefore not ever develop AS.

Finding the HLA-B27 gene does not necessarily mean a diagnosis of AS because the gene on its own does not cause AS. AS is thought to be caused by a combination of unknown triggers in the auto-immune system of individuals genetically predisposed to developing AS.



"Studies have shown that people who take an active role in managing their arthritis feel less pain and disability... physical, social and emotional well-being [can be enhanced by] your ability to participate in all aspects of daily life and leisure activities."

Associate Professor Nick Manolios, Director of Rheumatology Unit, Sydney West Area Health Service, Westmead NSW and University of Sydney

1 What is ankylosing spondylitis? (continued)



People with HLA-B27 have a 50% chance of passing the gene on to their children so an HLA-B27 positive child, of an individual with AS, has approximately a 1 in 5 chance of developing AS. If a parent has AS and is concerned they should discuss the option of genetic counselling with their healthcare professional.

How is AS diagnosed?

Early diagnosis of AS is important because spinal deformity can be minimised and progressive loss of mobility can be reduced with appropriate management. The objectives of treatment are to reduce pain and stiffness, maintain erect posture, and preserve mobility and normal daily functioning. Although there is currently no cure or measure that prevents the onset of AS, the treatment options have substantially improved in recent years.

The diagnosis of AS is made from an assessment of your symptoms, physical examination findings, blood tests and X-rays or MRI scans. These will be organised by your rheumatologist who can explain the result of each test. MRI is a diagnostic technique that produces computerised images of internal body tissues using magnetic waves.

Early symptoms

Sacroiliitis (pronounced 'sack-row-ill-ee-eye-tis') is an early feature in most people with AS. The pain caused by sacroiliitis is usually a dull ache felt deep in the buttock region, due to inflammation of the joint between the tail bone and the pelvis. The pain can also spread out over the buttocks. At first, it may come and go, it may just involve one side or move from one side to the other.

Chest symptoms - Pain at the front of the chest or between the shoulder blades (made worse by coughing and sneezing) is also a common early complaint.

What happens as AS progresses?

The course of AS is highly variable. Some people have only brief episodes of back pain with long periods of remission in between times. In others, the symptoms are more persistent.

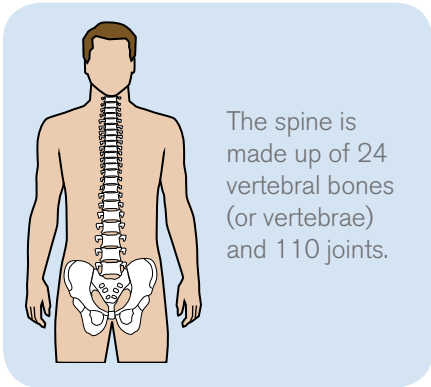
Most people with AS experience episodic flares of spinal pain and a slow decline of spinal flexibility. The long-term outlook in AS can usually be assessed by the severity of symptoms over the first 10 years. People with only minor restriction in spinal mobility and limitation of daily functioning after 10 years are unlikely to develop major problems with AS in the long term.

In people with AS, limitation of spinal mobility may appear several decades after the onset of symptoms. The most well recognised feature of AS, thoracic *kyphosis* (pronounced 'kigh-foh-sis'), is a late feature of this disorder. Kyphosis is exaggerated forward curvature of the thoracic region of the spinal column resulting in a rounded upper back.

Is there a cure for AS?

There is no cure for AS but with new medicines the disease can be managed positively. The effects of AS will vary with each individual and your healthcare team will strive to achieve periods of remission. This brochure helps provide tips to manage pain and maintain movement.

Back pain - mechanical or inflammatory?



The spine is divided into three sections:

- Cervical section: 7 vertebrae of the neck
- Thoracic section: 12 vertebrae of the mid-spine, which also join up with the ribs
- Lumbar section: 5 vertebrae of the lower back.

The lowest lumbar vertebra (the 5th) sits on a bone that forms the back portion of the pelvis called the sacrum or tail bone. The sacrum looks like a keystone in the bony ring or basin that forms the pelvis. The sacroiliac joints attach the sacrum to the ilium of the pelvic bone on either side.

Mechanical back pain

Back pain is a very common complaint in the community. Most people with backache do not have AS. In middle age, the most common causes of backache are ligament strain and

prolapsed disc. In older people, degenerative or 'wear and tear' changes of the lower spine are the most common cause of backache and unlike AS, these conditions cause 'mechanical back pain'. This pain is characteristically made worse by activity and improved by rest. Stiffness of the spine in the morning is minimal and short-lived, and the response to anti-inflammatory medicines is modest. Short periods of rest, appropriate exercise and physiotherapy programs form a basis for the treatment of mechanical back pain.

Inflammatory back pain

By contrast, AS causes inflammatory back pain, which is made worse by prolonged rest and inactivity. As a result, pain and stiffness in AS are usually worse early in the morning and when you first get out of bed. The severity and duration of morning stiffness is a good measure of the activity of AS.

For people with inflammatory back pain, regular stretches and exercise relieve symptoms. In addition, anti-inflammatory medicines usually provide considerable relief.

Does AS affect other parts of the body?

Although AS mainly involves the spine, other areas can be affected.

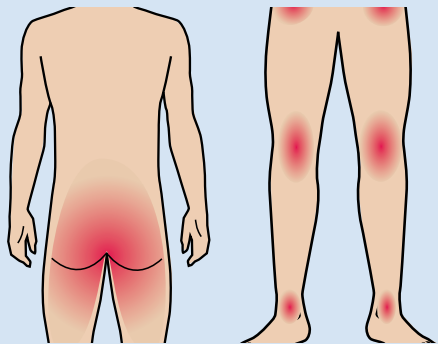
Peripheral joints

Approximately 50% of the people with AS have inflammation of the limb joints called peripheral arthritis, which causes pain, stiffness and swelling. The large joints (hips and shoulders) are most commonly affected. People with AS who have hip joint problems often have a more severe overall course of their disorder. Less commonly, the knees, ankles, and wrist joints can become inflamed.



Feet

Enthesitis (pronounced 'en-thess-eye-tis') is the name given to inflammation in areas where ligaments and tendons join to the bone and is a unique feature of spondyloarthritis. Enthesitis commonly occurs around the heel in conditions called Achilles tendonitis and plantar fasciitis. This can be challenging to treat and often requires management by a podiatrist or orthotist (see Chapter 3, Assemble your healthcare team).



You may feel pain in the buttocks and down your thighs. AS can also affect the hips, knee and ankle joints.

Eyes

Inflammation of the eye (called iritis or uveitis) may occur in about 30% of people with AS. In some cases, an episode of iritis or uveitis is the first sign of AS. Iritis or uveitis is inflammation of the middle layer of the eye's protective covering.

Typical warning signs might include eye redness and pain, an intolerance of bright light, and blurry vision. This usually occurs in one eye at a time. Inflammation of the eye can occasionally lead to a permanent loss of vision so it is important to treat symptoms early. If any of these symptoms occur you should see an ophthalmologist (eye specialist), GP or go to the Emergency Department of an eye or local hospital. If you have already been diagnosed with AS, tell your healthcare professional.

Bowel

Inflammation of the lining of the bowel wall may occur in more than half of people with AS. Most of the time, this inflammation is very minor and does not cause any symptoms. However, some people with AS have symptoms of inflammatory bowel disease (usually Crohn's disease or ulcerative colitis). Crohn's disease is an inflammatory condition that may affect the gastrointestinal tract. Ulcerative colitis is a chronic inflammatory disease of the colon that causes diarrhoea with discharge of mucus



and blood, cramping abdominal pain, and patches of bowel ulceration.

Skin

Scaly or flaky skin rashes (called psoriasis) can occur in AS. The areas affected are often the scalp, belly button, buttock crease, back of elbows and top of the knees. An arthritis called psoriatic arthritis may occur in one third of people with psoriasis.

Heart and Lungs

Occasionally, AS can cause scarring of the upper lobes of the lungs and/or a disturbance of the normal heart rhythm. AS can inflame the rib joints (enthesitis) and affect the muscles between the ribs making breathing, sneezing, coughing or yawning painful. In the later stages of AS the rib joints may become quite fixed and exercise is recommended to help maintain normal movement of the chest wall. (See specific AS exercise later in this booklet). Smoking should be avoided.

Fatigue

AS can cause fatigue and blood tests can help identify whether there is another cause so that appropriate treatment can be provided. Your healthcare team are the best people to advise you on this.

Depression and Mood

AS can contribute to mood changes or depression. Please be aware of any mood swings or changes and discuss these with your healthcare team or visit www.beyondblue.org.au or www.blackdoginstitute.org.au for assistance.

Bones

Clinical studies demonstrate that up to 60% of patients with AS have osteoporosis. Osteoporosis is a disorder that results in a decrease in the amount of bone tissue in the skeleton and increases the risk of having a fracture. Your doctor may perform a bone mineral density (BMD) test to assess the amount of bone tissue in the skeleton.

AS and sex

As AS usually begins in early adulthood, sexual and reproductive health is important to consider. Having AS should not interfere with lovemaking but the inflammation in hip joints and lower back can

make having sex painful and uncomfortable. Sometimes you may experience fatigue and tiredness, which can have an impact on your sexual relationship. This may mean that you and your partner may need to find ways to cope with these challenges. Seek help and advice from relevant healthcare professionals.

AS and pregnancy

Having AS does not appear to have any negative effects on fertility, pregnancy or breastfeeding.

If you are pregnant, your doctor or physiotherapist may suggest gentle physical activity and weight relieving water exercises.

If you have any questions or concerns about the effect of medicines, pregnancy or breastfeeding please discuss these with your doctor.



Assemble your healthcare team

There are several healthcare professionals who can provide advice, support and treatment. You, as the patient with AS, are the most important member of this team. Patient-centred care means that you and your team can develop, monitor and review your management plan together. Your needs will vary over time and your healthcare professionals are the best people to assist you to improve your quality of life.

General Practitioner

Your GP will help you to coordinate your care. They can arrange referral to a rheumatologist and assess if you are eligible for a "Care Plan". A Care Plan means you can access some short-term sessions by the Allied Health Care Team under Medicare.

Rheumatologist

Rheumatologists are doctors who specialise in diagnosing and treating bone, joint, and muscle disorders. Initially, your rheumatologist may be involved in diagnosing your AS. They will discuss your medical history, as well as perform a physical examination, X-rays and blood tests.

Once the diagnosis of AS is made, your rheumatologist will discuss treatment options such as exercise and the use of medicines. Regular visits to your rheumatologist are necessary to help manage your AS.

Physiotherapist

Physiotherapists can help with mobilisation techniques, stretches, and assisted movements and exercises that are appropriate to your condition and needs. They will help tailor an exercise plan to meet your individual needs. This includes ways to help manage your pain, your daily activities, posture, sport and recreation.

Hydrotherapy (exercises in water) can be a more comfortable way of exercising. The warmth and support of the water gives pain relief and allows a greater freedom of movement to relieve stiffness. Group or individual sessions specifically for people with AS can be helpful. Call 1800 011 041 for information about your nearest hydrotherapy class. Aquatic Physiotherapists can be found at www.physiotherapy.asn.au

Chiropractic, manipulation and osteopathy

Care is needed when using these treatments for AS. It is very important to discuss the level of manipulation that is suitable for your condition with your doctor or specialist before commencing these treatments.



Occupational Therapist

Occupational Therapists can provide advice and assistance with activities of daily living – such as rest and activity periods, work place advice and home modification. If necessary they may suggest the use of assistive devices to make day-to-day activities easier to perform. Further information is available from Independent Living Centres Australia at www.ilcaustralia.org

Podiatrist or Orthotist

A podiatrist or orthotist provides professional assessment and management of your feet. Provision of orthotics may improve symptoms and some simple measures such as better shock absorbing soles can be helpful.

Pharmacist

Your pharmacist is a valuable member of your healthcare team who can answer your medicine related questions. They can provide a Consumer Medicine Information (See Get to know your medicines section) document which explains the benefits and risks of each medicine you are taking for AS.

Psychologist or Psychiatrist

The diagnosis of a chronic rheumatic illness can be difficult for both the person with AS and their loved ones. Psychologists and psychiatrists are trained to improve your emotional wellbeing through counselling and medicines where appropriate. Visit www.beyondblue.org.au or www.blackdoginstitute.org.au

Other medical specialists may be recommended by your GP or rheumatologist. These may include an ophthalmologist for eye treatment, a dermatologist for skin treatments and a gastroenterologist for bowel problems.

Ideally, all of your healthcare professionals will communicate with each other and with you to co-ordinate your care.

Ankylosing Spondylitis Support Groups

AS support groups are a very valuable resource - providing support, information and social interaction. People who have similar difficulties can provide empathy and share daily experiences and challenges. For more information call 1800 011 041 or contact www.asaustralia.org

AS can be managed with a combination of medicines and specific exercises to relieve pain, maintain mobility and a correct posture, so that you can continue to do your daily activities.

In this chapter we will discuss the medicines that may be used to treat AS. Although there is no cure for AS, treatment options have substantially improved in recent years.

Before considering surgery, pregnancy or breast-feeding, the use of any medicine should be discussed with your doctor.

Consumer Medicine Information (CMI)

CMIs are available to help consumers use the medicines they take appropriately. There is a CMI available for all prescription and some over-the-counter medicines.

A CMI is factual, contains no advertising material, and must comply with the requirements set down in the Commonwealth Therapeutic Goods Regulations.

Ask your pharmacist or doctor for a CMI and they will print it from their computer. Sometimes the CMI is provided inside the packet or box with your medicine.

For further information on any of the medicines listed in this brochure please refer to the CMI.

CMIs are also available from the company making the medicine or the National Prescribing Service (NPS) Medicines Line 1300 888 763 available Monday to Friday 9am – 6pm or www.nps.org.au
See Chapter 7, Helpful contacts.



Risks and benefits

Some medicines may have side effects. Your doctor has weighed the risks of using this medicine against the benefits they expect it will have for you.

It is important that your doctor is aware of your full medical history, including any family history of medical problems and medicines that you are currently taking, so they can make an accurate assessment of the risk and benefits of prescribing medicines for you.

Other medicines including over the counter, herbal, complementary medicines and

supplements, as well as drinking alcohol can affect the way medicines work.

If you experience any side effects please discuss these with your doctor, healthcare professional or pharmacist. If you experience a serious side effect or have questions, seek medical advice quickly or contact the Medicines Line on 1300 888 763.

Analgesics (pain relievers)

Pain relievers, such as paracetamol, may be useful in combination with other medicines that your doctor has prescribed. They can help to manage the pain that may be associated with AS. If the pain is severe and unrelenting, you should see your GP or rheumatologist and have your treatment reviewed.

Non Steroidal Anti-Inflammatory Drugs (NSAIDs)

NSAIDs are usually the first medicines used in the treatment of AS. Examples of NSAIDs are ibuprofen, piroxicam and naproxen. A newer class of NSAIDs are the COX-2 inhibitors, which include celecoxib (Celebrex®), meloxicam (Mobic®) and lumiracoxib (Prexige®). NSAIDs can improve pain and stiffness by reducing inflammation. They are commonly used with other types of medicines to get the best result.

Common side effects include heartburn, raised blood pressure and swelling of the ankles. These side effects are more likely to occur in individuals over the age of 65 years. As everybody reacts differently to NSAIDs you may need to switch to a different NSAID to find the one that best controls your symptoms with the least side effects. Your doctor or pharmacist can advise you on how these medicines may affect you.

Disease Modifying Anti-Rheumatic Drugs (DMARDs)

DMARDs are medicines commonly used in rheumatoid arthritis that may improve some of the symptoms of AS, in particular inflammation of the limb joints.

Sulfasalazine (Salazopyrin®)

Sulfasalazine is helpful in patients with AS who have pain and swelling in a limb joint (e.g. knee, ankle, toes). The full effect of sulfasalazine is usually not seen for 1-3 months. The most common side effects are nausea, skin rash and headache. Sulfasalazine should not be used in individuals with an allergy to sulfa-drugs (such as Bactrim® or Septrin®).

Regular monitoring of blood counts and liver tests are mandatory.

Methotrexate (Methoblastin®)

Methotrexate is also useful for patients with pain and swelling in a limb joint. The full effect is usually not seen for 1-3 months. The most common side effects are nausea, mouth ulcers and fatigue. Folic acid is routinely prescribed to minimise these side effects. Routine monitoring of blood counts and liver tests are mandatory. Report any infection immediately to your doctor.

**Biologic Medicines**

Biologic medicines are the latest disease modifying medicines available for treating severe AS. They target the individual molecules that are involved in inflammation and joint damage.

A number of these medicines are directed against a molecule that promotes inflammation called tumour necrosis factor (TNF) which is a natural substance called a cytokine. In people with AS, TNF is present in the blood and joints in excessive amounts. TNF inhibitors block or neutralise TNF, reducing the inflammation and symptoms.

The biologic medicines are given either by injection under the skin, or by infusion into a vein. They can only be prescribed by a rheumatologist.

The biologics that are currently available for use in AS include: etanercept (Enbrel®), infliximab (Remicade®) and adalimumab (Humira®).

Corticosteroids (or steroids)

Corticosteroids are man-made substances that resemble hormones naturally produced by our body. They relieve pain and are powerful anti-inflammatory medicines.

You may be prescribed corticosteroid tablets, most commonly prednisolone.

These medicines have possible side effects and require careful monitoring of blood pressure, cholesterol, glucose levels and bone density.

Corticosteroids may also be given as a local injection into an inflamed joint. This injection can provide rapid control of pain and swelling as a short-term approach.

Tips for living with AS

If you manage your AS carefully, you should be able to carry out most of your usual activities. For the vast majority of people AS is not a barrier to employment, raising a family, or keeping physically active.

The effects of AS are different in each person. Learning about your condition and what you can do, along with help from others, is vital to making the most of your life.

Posture

Good posture is vital. It's very important to pay attention to how you stand and sit at all times. Stand as tall and straight as possible. Sit well supported and upright in a good chair. These everyday skills will help you change the tendency to bend forwards and stoop. It is also important to be aware of posture as you move about.

Poor posture may have a negative impact on the position and function of your spine. When experiencing pain in the spine, there is a tendency to stoop. If the position is not corrected, there will be chronic joint strain, difficulty breathing, compression of abdominal organs and tightness on the front of the shoulders. It becomes increasingly difficult to straighten up but with practice, you can improve.



Make good posture a habit. Changes happen slowly, so we often don't notice them at the time. It is important to check your posture regularly and discuss with your healthcare team.

For more information see the posture exercises included within this booklet.

Sitting

When sitting, ensure that you have a good supportive chair - at home and at work. It should be firm, upright and allow the feet to touch the floor with the knees and hips at a right angle. To avoid neck strain, if you are working at a desk or using a computer, ensure that the screen is level with your eyes. Back supports, lumbar rolls, wedge cushions and other devices may help to improve the seat you have. Advice on these items can be obtained from Independent Living Centres Australia at www.ilcaustralia.org

Standing

When standing, keep your bodyweight balanced and even on both feet. Think tall through your whole body, ensuring that you are not flexed at the hips, that you have some curve in your lower back, that your chest is lifted off your belt line, shoulders are relaxed (back and down), and that the back of your neck is long, allowing your chin to drop slightly forwards. Do not stand still for too long. When you move and walk, try to maintain this tall posture, but also remain relaxed.

Lying down & sleeping

A good night's sleep is essential for rest and repair of the body. The best mattress is one that is firm and gives support, but is not too hard. Use only one pillow if possible, which fits snugly into your neck and supports the head. Sleep in the position that you find most comfortable, whether on your back, front or side. To enhance freedom of movement during sleep, some people with AS prefer silk sheets and silken nightwear.

If lying on your front, don't always have your head turned to the same side. On your sides, avoid curling up with a lot of flexion (bending) at the hips and knees. A pillow placed under your top knee may ease back pain at times. If lying on your back, pillows and other supports may be useful - but avoid using them all the time as they may encourage muscle shortening. Try not to put pillows under your knees.



Many people wake in the early hours and find it hard to settle again, as they are feeling pain and stiffness. A few simple stretching exercises in the evening before going to bed may improve your sleep. This ensures that you are inactive for the shortest period of time. Alternatively, get up and do a few stretches and then go back to bed. If you continue to have problems with sleeping please discuss them with your healthcare team.

Flexibility

It is necessary to keep the whole body as flexible as possible to minimise rigidity and avoid injuries as much as possible.

Try to move your spine regularly. Not even the best position is as good as moving. Allow yourself to bend and straighten your spine, bend sideways and turn often. Do not sit for more than 20 minutes at a time. Stand up and walk about. Stretch and move often.

Staying active

People with AS can participate in a wide variety of sports and activities. Sports and activities that encourage good posture and spinal extension are recommended. Swimming, walking, tennis and low impact aerobics are all good. Golf, cycling and bowling may be good but these activities need to be tailored to your physical capability and fitness. After any exercise make

sure you stretch and reverse the posture you have been using. Contact and collision sports are usually not advised. High impact sports like football and parachuting are usually not recommended.

While sports and other physical activities are beneficial, they cannot be totally relied upon to ensure erect posture and flexibility. You still need to do the AS-specific exercises daily.

Work choices

Having AS usually does not make it more difficult to find employment or have a fulfilling life. Most people are able to continue in their choice of occupation. During bad times with significant inflammation, you may need to modify what and how you do things. Some time off work may be necessary. Research has shown that on average, you will not need more time off work than the rest of the population.

If you are choosing or changing jobs, it is helpful to choose something where you can have a range of postures, positions, tasks and time management. An active job, although physically hard at times with AS, is better than sitting in a chair all day. If your job prevents you moving much, compensate by moving more at other times. In some work settings the staff OH&S officer can undertake an ergonomic assessment of your physical environment.



Manage your energy

It is quite common for people with AS to complain that they feel tired. As the body is using a lot of energy to fight the inflammation that is present, fatigue is a recognised symptom of AS. Mild anaemia (which contributes to lowered levels of oxygen in the blood) may also be present. Your doctor can check for this with a simple blood test. It can be managed with medicine and there are also ways that you can help yourself. Plan your day and week, pace yourself, vary your activities, organise yourself and give yourself time to rest and relax. Moderate exercise and activity is also helpful.

Take extra care when driving

Prolonged periods of driving can increase pain and stiffness. Make frequent stops and use your exercises to assist your joints to be flexible and not stiff. You may need

a small cushion or back support to maintain a correct and comfortable position whilst driving. If your AS is affecting your neck, ensure that the head restraints are correctly adjusted for you. If you have some neck rigidity from AS your peripheral vision can be decreased. Investigate whether you can install more mirrors to assist you.

Make life easier

To help you to continue with your regular activities, extra resources are available. Specially designed chairs and supportive cushions are available to help you maintain correct posture while driving or sitting at a desk and simple devices are available to make gardening and other activities easier. For more information on these, talk with your healthcare team and/or have a look at some of the support sites listed at the end of this booklet.

Relaxation

A relevant exercise program is a big help for people with AS, but this needs to be balanced with appropriate rest and relaxation. Relaxation can help to prevent and reduce excessive levels of tension and anxiety that often accompany AS and arthritis. It can also decrease muscle tension and spasm. If you are having trouble sleeping, then it is important to include a dedicated period of relaxation just before bedtime.

Managing your stress is very important as many people report that high stress levels tend to make their symptoms worse.

Tips for effective relaxation:

- Find a quiet place, free from interruptions and loud noises
- Timing – not after exercise or a big meal
- A comfortable position – supporting painful joints
- A positive attitude - necessary to allow your mind and body to relax
- Regular practice – relaxing is a skill that gets better with practice
- Controlled breathing – take in several big, slow, deep breaths
- Mental focus – avoid distracting thoughts, perhaps by repeating a word each time you breathe out
- Look at a calming visual image - to help you focus

- Imagery – imagine doing something that is very important to you. Imagine the positive outcome. Daydreaming yourself to this special place can act as a mental release valve
- Progressive muscle relaxation – tense and relax muscles in a specific order. This helps relax part of your body that you may not have realised needed it
- Meditation – this is an excellent relaxation technique that involves focusing on breathing, clearing your mind and concentrating on an object
- Massage – there are several types of massage. Swedish (therapeutic) massage promotes relaxation, Shiatsu (trigger point) therapy relieves pain and Deep Tissue massage relieves tension.

Healthy Eating

Can certain foods affect arthritis?

There are many myths about food and arthritis. Unfortunately, most of it is wishful thinking. There is very little scientific evidence that diet has an effect on any form of arthritis, including AS. For example, it is unproven that 'acidic' foods or 'nightshade' vegetables, such as potatoes, eggplants, capsicum and tomatoes, cause arthritis to flare up.

Except for people with gout, most foods will not have an effect on AS or arthritis. Be very cautious of special diets or supplements that claim to 'cure' arthritis or to control its symptoms.

A good balanced diet is important for maintaining your general health because it will positively affect your total wellbeing. Remember, your body relies on you to feed it the nutrients it needs to fight disease and resist deterioration. Achieving and maintaining a healthy weight is important for everyone.

Omega 3 may reduce inflammation

While it's been said that there are a lot of unproven food claims, there is good scientific evidence that inflammation can be reduced by eating foods that contain Omega 3 fatty acids six times more often than foods containing Omega 6 fatty acids (found in vegetable oils and grains).

Foods that are rich in Omega 3 fatty acids include:

- Fish (salmon, tuna, herrings and sardines, canned fish is fine)
- Linseed and linseed oil (also called flaxseed)
- Canola oil (also called rapeseed oil)
- Wheat germ
- Walnuts and pecans.



If you can't eat these foods regularly, Omega 3 supplements that contain around 4 to 6g (4000-6000mg) per day of fish oil are recommended. It's best to talk with your health professionals about the safety and effectiveness of dietary supplements.

Dietary advice

Professional dietary advice can be found at the Australian National Health and Medical Research Council at www.nhmrc.gov.au

Exercise is one of the most effective treatments for AS. It helps to slow down the stiffening of the joints and soft tissues around the joints and can help you manage your pain. It is well known that regular exercise can strengthen your muscles, relieve tension and generally improve your overall health. This means you will be able to feel more in control of your AS and do more in your daily life.

Exercise to specifically combat AS

It is essential to perform exercises that are designed to stretch tight muscles and ligaments, encourage full mobility and to strengthen your postural muscles. A range of these exercises, developed by a physiotherapist who specialises in the treatment of AS, has been included in this chapter to either help get you started or to compliment your current exercise regimen.

Specific AS exercises for 30 mins per day, at least 5 times per week (preferably every day), are recommended. A moderate, consistent exercise program has been shown to be the most beneficial in achieving results for your AS. It should be individually tailored to meet your needs so as to provide quicker and better results for you.

As well as your AS specific exercises, it is important to do general exercise for fitness and well-being. Regular exercise will also improve your overall health and enhance your

strengthening and stretching routines. This may include walking, jogging, dancing, swimming, yoga, tai chi, gym programs, weight training, bushwalking, cycling, etc.

Tips to keep you exercising

It is important to plan your exercise for times when you're least tired and when your medicine is having maximum effect (times of least pain).

- Do activities that you enjoy! Vary them so you don't get bored.
- It's more fun to exercise with a friend or in a group.
- Be aware of joint pain and swelling. You should feel some stretching and discomfort with the exercises, but stop the activity if it causes you additional pain.



- If you are having a flare of your symptoms, temporarily reduce or modify your exercise, but do not stop.
- Set short-term goals and celebrate your successes.
- Keep an exercise diary, so you can see how you are progressing.
- Work with your physiotherapist to ensure that your exercise plan is best for you.

Your exercise programme mobility/stretching

Stiffness and loss of flexibility are the greatest problems for people with AS, so the most important exercises encourage movement. Specifically, exercises that help the body to loosen up and feel free work best.

Regular stretching improves the flexibility of muscles, tendons and other soft tissues, which as a result of inflammation can become sore and difficult to move. If they are not stretched, they become shorter and tighter. This can make it harder to stand up straight, to turn and bend, or to take a deep breath.

It is very easy to become a little stiffer and a little less straight without being aware of it – the process happens so slowly. The exercises in this book are designed to combat the damaging effects of AS. In many cases, when you start exercising and stretching, you can regain some of the movement you



may have lost. Some of the exercises involve stretching a specific muscle and some stretch several muscles and other tissues at once.

It is important to do these exercises with some vigour – but without hurting the body. It is usual to feel some discomfort, as you try to go as far as you can. If there is pain, check that you are doing it correctly. Good technique is vital to obtain the best results and minimise injury.

How to stretch muscles:

- Warm up first
- Don't hold your breath. Paying attention to your breathing can make the exercise more effective. It also helps you relax
- Keep stretches slow and gradual and avoid jerky movements
- Hold muscle stretches for at least 10 seconds
- Position correctly / watch your technique.

The PNF method

To effectively stretch muscles, a long, slow sustained stretch is necessary, while keeping the body relaxed.

PNF stands for Proprioceptive Neuromuscular Facilitation and it is a method of stretching muscles to maximize their flexibility. A muscle will stretch further and more easily if it is first made to contract or work, then relax completely, followed by a firm and steady stretch. The sequence is 'contract, relax, and then passively stretch'. The objective is to have muscles contract isometrically (without movement), then after relaxing, be passively stretched. Hold this stretched position, but keep yourself relaxed (don't hold your breath or tense your body). Repeat this sequence another 2 times, each one from the advanced starting position.

Persist

Each gain may be small, but it all adds up. Giving a stiff joint another few degrees of movement is worth having. If you don't stretch your muscles, in time they will become tighter. Remember to use the extra movement you gain from the exercises in your daily life. Reach up to taller shelves and turn and look further behind you.

Strength

Strong muscles support the body. The muscles that are important to

strengthen are the ones that hold us up straight – the postural or anti-gravity muscles. These exercises are designed to increase the strength and endurance of these muscles, to make it easier to keep in an upright position with good posture.

FLOOR EXERCISES

These exercises have been designed by a physiotherapist specifically for people with AS. They target the areas most commonly affected and will give you a general workout. It is advised that you consult a physiotherapist to help you with identifying which are the most important exercises for you. They will also be able to check that you have correct technique and that you are doing them safely. They can also provide modifications to suit your particular needs. Regular reviews with a physiotherapist are recommended.

Warm up

It can be helpful to warm up before you exercise. A few minutes walking on the spot, or moving about, or a warm shower can help.

Counting

Do each exercise at least 5 times. If the exercise is for one side of your body then make sure you do an equal number for the opposite side – for balance.

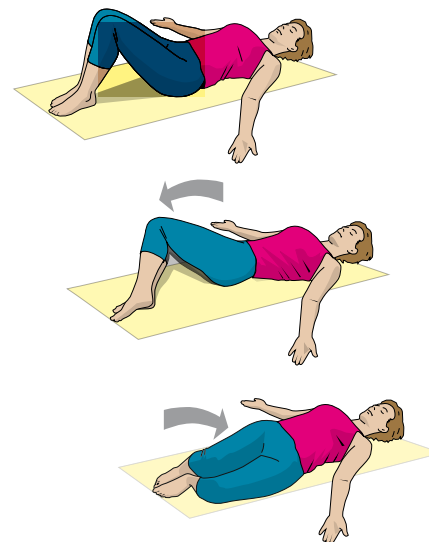
Breathing

Time your breathing with the exercise. This helps you to relax, to focus and to involve the chest appropriately. Do not hold your breath.

A. LYING ON YOUR BACK

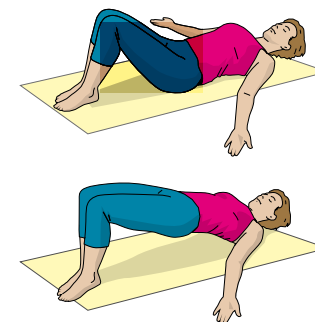
Exercise 1. Knee Rocking

Lie on your back with your arms straight, palms up and out from your sides, at shoulder level if possible. Bend both knees and place your feet on the floor. Rock knees from side to side. Gradually make the movement larger, but keep your shoulders still. You may turn your head to the opposite side.



Exercise 2. Bridging

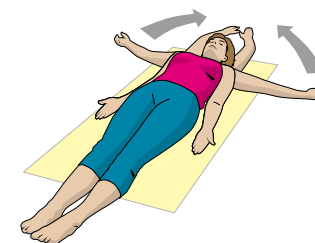
Lift your buttocks off the floor. Hold for 5 sec and lower slowly. Try to lift your buttocks enough to have your shoulders, hips and knees in a straight line.



Exercise 3. Arm Sweeps

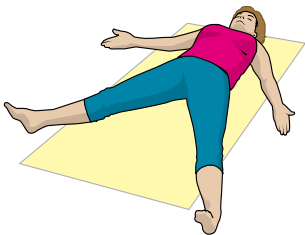
Take your arms from your sides, sliding along the floor, to up and over your head keeping the backs of your fingertips touching the floor throughout.

Slide back again. Breathe in and out as you stretch.



Exercise 4. Legs Wide

Slide your feet apart, pushing the ankles out, heels leading. Take legs as wide as you can, but keep your legs straight and your bottom flat. Slide back together.

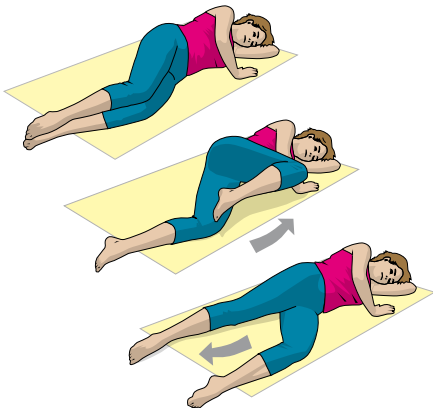


B. LYING ON YOUR SIDE

Make sure you are on your side, not leaning forward or back, especially at the hip.

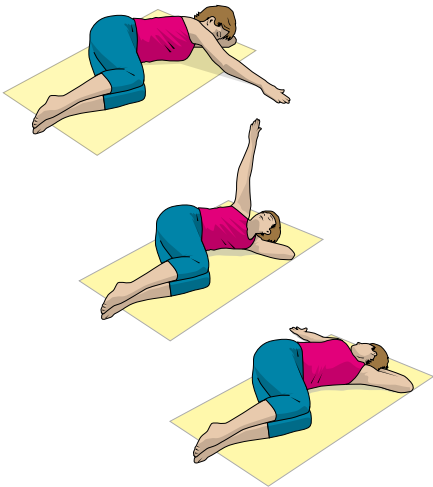
Exercise 5. Cycle

Bend your top leg up towards your chest and then stretch it down straight. You can also make a cycling action with this top leg. Lead with the heel when the straight leg goes backward.



Exercise 6. Upper Body Roll

Keep knees together and slightly bent. Reach forward with your top arm as far as possible, allowing your chest to roll forwards. Then lift this arm up and over your body and back behind you, aiming to touch the floor with back of your hand. Let your chest roll backwards. Look at your hand throughout the movement.

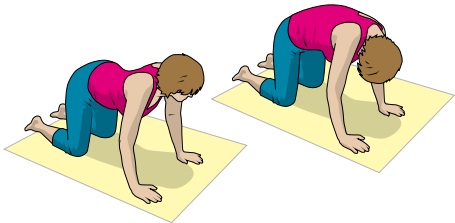


C. FOUR POINT KNEELING

On all fours: position yourself on your hands and knees, keep your elbows straight.

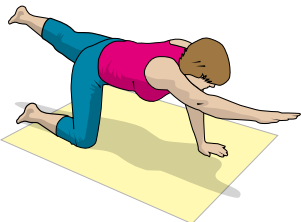
Exercise 7. Cat Stretch

Let your head relax down between your arms and arch your back upwards. Feel a stretch in the upper back as well as the low back. Now relax the back and let it sag towards the floor. Feel this stretch in both the upper back and the lower back as well. Look forwards, not upwards, with your head, lifting your chest.



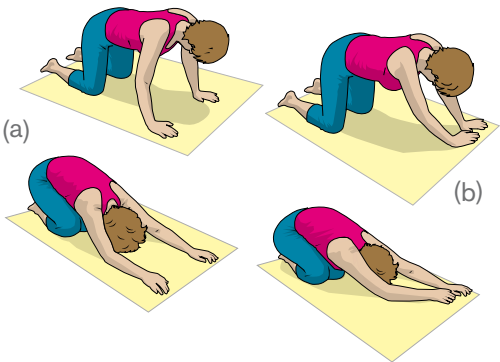
Exercise 8. Arm and Leg Lift

Keep your body steady and balanced, slowly lift your right arm forwards, keeping it close to your ear, and straighten your left leg behind you, leading with your heel. Stretch long through your body, from finger tip to toe. Hold this position for 10 sec, then lower and repeat with the other limbs. Look forward at your hand.



Exercise 9. Back Stretch

Rock back onto your haunches, leaving your arms in front. Try to drop your chest as low as possible to the floor and look down at the floor. You may also do this with both hands to one side (b) and then to the other, to help stretch the sides of the body.

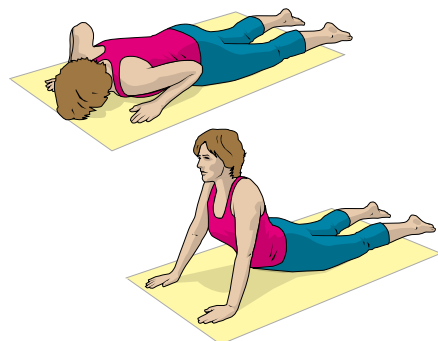


D. LYING ON YOUR TUMMY**Exercise 10. Chest Lift**

Lie on your tummy with your arms relaxed at shoulder height. You may prefer a small pillow under your chest. Lift your upper body – head, chest, and arms – off the floor. Do not lift too high, but make sure you straighten your back. Keep looking down at the same spot on the floor. Hold for 5 sec, and then relax before repeating.

**Exercise 11. Press-up**

Lie flat on your tummy. Place your hands on the floor just in front of your shoulders. Push through your hands to straighten your arms. Keep your hips on the floor and allow your back to arch. Look forwards and lift your chest.

**E. SITTING**

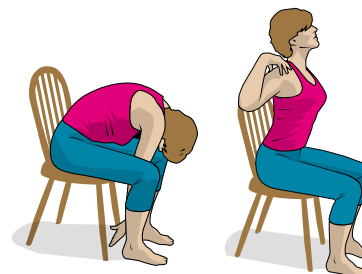
Have a firm, straight chair. Sit with your feet supported. Sit tall and straight.

Exercise 12. Side Stretch

Let your hands hang by your sides. Lean to one side as far as possible, keeping your buttocks firmly on the seat. Avoid letting your trunk turn or roll and keep your face looking forwards. You may also take your other arm up and over your head and over to the same side. Come back to straight and then lean to the other side.

**Exercise 13. Back Stretch and Arch**

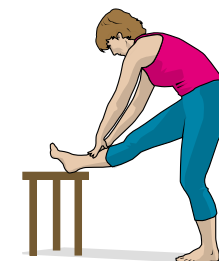
Let your hands reach towards the floor, curling your whole back. Go as far as you can – reach through under the chair if you can. Hang and relax for a few seconds and then sit up straight, arch your back away from the back of the chair, place your hands on your shoulders and take your elbows wide, feeling a stretch across the front of the chest.

F. STRETCHES

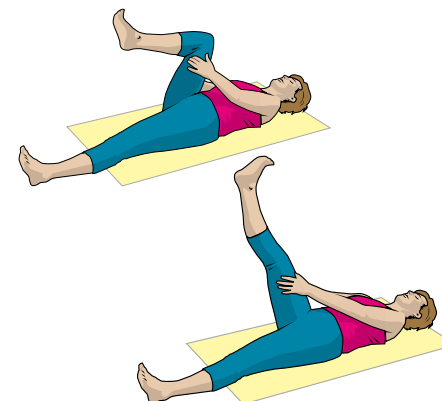
There are several muscles, which are important to stretch regularly. A few are described here. Others include the calf, hip adductors, and quadriceps in the leg and the pectoral muscles at the front of the shoulder.

Stretch 1. Hamstring / Back of Thigh

Standing – Place your heel on a small stool in front of you. Keep your knee straight, your toes pointing up and lean your trunk forwards towards your knee. Keep your chest up and look at your foot, to avoid curling your back.

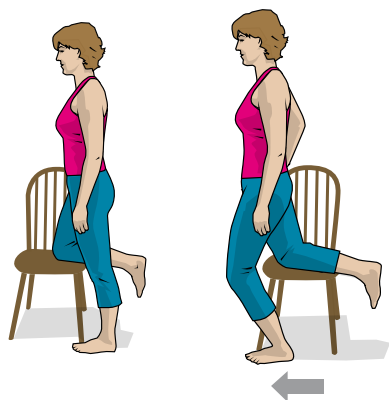


Lying – Lie on your back, one leg out straight and bend the other knee towards your chest. Straighten this leg to the ceiling. You may support it behind the thigh or you may hold the foot with a towel.



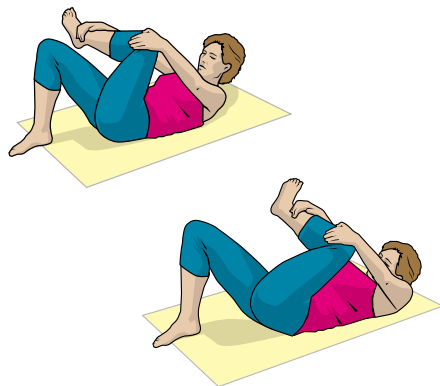
Stretch 2. Hip Flexors / Front of Thigh

- Stand beside a firm chair with one knee/shin on the chair.
- Step through with your standing leg to place it in front of your bent leg. Tuck your tummy in, flatten the arch in your lower back and lift your chest.
- Bend your standing leg and move your trunk forwards a little. Do not lean sideways.



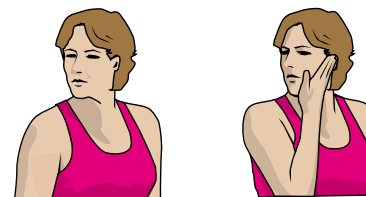
Stretch 3. Piriformis / Deep Buttock

Lie on your back, bend your left knee towards your chest and hold it with your left hand. Hold your left foot with your right hand. Let your knee drop out and then pull with both hands to bring your shin towards your right shoulder.



Stretch 4. Neck – Rotation / Turning

Sit straight in a firm chair, feet on the floor. Look to the right as far as you can. Bring your right hand up to your face and place it on your left/front cheek. Keep your left shoulder back, (sit on your hand or place it behind the chair). Use your right hand to help your head around just a little bit further. Take this gently but firm, no jerking. Keep your chin up and eyes level.



It is also important to stretch your neck forwards, backwards, side-bending and diagonally. It is important that a physiotherapist demonstrates these stretches.

G. POSTURE CHECK

Throughout the day, the effects of gravity try to pull you forward and make it hard to keep straight. Several positions can help you reverse these stresses and help you to check if you are keeping straight.

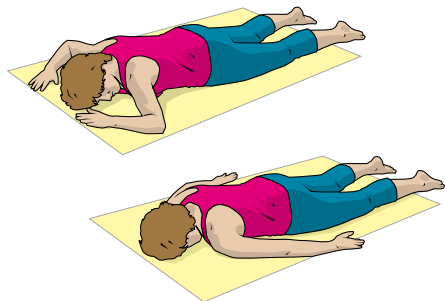
Long Neck

Lie flat on your back on a firm surface. Keep your chin gently tucked in, avoiding the chin pointing up. Keep the back of your neck long. This may also be done in sitting and standing.

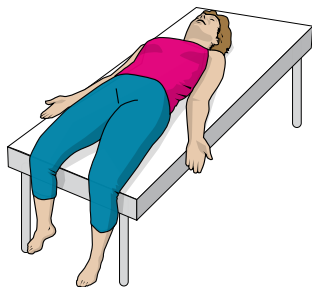


Hip Stretch

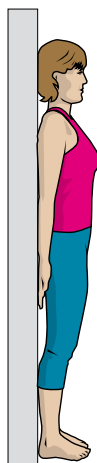
Lie on your tummy. This position helps to keep the front of the hips stretched. You may wish to have a small pillow under your chest, and it is helpful to turn your head to each side for some of the time.

**Bed Edge**

Lie on your back on a bed, with your lower legs hanging over the edge. This position also helps to stretch the front of your hips without being on your tummy. Do not let your back arch.

**Stand Tall**

Stand with your back to a wall. Your buttocks, shoulders and head should all touch the wall. Look straight ahead, tuck your chin in and feel long and tall through your spine and back of the neck. Walk away from the wall, keeping in this tall posture.



To contact your Arthritis State office – Freecall: 1800 011 041

Arthritis NSW:

www.arthritisnsw.org.au

Arthritis Australia (National and ACT):

www.arthritisaustralia.com.au

Challenging Arthritis by Arthritis NSW:

www.challengingarthritis.org

AS Support Groups:

www.asaustralia.org

Arthritis Victoria:

www.arthritisvic.org.au

Arthritis Queensland:

www.arthritis.org.au

Arthritis Foundation of WA:

www.arthritiswa.org.au

Arthritis and Osteoporosis Tasmania:

www.arthritistasmania.com.au

Arthritis South Australia:

www.arthritissa.org.au

Arthritis Northern Territory:

www.aont.org.au

Ankylosing Spondylitis International Federation (ASIF):

www.asif.rheumanet.org

National AS Society (UK):

www.nass.co.uk

US Arthritis Foundation:

www.arthritis.org

Spondylitis Association of America:

www.spondylitis.org

Independent Living Centres Australia:

www.ilcaustralia.org

Australian Government Health Website:

www.healthinsite.gov.au

Medicines Information Line:

Phone toll free: 1300 888 763

Beyond Blue:

www.beyondblue.org.au

Black Dog:

www.blackdoginstitute.org.au

Australian Physiotherapy Association:

www.physiotherapy.asn.au

Rheumatology Health Professionals Association:

www.rheumatology.org.au

Osteoporosis Australia:

www.osteoporosis.org.au

National Prescribing Service:

www.nps.org.au

Talking with your doctor or pharmacist about medicines is always recommended.

Contact the Arthritis Foundation in your state on 1800 011 041 to find out what support is available in your area.

Ankylosing Spondylitis

Information for patients, families and carers



Arthritis NSW, 13 Harold Street,
North Parramatta NSW 2151

Mail: Locked Bag 16, Post Office,
North Parramatta NSW 2151
Australia

Phone: 02 9683 1622

Fax: 02 9683 1633

Email: info@arthritisnsw.org.au

Web: www.arthritisnsw.org.au

Free telephone advice: 1800 332 131

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