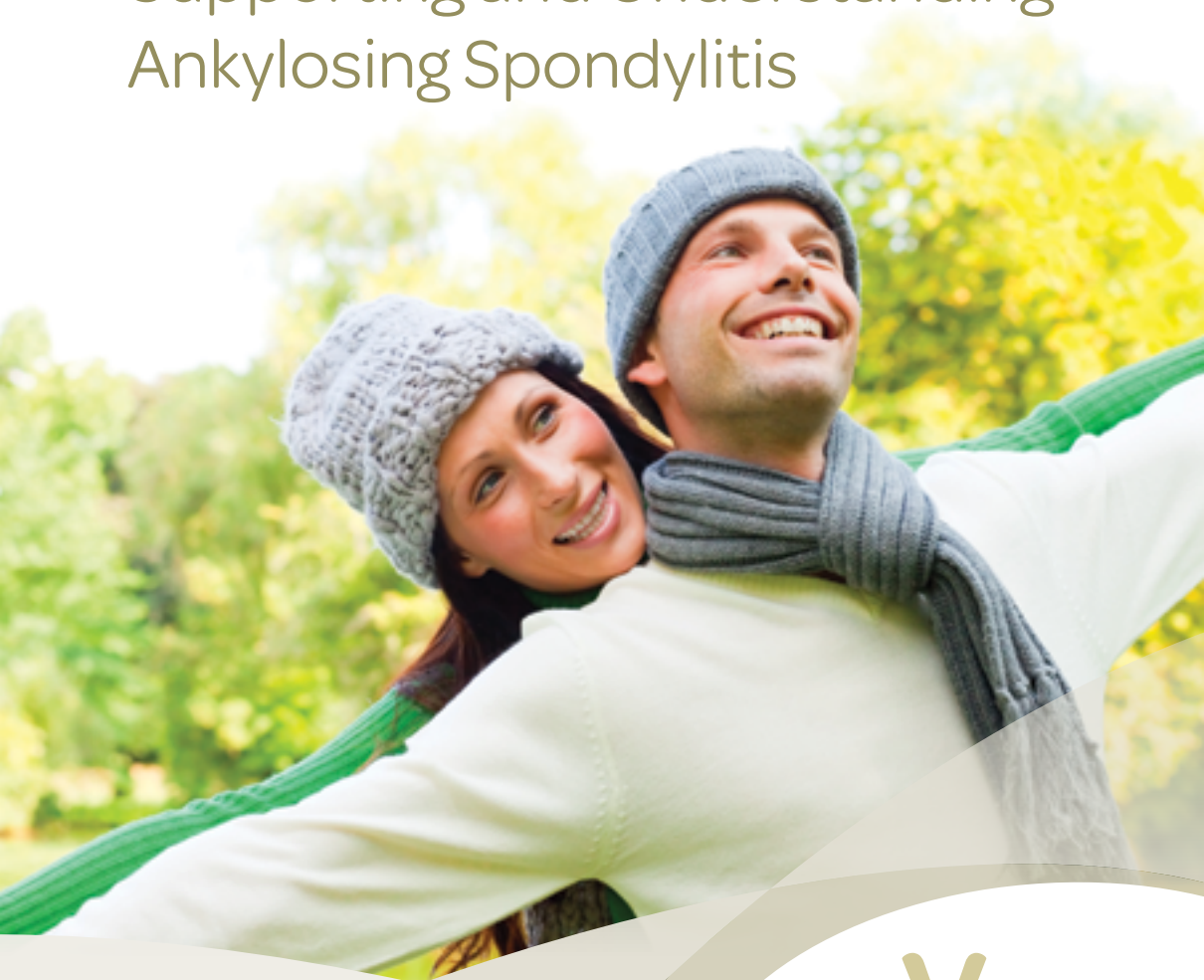


SUAS

Supporting and Understanding Ankylosing Spondylitis





This booklet is part of a programme for people affected by Ankylosing Spondylitis (AN-kuh-low-sing sponduh-LIE-tis) or AS for short. You may be affected either by having the condition yourself or by knowing somebody who has. At the Ankylosing Spondylitis Association of Ireland (ASAI) we have produced this booklet to help you:

- Better understand your condition
- Talk with your doctor about your diagnosis and treatment
- Learn about possible treatments and useful tips for living with AS

As with most medical conditions, the more you know about it the better you can manage it. This booklet, developed in association with Waterford Regional Hospital Rheumatology Unit, is not just aimed at people with the disease as family, friends, work colleagues and possibly the person's GP, might all be interested in knowing more about the illness.

You are not alone – and you can take action

As people with the condition ourselves, we can appreciate what a patient and the people connected with them 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. However, both research and our own experience shows that people who take an active interest in their condition can positively influence its outcome.

AS is a medical condition affecting millions of people. The important thing to remember when you have AS is that it does not define you as a person. Continue to try to learn about your condition. Having the right information about AS can help you work with your doctor and healthcare team, making you feel more in control. This can help you feel better about your condition.

Seoirse Smith
Secretary, ASAI

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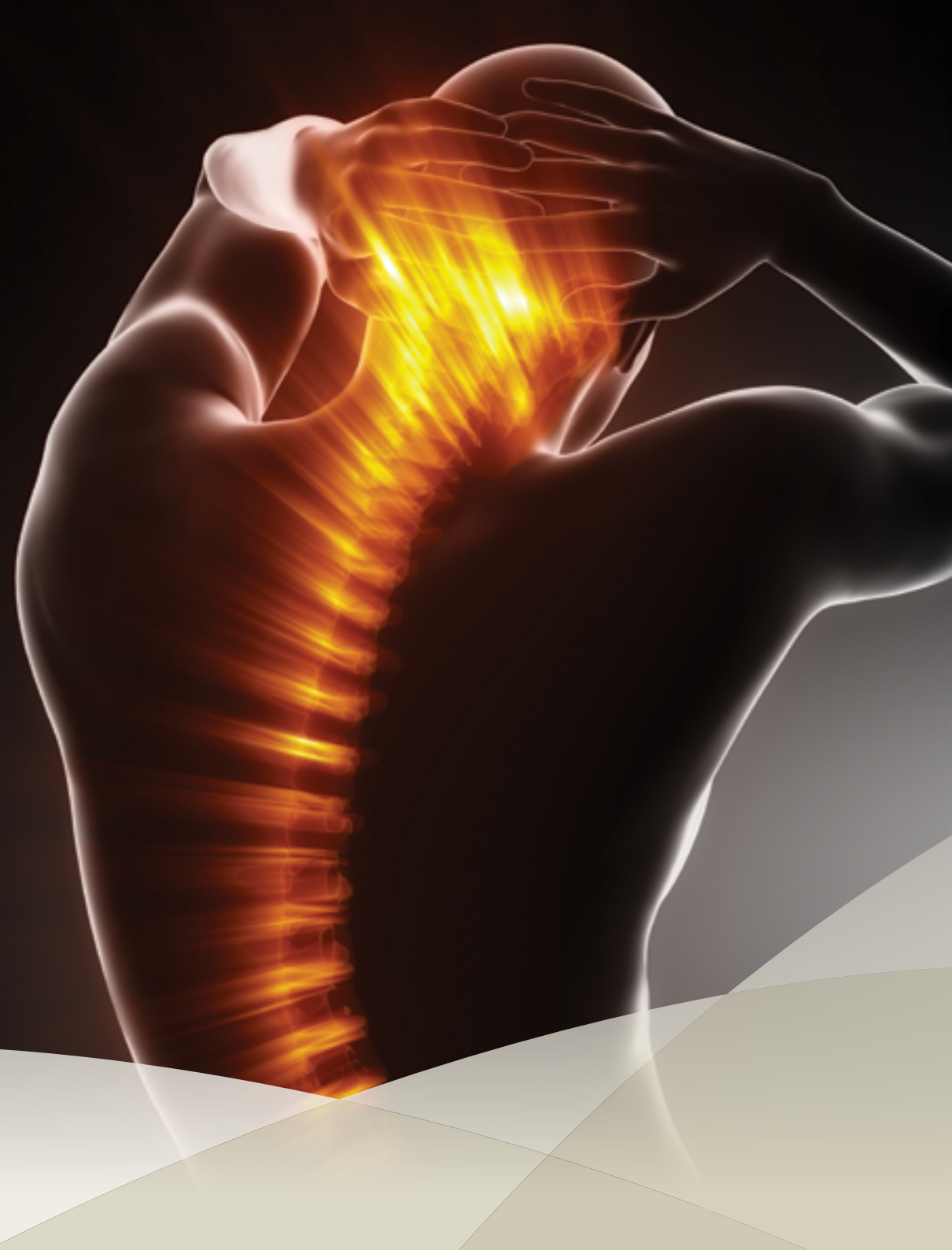
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What is Ankylosing Spondylitis?



What is Ankylosing Spondylitis?

AS is a form of arthritis which can make your neck, lower back and buttocks feel painful and stiff. In some people, it can also affect the shape of the spine.

“Ankylosing” means “fusing together”. “Spondylitis” means “inflammation of the spine”, which causes stiffness, tenderness and discomfort. AS can lead to new bone formation in your spine.

Although it mainly affects the spine, AS can also cause pain and/or swelling in the shoulders, hips, knees, heels, chest/ribs and small joints of the hands and feet. Sometimes, the eyes are also affected. In rare cases, the heart and lungs can be affected, too.

The severity of AS symptoms varies greatly. Some people will have mild neck/back pain and discomfort for short periods; others will have severe pain and stiffness in several parts of the body for a long time. In severe cases, AS can seriously impact on everyday life and lead to disability.

Over time, AS can cause the spine to become rigid and curved, giving the person a “bent forward” posture. This is known as kyphosis. It’s important to note that not everyone with AS will develop kyphosis.

Significant medical advances in recent years mean that new treatments can reduce the pain associated with and symptoms of the condition and help improve the quality of life for people living with AS.

What causes Ankylosing Spondylitis?

At the moment, it is not known exactly what causes AS. However, a combination of environmental and genetic factors may make you more likely to have AS. Environmental factors such as infections may also be involved.

What are the symptoms?

Although the symptoms of AS vary from person to person, and between men and women, they include:

- Pain and stiffness in the lower back and buttocks, worsening over weeks or months.
- Pain and stiffness that is worse in the mornings and during the night, but may be improved by light exercise.
- Mild fever.
- Loss of appetite.
- Pain and tenderness in the ribs, shoulder blades, hips, thighs and heels.
- Fatigue.
- Mild to moderate anaemia (shortage of red blood cells), which can make people pale, tired and short of breath.
- Inflammation of the bowel.
- Inflammation of the eyes (iritis or uveitis), making them painful, watery, red and sensitive to bright light.

How common is Ankylosing Spondylitis and who gets it?

The condition is not common. AS can affect anyone – young or old, male or female, although it is more common in young men. It is more likely to start early – in the late teens or early twenties.

AS is linked to the genes we inherit but it is not a certainty that a child will inherit the condition if a parent has it. Certain factors can make a person more likely to develop AS, such as a family history of the condition.

**CHECK ANY AREA THAT
IS PAINFUL OR TENDER**



NECK

SHOULDERS

RIBS / CHEST

LOWER BACK

HIPS

BUTTOCKS

HEELS



Just Been Diagnosed?

How is Ankylosing Spondylitis diagnosed?

When you visit your doctor/consultant a detailed history of your symptoms will be taken. This will include some questions about the type and pattern of your pain and stiffness.

Some questions that may be asked include:

- How long have your symptoms lasted for?
- How does the pain and stiffness feel when you wake up in the morning and how long does it take to subside?
- What happens when you engage in physical activity or exercise?
- How does the pain and stiffness respond to non-steroidal anti-inflammatory drugs (NSAIDs)?

Questions about your medical and family history will also be required.

Are there any special tests that are used to diagnose Ankylosing Spondylitis?

Your doctor will give you a thorough examination which will include assessing the areas where you are experiencing pain or inflammation, determining how much spinal mobility you have and checking to see how far your chest can expand.

- Your doctor may order some routine blood tests that tell us about your general well being and about inflammation in the body.
- She/he may order a specific blood test which is called a HLA-B27. This is a genetic marker, the presence of which is often associated with AS.
- X-rays of the spine are taken to determine whether the joints show signs of damage. If the x-rays don't show changes caused by AS, in some cases the doctor may order an MRI (Magnetic Resonance Imaging) scan.
- The MRI scan can illustrate changes called sacroilitis. You may be diagnosed with non-radiographic axial spondyloarthritis – this means that the changes are not seen on an x-ray but the MRI has detected changes showing active inflammation.

Your Healthcare Team

Your Healthcare Team

The Rheumatology Team

Consultant Rheumatologist

A consultant rheumatologist is a doctor that specialises in diagnosing and treating arthritis and diseases related to rheumatology. Rheumatologists will manage a wide range of musculoskeletal conditions.

Your rheumatologist will organise tests to find out more about your condition.

The rheumatologist will recommend a programme of treatment for you. This may include drug treatments and referral to the other members of the multidisciplinary team.

Rheumatology Nurse Specialist

A rheumatology nurse specialist is a nurse that has expertise and training in caring for patients with a wide range of arthritis-related diseases.

Their role is to provide emotional, physical and social support to patients. You may be referred to see the nurse specialist when you get your diagnosis to discuss the treatment of your AS and the medication that the doctor may prescribe.

The nurse specialist will provide ongoing support and advice and most nurse specialists run telephone advice lines that you can contact.

Chartered Physiotherapist

A physiotherapist is a healthcare professional who helps you remain active and independent both at work and at home. A range of motion exercise programme may be devised for your neck, mid back and lower back which should be done daily. A strengthening programme for the core muscle groups may also be devised as well as a plan for managing your posture.

The physiotherapist can help you understand what happens to your joints and muscles when you have AS and how you can minimise the effect these changes may have on your life.

Occupational Therapist

The occupational therapist will assist you in developing and/or regaining skills important for independent functioning, health and well-being.

The occupational therapist works with you to improve or maintain your ability to perform activities of daily living that are meaningful at home, at work and in the community.

Talking to Your Healthcare Team

Having AS means that a good relationship with your team of healthcare professionals is vital.

When you have an appointment with a member of your healthcare team it is important to make the most of that consultation session. There are some steps you can take to help you do this:

- Prepare for the appointment. Make a short list of any questions and concerns or worries you may have.
- If it's your first appointment with a new member of the team it may be helpful to bring someone along with you – they can take note of any information and be there to support you.
- Ensure you are clear on any new changes to your treatment plan, medication or investigations that may be made on the day.
- Take note of any important information or instructions that you have been given.
- If there are any issues that are personal to you in adhering to the treatment plan (such as financial, work or emotional matters) be sure to mention them.
- Most rheumatology units have a contact number for patients should you have any concerns or worries. Make sure to keep that number and contact your team if you have any concerns in between appointments.

Treatment Options



Treatment Options

What treatments are there for Ankylosing Spondylitis?

Many of the treatments used for AS are also used to treat other types of arthritis. In the past, treatment only dealt with pain and inflammation. Although these medicines are still used today, some new therapies may also improve other aspects of the underlying disease. It is important to remember that medication is only one part of treating AS and any course of medication should be taken in conjunction with an exercise regime.

Drug treatments for Ankylosing Spondylitis

Getting medication to treat AS is not as easy as walking into a pharmacy and buying a product over-the-counter. Many of the medications required for treatment need to be prescribed by your doctor.

New drugs appear on the market regularly, so finding the one that is right for you may mean working closely with your treatment team and rheumatologist.

Remember, not every medication will work the same for everyone, so please consult with your GP or hospital consultant if you feel that your medication is not working for you. Many drugs are prescribed in conjunction with others, so it is highly recommended that you ask your doctor about the many options available and what's best for you.

The medicines that treat AS fall into two broad groups: those that give pain control and those that are condition modifying.

Pain Control Treatments

Within this first group are two main categories: Non Steroidal Anti-Inflammatory Drugs (NSAIDs) and Steroids.

These medications can reduce inflammation, but are not disease-modifying and do not prevent joint destruction.

NSAIDs

Non-steroidal anti-inflammatory drugs reduce the effects of one or both types of chemicals that can cause inflammation.

NSAIDs reduce the effects of a chemical called cyclo-oxygenase (COX), which occurs naturally in the human body.

Signs of inflammation include pain, swelling and loss of function. NSAIDs have desirable effects such as reducing inflammation as well as undesirable effects, potentially causing stomach upset or the formation of ulcers in the stomach or intestine.

It is possible that your doctor will prescribe medication to help prevent the occurrence of these side-effects.

NSAIDs reduce pain and swelling, but they do not prevent tissue damage or progressive joint deterioration.

Steroids

Steroids (called corticosteroids) can be very effective in reducing inflammation. They are hormones that regulate a variety of functions within the body, including immune function.

Corticosteroids are strong medicines that suppress signs of inflammation including pain, swelling and loss of function.

Although scientists have not determined exactly how these agents work, they appear to block some of the chemicals that cause inflammation.

They may be given both orally and by injection, and relieve symptoms in patients with active AS.

The potentially serious side effects associated with the long-term use of oral corticosteroids include high blood pressure, high blood sugar and osteoporosis (thinning of the bones).

If you have been on steroids for more than two years, your doctor may recommend a bone density scan.

Biologic DMARDs

The biologic disease-modifying anti-rheumatic drugs (DMARDs) are among the most recent AS treatments. Biologic DMARDs block immune system messengers known as cytokines.

A cytokine called TNF α (tumour necrosis factor α) is known to be involved in causing AS. Anti TNF α agents block the effects of this cytokine.

These agents can be either injected under the skin or given intravenously (by drip). These include Humira (adalimumab), Enbrel (etanercept), Remicade (infliximab) and Simponi (golimumab).

Biologic DMARDs improve the symptoms of AS, including the pain and stiffness in the lower back and buttocks. They reduce the symptoms of AS by helping the body's own immune system to slow down the inflammatory process.

Infections and reactions at the site where the medication was injected or infused are the most commonly reported side effects. These reactions can include redness, swelling, inflammation, itching, or pain.

Reactions such as breathing difficulty, flushing (temporary redness of face and neck), headache and rash, may occur while the medicine is being given.

This does not always mean that you should discontinue your medications. Do consult your GP if you have any concerns.

Infections are associated with these medications and you should be tested for inactive tuberculosis infection as well as any active infections before receiving these treatments.

Your healthcare team will monitor you closely to make sure you do not develop any new infections either during or after treatment. If you are taking a biologic agent, you should tell your doctor or nurse about any signs of infection that you may experience.

Payment of your medication

If you have a medical card, your medication costs will be covered by this.

If you are not entitled to a medical card you can apply for a Drug Payment Card.

For more information on how to apply for the card and what the card covers, you can contact your Local Health Office or log on to www.hse.ie. This website provides details on the drug payment scheme, medical card application and GP visit cards. All of which may be helpful in the long term management of your AS.



Chartered Physiotherapy

A chartered physiotherapist will focus on reducing pain, stiffness and inflammation and increasing movement through a range of spinal mobilisation techniques. The physiotherapist will also work with you to increase range of movement, to strengthen the core muscle groups, to maintain good posture and to improve your flexibility.

In conjunction with medications prescribed by your doctor, physiotherapy and exercise can significantly benefit the treatment of AS.

Flare Management

Flare Management

Managing a flare of your Ankylosing Spondylitis

A flare, or acute episode of inflammation, occurs when you have painful or swollen joints that won't settle down, and/or increased pain. A flare can happen at any time; it may happen after you have had an infection or when you are experiencing a stressful situation in life.

Step 1: Recognise a flare

- The first thing you can do in managing a flare is to realise that you are having one.
- Don't ignore the flare and hope it goes away/gets better on its own.
- By recognising that you are experiencing a flare early you can get a head start on managing it.
- Be aware of your own body and how it feels.

Step 2: Find the reason

There are a number of factors that can trigger a flare, so the first thing to do is a checklist:

- Medication check – Are you taking your medications correctly? Are you worrying about side effects or feeling better and forgetting to take them?
- Overdoing it – Doing too many activities or work and becoming severely tired.
- Overusing the joint – Over-working a joint may cause a flare. If swelling occurs think back to what you've done over the last few days.
- Stress – Sometimes stress can trigger a flare. It's important to remain calm and try not to worry during a flare.

Getting used to, and understanding the nature of AS and its ups and downs is important in managing a flare.

Step 3: Manage a flare

- Don't panic.
- Plan, pace and prioritise your activities.
- Talk to your family, friends and work colleagues.
- Balance rest and activity.
- Get a good night's sleep.
- Continue with a light range of exercises/stretching.
- Use deep breathing and relaxation techniques.
- Contact your healthcare team if necessary.



Posture

Posture

Posture / Neutral Spine

Posture relates to the position of your body at any time during the day or night. It is important to be aware of your posture and try to correct it not only during exercise times, but also during the day when standing, sitting and walking.

'Neutral Spine' refers to the optimal alignment of the spine. In this position, the joints muscles and ligaments of the spine are under the least stress and strain.

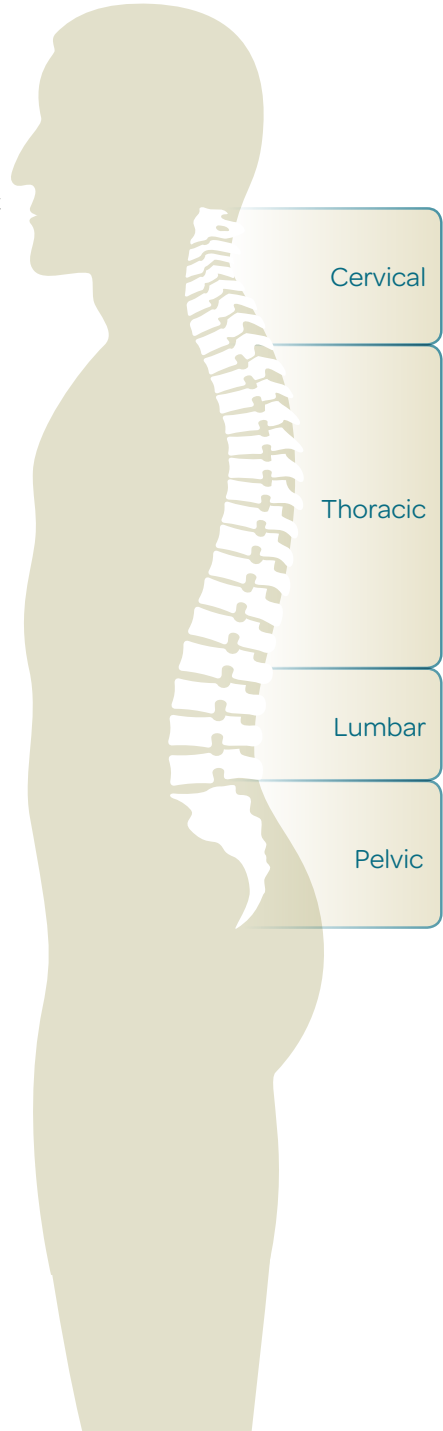
Three curves should be present – an inward curve at the neck (cervical spine), a small outward curve at the upper back (thoracic spine) and a small inward curve at the lower back (lumbar spine).

Try to imagine these small curves in your spine. Maintaining 'neutral spine' is a key element of ensuring the effectiveness of your exercise programme.

If you perform exercises in a slouched posture, this will cause extra strain on the spine. This could potentially lead to injury and pain when performing exercise.

Postural cues:

- Try to move your spine regularly.
- Think tall.
- Draw your chin back as if making a double chin.
- Bring your shoulders back and down.
- Tighten your stomach muscles by bringing the belly button back to the spine and tuck down your tail bone.
- Maintain even breathing.



Postural Exercises:



Prone Lying

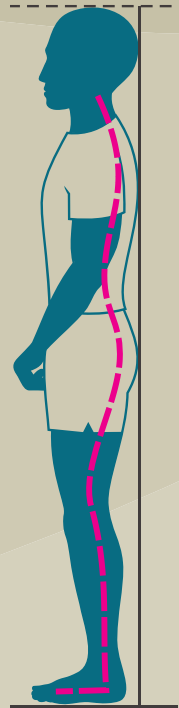
Lie face down on a firm surface for 20 minutes daily. If unable to lie flat, place a pillow under your chest and a towel under your forehead.

Back against the wall

Stand against a wall. Place your heels 4 inches away from the wall. Your buttocks and shoulders should be as close to the wall as possible. Try to hold this position for 5 seconds and repeat 3 times daily. It is possible to keep a record of spinal alignment by measuring from the back of your head to the wall.

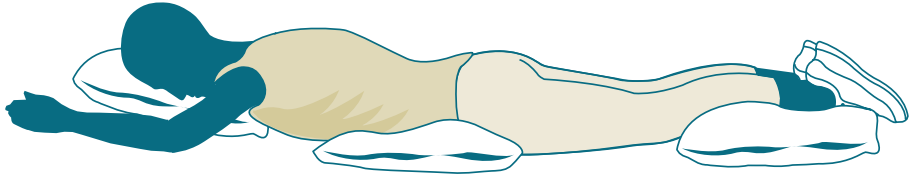
Pillows

- Use one moderate sized pillow.
- Sissel Orthopaedic Pillows/Memory Pillows are effective for supporting your neck and keeping the shoulder girdle in place.



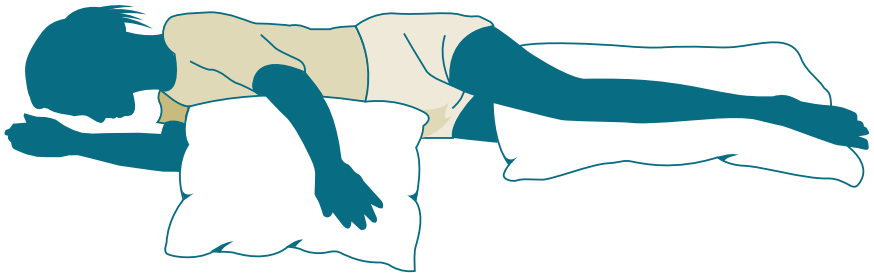
Posture – lying prone

- Prone lying is recommended as one of the best stretches for people with AS.
- Note the pillow support at the hips, lower legs and again under the head in the picture below. The aim is to keep the lumbar spine in a neutral position.



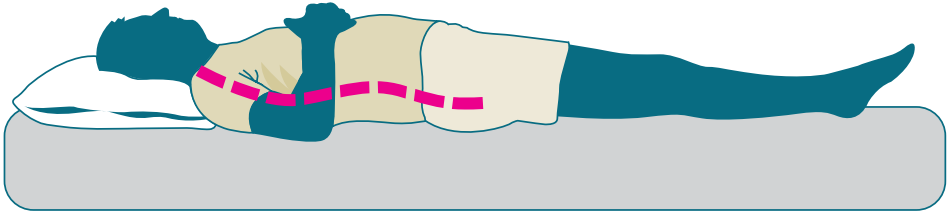
Posture – on your side

- Position top leg forward and bottom leg straight underneath to maintain side lying position. A pillow should be placed between your knees.
- Make sure there is no pressure on your shoulder.



Type of mattress for people with AS

- Medium firm orthopaedic mattress is recommended.
- Avoid basing selection on coil count and design. Coils have minimal effect on the quality or durability of your mattresses.
- Try out mattresses for personal comfort before purchasing. Speciality memory foams and custom options are not always the most comfortable choice.



How to select a mattress?

Use this simple check list to help you assess the correct support. Lie down on your back and slide your palm down between the small of your back and the mattress.

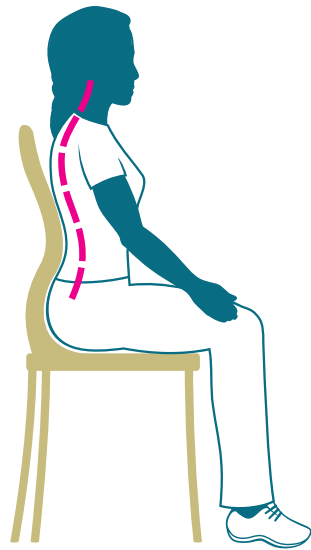
- Can you slide your hand through fairly easily but without there being a large gap? Then the bed support is about right.
- Is there a large gap? Then the bed is probably too hard.
- Is it hard to push your hand through? Then the bed is probably too soft for you.
- If you feel that your head and upper body are lying lower than your feet, the mattress is probably too soft.

This test is ideal when normal curvature is present. Remember not all people with AS will find this as effective.

The right bed should be comfortable and supportive. It should maintain your backs three natural curves and facilitate ease of movement. It should mould to the contours of your body to provide support for its hollows and curves.

Posture – sitting

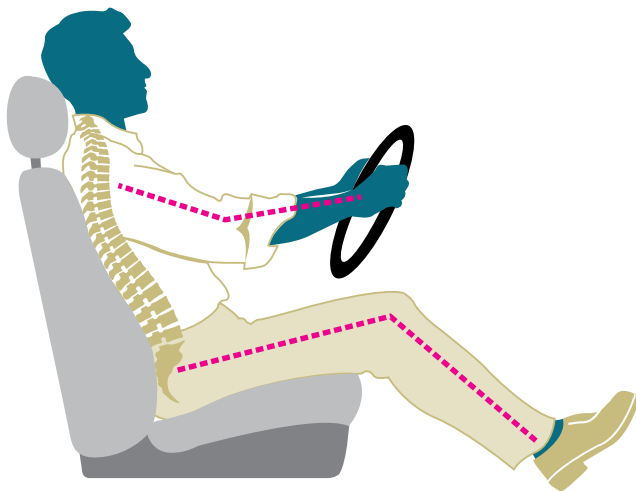
- Adjust the height of the chair according to the height of the work area.
- Keep your chin in.
- Ensure your shoulders are relaxed and without strain (shoulders back, ribs in).
- Where possible, ensure the lumbar support of the chair supports the natural curve of your spine.
- Feet must be flat on the floor and supported. Don't curl your toes.
- Take regular intervals (5 minutes every hour) and perform stretch and relaxation exercises.



Posture – driving

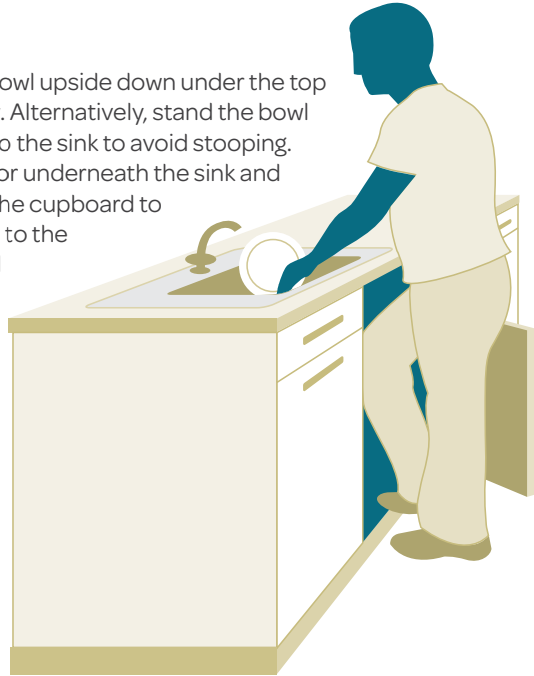
- Driving position:
 - Legs are apart and left foot is extended to a supporting position.
 - Sit at a comfortable distance from the steering wheel with knees slightly bent.
 - Place a rolled up towel or a back support behind the lower back for support.
 - Arm position lets hands complete a full turn of the wheel when your back is against the seat.
- Seat belt position:
 - Low across the hips.
 - Flat with no twists.
 - Firm with no slackness.
- Mirrors:

Special mirrors that offer a wider view of what's behind you could be fitted onto your car. These mirrors reduce the need to turn the head to check for cars in the driver's "blind spot." Many of these types of mirrors are on the market; however it is important to take time to practice parking using these new attachments.



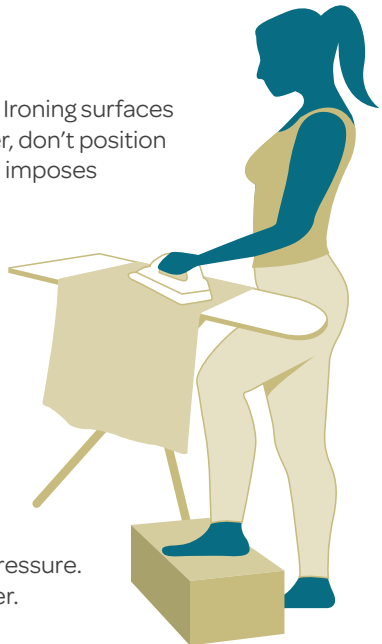
Posture – in the kitchen

- When washing up, place a second bowl upside down under the top one if the sink is too deep or too low. Alternatively, stand the bowl on the draining board. Stand close to the sink to avoid stooping. Consider opening the cupboard door underneath the sink and putting a foot up on the bottom of the cupboard to help ease back strain and get closer to the washing up. The bottom of the bowl should be at wrist level so that you can put the palms of your hands in the bottom of the bowl.
- Work surfaces should be high enough to avoid bending over. If the surface can't be raised, sit down.
- Keep items that are often used such as food, pots and pans within easy reach at waist height.
- Sit on a high stool when cooking, preparing food or washing up.
- Use your feet to close low drawers and cupboards.
- Never twist and bend at the same time. Always bend your knees, not your back, when using an oven or the fridge/freezer.
- If your cooker is low, make sure you bend your knees and hips, not your back.



Posture – ironing

- Ensure your ironing board is at the correct height. Ironing surfaces should be high enough to avoid stooping. However, don't position this too high as having the arms continually raised imposes strain on the shoulder, neck and upper back.
- Stand as close to the ironing board as possible with one foot slightly forward or consider raising it on a small box.
- Use your bodyweight and sway from one foot to the other as you move the iron sideways over the garment.
- Keep clothes on a stool at the side of the ironing board to save bending.
- Use a high stool to perch or sit down for at least some of the time. Change your position from sitting to standing.
- Use a steam iron if possible as this requires less pressure.
- Stand at an angle as this keeps your back straighter.
- Avoid twisting.



Posture – hoovering

- Ensure you use two hands while hoovering.
- Upright hoovers tend to be heavier to use and can cause you to twist.
- Cylindrical hoovers are usually lighter to use and you can buy an extension pole to make the handle longer. You can also do some of the hoovering on your knees.
- Use the power of your legs and walk with the hoover. Move the whole body forwards and backwards with the sweeping action. Don't stoop, keep your back straight and avoid twisting movements.
- Consider a carpet sweeper. They are often light and easy to use. Some people keep one upstairs to avoid carrying the hoover up and down the stairs.
- Use long handled equipment such as a mop for cleaning the floor.



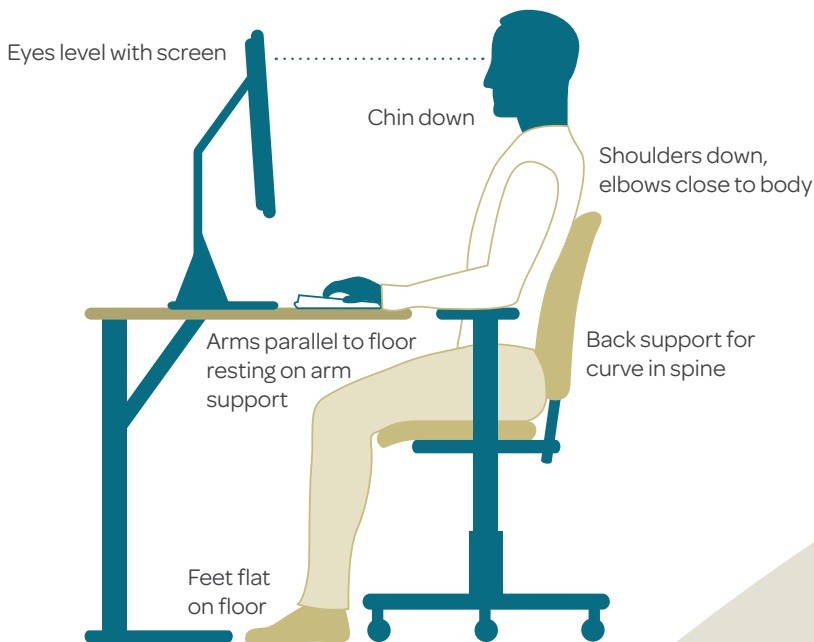
Posture – lifting

- Bend at the knees so you can keep the back straight.
- Never bend or twist while lifting.
- Avoid quick, jerking movements.
- Keep the load close to your body.
- Place heavier loads somewhere they will be easy to pick up.
- If it is too heavy, get help.
- Lift smart – use a pull cart etc.
- Lift loads symmetrically – carry equal weight in each hand.
- Think before you lift – many injuries occur when people get careless with everyday loads.
- Make it a habit to always lift with proper posture.



Posture – computer

- Maintain good posture when working at the keyboard. Your back curves should be maintained with the use of a chair with a back support.
- Keep your feet supported either on the floor or on a footrest when you work to reduce pressure on your lower back.
- Avoid twisting or turning your trunk or neck when working.
- Keep your shoulders relaxed with your elbows close to your side when working.
- Avoid resting your elbows on the hard surface or edge of your table. Pads can be used to protect your elbows if necessary.
- Elbows should be positioned 100 or 110 degrees when working in order to keep a relaxed position at the keyboard. This should require a slight negative tilt (front of keyboard higher than the back) when working in upright position. If reclined on your chair the keyboard could be at a positive angle to maintain this position.
- Your wrists should be in neutral position when keying or using a pointing device or calculator.
- Wrist rests can assist you in maintaining a neutral position when used properly during pauses.



Sleep and Fatigue

Sleep



How to Improve Your Sleep Routine

- Spend the hour before going to bed relaxing.
- Go to bed at the same time each night – have a routine!
- Monitor diet, TV and online activities which do not lend to sleep.
- Try to avoid worrying in bed. Try stress management strategies.
- Do not think about getting to sleep.
- If you are unable to sleep after 20/30minutes, get up.
- Be wary of what you take on when you get up.
- Ensure you have a range of different ways to get comfortable.
- Set your alarm and try to get up at the same time every day.
- Remember sleeping at other times of the day will form the overall pattern of your sleep.
- Take deep breaths – breathing in through the nose all the way down to the stomach, and breathing out through the mouth by pulling the stomach in.
- Ensure muscles are as relaxed as can be – deep breathing/relaxation techniques may help with this.

Fatigue

Fatigue, also known as weariness, tiredness, exhaustion or lack of energy, is one of the most common symptoms of AS. To effectively manage fatigue you need to be aware of it and work to identify its cause and the affect it may have on you.

Fatigue affects people in a variety of ways:

- Feeling very tired with no energy.
- Increasing/aggravating pain.
- Feeling a loss of control.
- Feeling irritable/frustrated/agitated.
- Poor or excessive sleep.

What you can do and how you can do it:

Activity management –

- Be aware of activity cycling – this is when you go from doing a lot of activity to doing very little.
- Look at the activity/task and analyse by keeping a diary.
- Think little and often – pace yourself.
- Change intensity and type of activity regularly.
- Prioritise and plan activities.
- Be mindful.

Fatigue management and energy conservation:

- Pace – avoid rushing. Use a slow relaxed speed.
- Prioritise, plan ahead and schedule time for rest breaks.
- Eliminate unnecessary movements and loads.
- Simplify the task.
- Be aware of posture and use good body mechanics.
- Make the job as easy as possible!

Exercise and AS

Exercise and AS

Exercise is known to have many benefits for people with AS. The purpose of exercise is to reduce pain and stiffness as well as optimise movement and posture.

Exercise is a high priority in overall management of your AS. It is important to do some AS specific exercises every day.

While sports and other activities are beneficial they may not be adequate to achieve ideal posture and flexibility.

The best exercise programmes are individually tailored. A physiotherapist can help design a programme that will meet your specific needs.

Physiotherapists are specialists in exercise prescription. A chartered physiotherapist will teach you a specific exercise programme to maximise your joint flexibility and muscle strength. They will also advise on the best form of general exercise to suit your individual needs and lifestyle.

Getting started: Tips for success

Exercise gets the best results when done on a regular basis.

- The exercises shouldn't increase pain although you should feel a stretch.
- Start slow and increase exercises gradually.
- Pay attention to posture and alignment during exercise.
- Choose the best time of day (stiffness may vary at different times in the day).
- Wear suitable clothing and footwear.
- Set attainable exercise goals.
- Track progress.

Safety precautions when exercising

As with commencing any exercise programme, it is advisable to consult your doctor to assess suitability of the exercises for you. This is especially important in the following circumstances:

- After spinal or joint replacement surgery (if you had a hip replacement there may be a risk of hip dislocation with some of the exercises).
- You have a medical condition (especially if it affects the heart or the lungs).
- You are on medication for heart or blood pressure.
- You experience chest pain, palpitations, dizziness or unexplained breathlessness.
- You are pregnant.

Avoid jarring movements and high impact activities.

Exercises should not cause an increase in pain. In this case it is advisable to stop the exercise and seek guidance from a physiotherapist.

Warm up

A good warm up:

- Prepares the body for exercise.
- Increases the circulation and temperature of muscles.
- Makes movement less stiff and easier.
- Reduces risk of injury.

Warm up should be:

- 5 to 10 minutes duration.
- Low intensity activity.
- Examples: slow walking, marching on the spot.

How much exercise should I do?

- Everyone is different and can manage different activity levels.
- The type and amount of exercise depends on your current fitness level.
- In general, it's better to start at a low intensity level for a short time.
- It is normal to feel some joint or muscle discomfort when beginning an exercise programme.
- If pain or fatigue lasts into the next day its likely the exercise was too vigorous.
- Specific AS exercises are recommended for up to 30 minutes daily.
- You will gain exercise benefits in bouts of 10 minutes (i.e. $10 \times 3 = 30$).
- Aim to achieve a balance between aerobic, mobility, flexibility and strengthening types of exercise.
- Try to exercise at least 5 times a week (preferably every day).



Different Types of Exercises

Mobility exercises

Exercises designed to improve movement at joints.

Flexibility exercises

- Stretches muscles to their full length.
- Help maintain mobility at joints.
- Tight/shortened muscles can stop you achieving an erect posture.
- Reduces risk of injury during exercise.
- Helps reduce soreness after exercise.

Strengthening exercises

- Build muscle strength.
- Help improve joint stability.
- Help reduce pain.
- Movement should be smooth not jerky.
- Choose a weight so that you can do 8-10 repetitions without increased pain or fatigue.
- Examples: use of free weights, body weight, therabands.

Breathing exercises

- Designed to maximise chest expansion and lung volume.
- Practice daily.

Aerobic exercises

Endurance exercises that work to increase the heart and breathing rates.

- Improve heart health.
- Lower blood pressure.
- Improve fitness.
- Examples: walking, swimming, cycling.

Exercise Classes

What do I need to know before I start an exercise class?

Is the class low or high impact? Low impact classes are better to ensure your joints are not irritated during and after exercise.

Does the class have an element of “body contact”? Body contact in exercise should always be avoided.

Are there different levels of class on different days? Always start with a beginners class if you are new to the form of exercise – learning good techniques from the start is essential to gain the best benefit.

Different types of exercise and classes

- | | | | |
|------------------|--------------|------------|-------------------|
| 1. Swimming | 3. Gym Class | 5. Yoga | 7. Contact sports |
| 2. Aqua aerobics | 4. Pilates | 6. Walking | 8. Golf |

1. Swimming

Swimming as a leisure activity or sport has the ability to help people with AS with widely differing symptoms. Swimming is a great way to improve general fitness, flexibility and strength in a safe, low impact environment. As the buoyancy of the water reduces stress on joints it is a low impact sport. However it is important to swim the right strokes, in the right way.

What stroke is best to use with AS?

Front crawl is considered the best stroke for people with AS to use. Your body position remains extended throughout, including your neck, and the stroke ensures that your spine rotates gently throughout this continuous action.

It is also worth being able to swim some back crawl as you are balancing the muscles by using them in the opposite direction and you do not have to rotate your head. This helps stop your shoulders being brought forward in your post session posture.

Strokes to be avoided include butterfly, due to the excessive arching (hyperextension) of the lower back. Be cautious with the breast stroke, as it can put excessive strain on the lower back and neck. In addition, kicking the legs out can aggravate hip and pelvic pain. However if this is the only stroke that you are able to do and it is done gently it is still beneficial.

2. Aqua aerobics

This low impact form of exercise class involves a full aerobic workout in a swimming pool. The class allows a full body workout for cardiovascular fitness, joint movement and stretching but has the added advantage of placing minimal stress on the body's joints – an essential benefit to those with ankylosing spondylitis. A standard class involves exercise which would be performed in any standard 'land aerobics' class but can often make you work hard as you have the resistance of the water to work against.

3. Gym Classes

To maintain your motivation to exercise you may wish to look at joining a gym class.

When thinking about joining a class:

- Get as much information about a class as you can before you take part.
- Question whether it is high impact or low impact, what level of fitness is required, is there an element of body contact, etc.
- Make sure that any class instructor is aware of your AS.
- This will mean that your instructor is aware of any limitations that you may have and will also help them to provide alternative positions or instruction on any of the exercises if you are finding them difficult.
- Remember your ability to exercise may change from week to week so an exercise that you found easy one week may be temporarily slightly more difficult to do the next week.
- Informing your instructor of your AS will mean you get the most out of every class that you do while also staying safe.

4. Pilates

Pilates classes focus on core stability and postural control through exercises aimed at strengthening the muscles that support the spine. Pilates classes are low impact, however it is very important to start at a beginners class and learn the correct technique before you progress on to a higher level. Pilates classes use positions of lying and sitting to teach awareness of breath control, spinal alignment and strengthening of the core muscles that strengthen the trunk.

While there is no direct evidence showing any change in an individual's AS, these classes could help you to maintain good posture – a key aspect of managing your condition.



5. Yoga

Yoga classes incorporate exercises and postures aimed at maintaining balance in the body through strength and flexibility. There are many different forms of yoga so a range of exercises can be performed. Yoga uses a combination of stretches, postures and poses with deep breathing which also promotes relaxation.

There tends to be a spiritual element to some forms of yoga, depending on the yoga being taught. If this spiritual element is not of interest do not let this put you off as many people do yoga simply to gain the benefits of a low impact exercise on flexibility, strength and improved balance and posture. Ensure that you start at a beginners level and learn the correct techniques to gain the most benefit.

6. Walking

This is a simple, free form of exercise that many people do not think of as serious and effective. However walking is an excellent low impact way of toning your muscles as well as burning some calories. You can set your own pace with walking according to how you feel day to day. If you want to improve your motivation ask a friend or family member to join you.

7. Contact sports

Sports considered under this title include rugby, karate, hockey, hurling and gaelic football to name but a few. Extreme caution should be taken when considering playing these sports when living with AS. Part of your condition means that you are more at risk of having thinner bones (osteoporosis). This combined with possible stiffening of the spine means that you may be at risk of sustaining a break of one of the bones in your spine (your vertebrae). All of the sports/activities listed above mean that you may experience hard knocks and blows during the activity that may cause a bone to break.

8. Golf

Although not considered as true exercise by many people, golf does actually help to maintain your fitness simply through the amount of walking involved. Importantly for those with AS, golf also helps to maintain both spinal and shoulder range of movement and it also works your core stability. Although it is low impact, it is important that you do a good warm up before you play any round of golf and perform stretches at the end of the round in the opposite direction to which you swing your golf club. Additional stretches during your weekly programme should focus on shoulders, spine and arms if you play golf regularly.

Check out the guided exercise videos in the **SUAS iPhone app**.
Visit www.ankylosing-spondylitis.ie for more information.



Work and AS

Work and AS

Multiple international studies have shown that unemployment is generally harmful to physical and mental health and that work is associated with well-being.¹

However, very high rates of work disability have been identified in people with arthritis.²

Unemployment rates in people with AS can be three times higher than in the general population.³

In a survey carried out by the National Association of AS in the UK (2009), factors that affect ability to work were identified as follows; fatigue, pain, physical limitations, stress, needing to take time off sick, feeling depressed and anxious, having to attend appointments, lack of support or understanding from the employer/colleagues, and difficulty getting to work.

There is clearly a high level of unmet vocational need among Irish people with arthritis and there are very significant healthcare and welfare costs associated with work disability in this group.

An occupational therapist can address these issues with you and help you to apply self management strategies and engage in vocational rehabilitation.

A strong evidence base exists to support self management and vocational rehabilitation interventions for reducing work disability⁴.

Vocational Rehabilitation (VR) may be described as “a process to overcome the barriers an individual faces when accessing, remaining or returning to work following injury, illness or impairment. This process includes the procedures in place to support the individual and/or employer or others (e.g. family and carers), including help to access the VR and to practically manage the delivery of VR”⁵.

AS affects people of working age and it is vital to ensure that you remain in fulfilled and productive employment. It is essential that all adolescents and people with work instability and disability have access to VR.

References:

1. Waddell, G. and Burton, A. (2006) Is work good for your health and well-being? 2006, London: TSO (The Stationary Office).
2. Bevan, S., McGee, R. and Quadrello, T. (2009) Fit For Work? Musculoskeletal Disorders and the Irish Labour Market, London: The Work Foundation.
3. Boonen, A., Chorus, A., Miedema, H., van der Heijde, D., Landewe, R., Schouten, H., Van Der Tempel, H. and Van Der Linden, S. (2001) 'Withdrawal from labour force due to work disability in patients with ankylosing spondylitis', *Annals of the Rheumatic Diseases*, 60(11), 1033.
4. Burton, W., Morrison, A., Maclean, R. and Ruderman, E. (2006) 'Systematic review of studies of productivity loss due to rheumatoid arthritis', *Occupational Medicine*, 56(1), 18-27.
5. Dadoniene, J., Stropuviene, S., Venalis, A. and Boonen, A. (2004) 'High work disability rate among rheumatoid arthritis patients in Lithuania', *Arthritis and Rheumatism-Arthritis Care and Research*, 51(3), 433-439.



Benefits of Work

- Therapeutic – promotes recovery and rehabilitation.
- Better health outcomes.
- Minimises harmful physical, social and mental effects of long-term work absence.
- Reduces poverty and generates financial gain.
- Improves quality of life and well-being.
- Promotes full social participation and independence and gives meaning to the concept of leisure.
- Provides structure and purpose to the day.

Work can be categorised into:

- Formal paid work in the public, private and voluntary sector (e.g. paid barrister).
- Formal unpaid work in the public, private and voluntary sector (e.g. unpaid barrister, care assistant or any form of volunteering).
- Informal paid work (e.g. paid babysitting for friends or neighbours).
- Informal unpaid work (e.g. unpaid care for sick or elderly neighbour, training local football team, committee work in local organisation).
- Paid work in private (e.g. paid babysitting within the family).
- Unpaid work in private (e.g. unpaid care for sick or elderly relative, maintaining the home).

Finding work that is beneficial for you involves a combination of the right work in the right place, with the right employer, the right tasks, the right hours, the right colleagues and the right support.

Vocational navigation – asking the work question:

When providing intervention related to work, your occupational therapist will begin by ‘asking the work question’ and determining your starting point for assessment. You will fit into one of three categories which are outlined on the next page.

Once the occupational therapist has established your starting point, assessment of relevant dimensions of a person (e.g. education, functional capacity), occupation (e.g. risks, job demands) and environment (e.g. size of company, physical environment) will be completed.

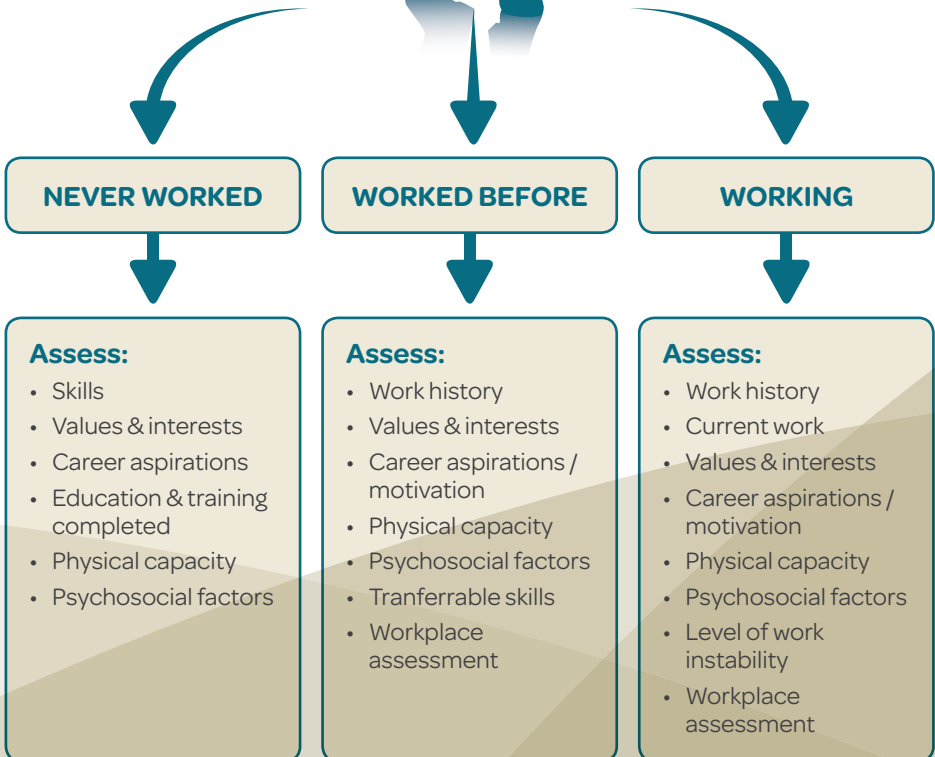
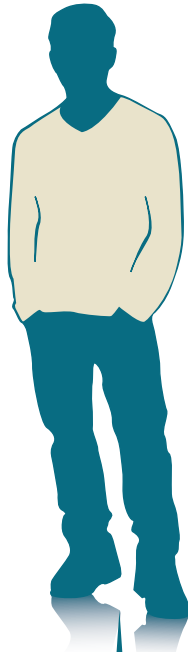
A variety of barriers; social, organisational or personal may get in the way of an individual taking part in the right type of work for them. Once these barriers are identified and addressed, then problem solving may begin to overcome them.

“Work instability” refers to those who are in work and struggling (the consequences of a mismatch between an individual’s functional ability and their work tasks).

Check out the work instability questionnaire in the **SUAS iPhone app**.
Visit www.ankylosing-spondylitis.ie for more information.



ASSESSMENT STARTING POINT



Managing AS in the Workplace

Tips to consider with regard to work:

- Effective early communication and advice for employee and employer is important.
- Negotiate flexible working hours with your employer – start and finish times, working from home, working flexi or reduced hours, or more frequent rest breaks.
- Look at changes in the work place in terms of the role, demands or routine to promote work ability and performance.
- Consider changing the work environment through workplace accommodations, environmental adaptations, ergonomic reviews and site visits.
- Be mindful of your commute – this must be a part of your negotiation.
- If you are having difficulty, seek out a qualified health professional to advocate on your behalf i.e. occupational therapist or GP.

Supports to return to or maintain work and education

When living in Ireland you have certain entitlements under the Irish social welfare system.

All social welfare payments require that you satisfy specific personal circumstances that are set out in the rules for each scheme.

Some are based on PRSI contributions, others are means tested or are universal payments. If you wish to apply, contact your local social welfare office at www.welfare.ie

Independent advice is also available at local Citizens Information centres www.centres.citizensinformation.ie

In order to be eligible for Disability Allowance you must be substantially restricted in undertaking work that would otherwise be suitable for a person of that age, experience and qualifications.

Application for Disability Allowance includes a medical exam and one must satisfy a means test.

There are a range of schemes and supports to encourage those who are long-term unemployed and those with chronic conditions to return to work.

Supports for employers assisting the return to work of an ill/injured employee:

- The Employee Retention Grant Scheme assists employers (in the private sector) in retaining employees who acquire an impairment which impacts on their ability to carry out their job.
- This scheme provides funding to identify accommodation/training to enable the employee remain in current position or take up another position within the company.
- Workplace Equipment/Adaptation Grant assists in the provision of more accessible workplace or adapted equipment to promote work ability.
- Wage Subsidy Scheme offers financial incentives to employers (private sector) to employ disabled people who work more than 20 hours per week.

For more information visit www.fas.ie

Legislation

Employment law in Ireland includes a range of legislation offering employment protection.

The Citizens Information Bureau website is a comprehensive resource in relation to Irish employment legislation. Visit www.citizensinformation.ie

Note that employers are not obliged to provide special treatment or facilities whereby in doing so more than a disproportionate burden is likely to be incurred (they must provide reasonable accommodation).

Community Resources

Qualifax is Ireland's National Learners' Database and provides comprehensive information on further and higher education and training programmes. The website has a 'search all courses' function and an 'interest checklist' function. The site also allows identification of FETAC assured courses.
www.qualifax.ie

The **National Learning Network** (NLN) is the training and education division of the Rehab Group. NLN assists learners (aged 16yrs+) at a disadvantage in the labour market to learn the skills needed to build a career or progress with learning. No fees apply and there are no formal entry requirements.
www.nln.ie

Vocational Education Committees (VECs) have responsibility for vocational education training and management of a range of adult and further education colleges.
www.ivea.ie

Lifestyle Information

Lifestyle and AS



Diet and AS

Many people have an interest in diet and its association with arthritis – seeking to know if there are diets that can help improve AS or help the immune system. Unfortunately, there is no diet that has been proven to significantly change the course of AS or other types of arthritis. It is important to have a healthy, well balanced diet and to maintain a healthy weight as it can reduce the load on weight bearing joints such as your hips and spine. Little or no exercise will greatly increase the risk of weight gain if dietary intake is not altered accordingly. It is important to maintain the exercise programme that your physiotherapist will have discussed with you.

Alcohol and AS

There is some evidence that small amounts of alcohol provide some protection against heart disease but it is not recommended to have alcohol as part of a healthy diet. If you do drink, spread your drinking over the week and stick to the recommended upper limits i.e. 17 standard drinks a week for men and 11 standard drinks a week for women. There are some medications that can interact with alcohol and so it is important to discuss this with your nurse or doctor.

Smoking and AS

Cigarette smoking, whether you have AS or not, has no positive effects on any aspects of your health. It is strongly discouraged in people with AS as it can accelerate lung scarring and seriously aggravate breathing difficulties. It can be especially harmful to people with AS whose upper spine is affected by the disease. The reason being that when the upper spine becomes inflamed the bones may fuse together, making it harder to breathe in deeply.

Several studies have demonstrated that smoking is associated with poor long-term outcomes in people with AS. There are many other reasons to stop smoking other than your AS (e.g. heart and lung disease).

If you are a smoker with AS, one of the best things that you can do for your overall health is to quit smoking.

If you need help or advice to stop smoking you can contact the National Smokers Quit Line on **1850 201 203** or www.quit.ie

Pregnancy and AS

AS has no effect on your fertility or your ability to get pregnant. If you are pregnant, or planning a pregnancy, it is important to discuss this with your nurse or doctor. Talk to your healthcare team to review your medications and develop a pre-pregnancy plan. Some medications can be harmful to an unborn baby. You may be taking medications that will have to be discontinued prior to pregnancy and a plan of how to manage without your medication if your AS flare needs to be put in place. Keep in contact with your healthcare team and contact them if you have any concerns.

Sexuality and AS

Long-term health conditions like AS can affect many different aspects of your life including your relationships and your sex life. Adapting to physical changes and challenges such as pain and fatigue can reduce your enjoyment of sex and other activities that you may do as a couple. You may also experience fatigue, low mood and self-esteem.

It is important to discuss your condition with your partner (particularly when you first get diagnosed) to talk about the challenges that you might face as a couple so that you can arrive at a solution that's right for both of you.

Resources

AS Support on the Go – Introducing the SUAS iPhone App

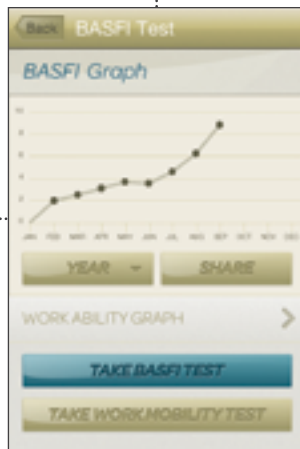
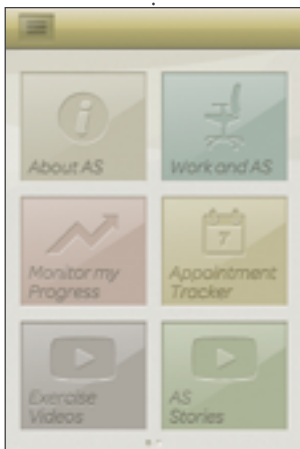
Using the **SUAS – Supporting and Understanding Ankylosing Spondylitis** – application you can now access reliable and comprehensive information about AS on your iPhone. This application, developed by the ASAI in partnership with Waterford Regional Hospital Rheumatology Unit, allows people living with AS to:

- Learn about the condition, symptoms and treatment options.
- Access information which will help you to better manage flares.
- Read about posture techniques and sleep management.
- Find out how to manage fatigue.
- Track and graph your progress over time using a functionality index.
- Learn about work and AS and managing the condition in the workplace.
- Access useful support resources and information on illness or disability payments to return to work, enter education, training or employment.
- Hear about living with AS from people with the condition.

A key feature of the app is a suite of guided exercise videos compiled by the rheumatology team unit at Waterford Regional Hospital. Using the app you can:

- View exercise videos with audio instructions.
- Create a customised exercise programme to ensure your routine is always interesting.
- Rate your videos and save your favourites.
- Unlock new exercises as you progress with your programme.

Download the SUAS – Supporting and Understanding Ankylosing Spondylitis – app from the App Store today or log on to www.ankylosing-spondylitis.ie for more information.



Resources

Useful contacts

Ankylosing Spondylitis Association of Ireland (ASAI) – Ireland’s resource site on AS, focusing on Irish people living with the condition.

www.ankylosing-spondylitis.ie

Arthritis Ireland – Ireland’s only organisation working to provide information and support for people with arthritis.

www.arthritisireland.ie

National Ankylosing Spondylitis Society (NASS) – Useful resource site on AS, focusing on British people living with the condition.

www.nass.co.uk

AS Research – UK site commissioned by NASS that summarises the latest research in AS.

www.asresearch.co.uk

Spondylitis Association of America (SAA) –an American AS resource site, with up to date research findings, message boards and online forums.

www.spondylitis.org

Ankylosing Spondylitis International Federation (ASIF) –The homepage of ASIF with details of and links to AS patient organisations around the world.

www.asif.info

Irish Society of Chartered Physiotherapists – national, professional body recognised as the voice of physiotherapy in Ireland.

www.iscp.ie

Association of Occupational Therapists – the professional body for occupational therapists in the Republic of Ireland.

www.aoti.ie

Heath Service Executive – This site will direct you on how to apply for a GP card/Medical Card and Drug Payment Card.

www.hse.ie



Ankylosing Spondylitis Association of Ireland

C/O Arthritis Ireland,
1 Clanwilliam Square,
Grand Canal Quay
Dublin 2

Helpline: 1890 252 846

Visit: www.ankylosing-spondylitis.ie

In association with:

Rheumatology Team

**Waterford
Regional
Hospital**



Visit www.asif.info

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