

# Living well with axial SpA

For anyone living with axial spondyloarthritis



Axial SpA  
works silently.  
We don't.

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# What is axial spondyloarthritis?

**Axial Spondyloarthritis (axial SpA) is a painful form of inflammatory arthritis.**

Throughout this guide we will use the term axial SpA to describe the condition.

The main symptom is back pain but it can also affect other joints, tendons and ligaments. Other areas such as the eyes, bowel and skin can also sometimes be involved.

**This guide explains axial spondyloarthritis and how it is managed.**

Axial spondyloarthritis is an umbrella term. It includes:

### **Non-radiographic axial spondyloarthritis**

Where x-ray changes are not present but inflammation is visible on MRI or you have symptoms.

Around 7 in 10 people with non-radiographic axial spondyloarthritis have visible inflammation in the sacroiliac joints or the spine when an MRI of the back is carried out.

Around 3 in 10 may not have any inflammation visible on MRI despite symptoms of back pain. Some may never go on to develop visible inflammation on MRI. The reasons for this are still not well understood but may be due to the sensitivity of MRI.

### **Ankylosing Spondylitis (sometimes also called radiographic axial SpA)**

Where there are changes to the sacroiliac joints or the spine that can be seen on x-ray.

## Typical symptoms

- Slow or gradual onset of back pain and stiffness over weeks or months, rather than hours or days.
- Early-morning stiffness and pain, wearing off or reducing during the day with exercise.
- Persistence for more than 3 months (as opposed to coming on in short attacks).
- Feeling better after exercise and worse after rest.
- Weight loss, especially in the early stages.
- Fatigue or tiredness.
- Feeling feverish and experiencing night sweats.

## What's going on in your body with axial SpA

Your body is over-producing inflammation.

1. Inflammation occurs at the site where ligaments or tendons attach to the bone. This is known as enthesitis.
2. The inflammation is followed by some wearing away of the bone at the site of the attachment. This is known as enthesopathy.
3. As the inflammation reduces, healing takes place and new bone can develop. Movement will become restricted if bone replaces the elastic tissue of ligaments or tendons.

4. Repetition of this inflammatory process can lead to further bone formation and the individual bones which make up your backbone (vertebrae) can fuse together.

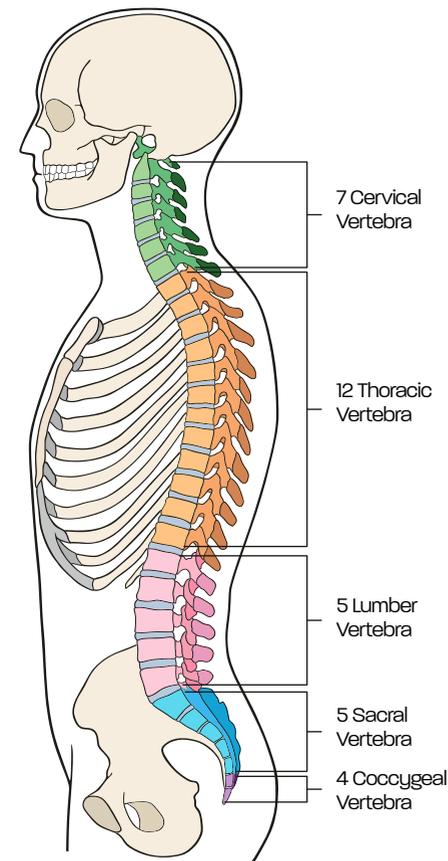
Do remember that this is a long-term process and the full process won't happen for everyone. Many people will only experience stage 1, non radiographic axial spondyloarthritis.

## Understanding your spine

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

There are 3 sections: cervical, thoracic and lumbar.

- The cervical, or neck section, is the most mobile.
- In the thoracic section each vertebrae has a rib attached to it on each side.
- Below the lumbar section is the diamond-shaped sacrum which locks like a keystone into the pelvis.
- The joints between the sides of the sacrum and the rest of the pelvis are called the sacroiliac joints. This is usually the starting-point of axial SpA symptoms.



## Causes of axial SpA

Research is still ongoing into the underlying causes of axial SpA. We still don't have all the answers but our understanding of the genetic factors involved has increased in recent years.

The risk of developing axial SpA is considerably increased if you carry a particular gene called HLA B27.

Just 8% of healthy white Europeans carry the HLA-B27 gene but up to 85% of people with axial SpA carry it.

Only about 1 in 20 of the general population who are HLA-B27 positive actually go on to develop axial SpA. This figure doubles if you have a first-degree relative (parent, sibling or child) with axial SpA.

This means that while HLA-B27 is one of the main genes involved, it's certainly not the only gene responsible. Current research (partly sponsored by NASS) reveals there are at least 100 genes involved in this process in some way or another.

One of these genes, called ERAP1, works together with HLA-B27 to increase your risk of developing axial SpA but some variants of this gene actually protect against developing the condition. Another gene, IL23R, affects the function of certain immune cells in the body to increase the risk of inflammation.

By the use of medication to block these effects, it may be possible to develop new ways of treating axial SpA in the future. There are currently very promising clinical trials of these agents.

Researchers believe that there is more to the development of axial SpA than genetics. Important studies of the gut are helping to increase understanding. Small and large bowel inflammatory changes are well recognised in most people with axial SpA and an imbalance of gut micro-organisms has been suggested by several studies although no consistent changes have yet been identified. If researchers can identify this, the role of diet will become of increasing interest.

### Inheriting axial SpA

If you have axial SpA and you carry the HLA-B27 gene there is a 50% chance that your child will inherit the gene.

This does not mean that they will go on to develop axial SpA.

On average the child of someone with axial SpA has only a 7% chance of developing the condition. If the child has inherited the HLA-B27 gene this risk doubles to about 13%. The risk is much lower (probably less than 1 in 15) if it was a grandparent or uncle who was affected by axial SpA.

There is a much greater chance (almost 10 to 1) that your child will not inherit your axial SpA. This means routine genetic screening of children is not recommended unless they develop symptoms.

### Incidence of axial SpA

Axial SpA affects around 2 to 5 adults per 1,000 in the UK. This means an estimated 200,000 in the UK have axial SpA.

It usually begins in your late teens with the average age of diagnosis being 24.

## Getting your diagnosis

Your first step is to go to your GP. You should be ready to explain:

- What symptoms you are experiencing.
- How long these have been going on (weeks, months, years).
- How the symptoms started (suddenly or came on slowly over time).
- What impact your symptoms are having on your daily life and what are they stopping you from doing (be sure to highlight any issues around sleeping and work).

If another member of your family has axial SpA please make sure that you highlight this to your GP. Do also tell your GP if you have ever suffered with:

- Inflammation in your eyes (uveitis).
- Inflammatory bowel disease.
- Psoriasis.

If your GP suspects axial SpA you should be referred to a rheumatologist at a hospital.

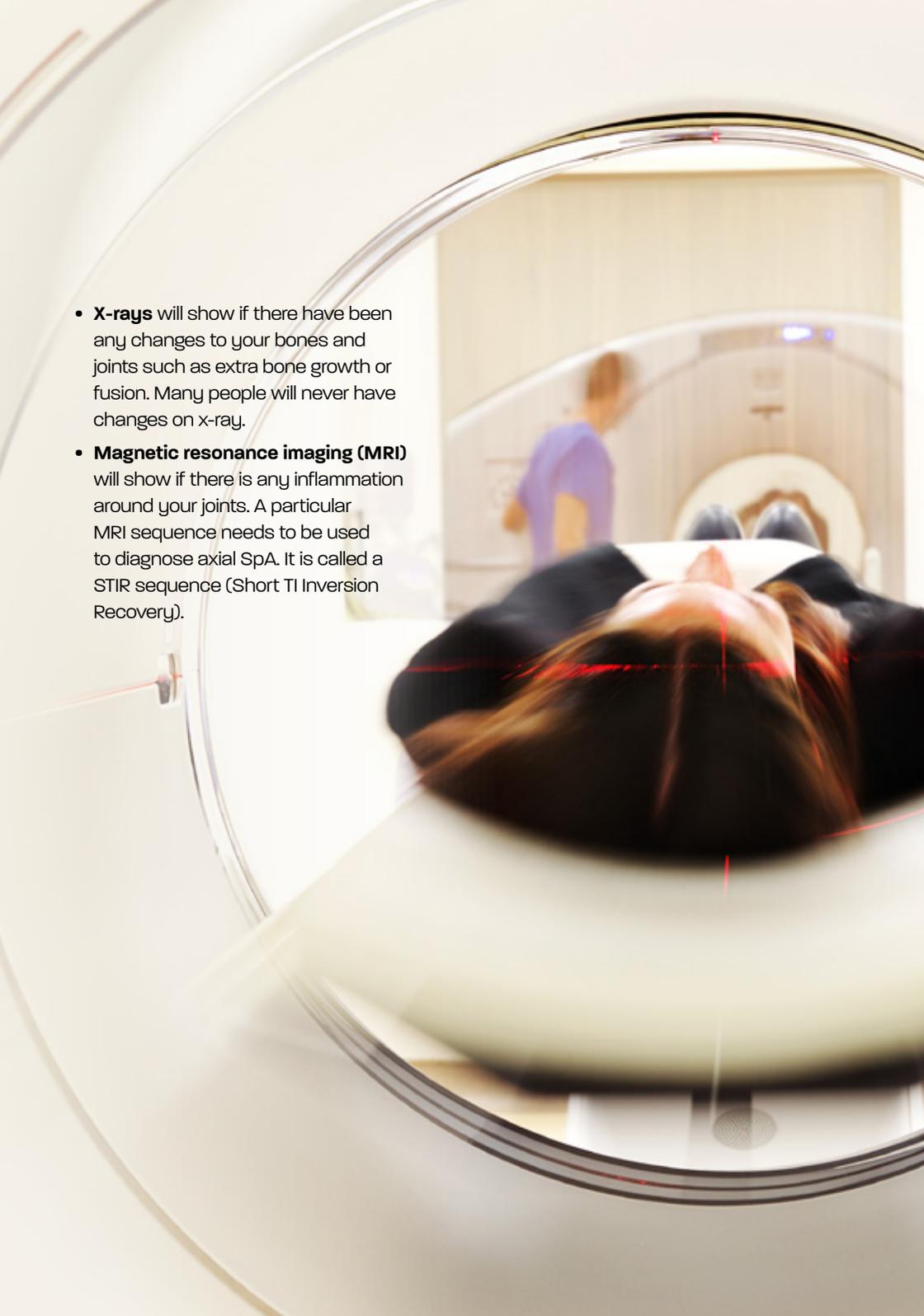
A rheumatologist will confirm your diagnosis, discuss your initial treatment and manage your condition in the long term.

### Tests which might be used to confirm your diagnosis

- **A physical examination** by a nurse, physiotherapist or rheumatologist to assess your flexibility and joint tenderness.
- Blood tests to look at **inflammatory markers**. If you have inflammation in a part of your body, extra protein can be released from the site of inflammation and circulates in the bloodstream. Erythrocyte sedimentation rate (ESR), C-reactive protein (CRP) and plasma viscosity (PV) blood tests can be used.

Do remember that in around half of all cases, inflammatory markers will be within the normal range. If your inflammatory markers are normal it doesn't necessarily mean you don't have inflammatory arthritis.

- A blood test which can identify if you carry the **HLA-B27 gene**. Just carrying the HLA-B27 gene does not necessarily mean you have axial SpA or that you will go on to develop it but it's a clue that your symptoms might point towards axial SpA. Do remember around 10% of people with axial SpA are HLA-B27 negative.



- **X-rays** will show if there have been any changes to your bones and joints such as extra bone growth or fusion. Many people will never have changes on x-ray.
- **Magnetic resonance imaging (MRI)** will show if there is any inflammation around your joints. A particular MRI sequence needs to be used to diagnose axial SpA. It is called a STIR sequence (Short TI Inversion Recovery).

## About axial SpA

### Your eyes

About a quarter of people with axial SpA will have an attack of acute anterior uveitis (also known as iritis) at some time in their life.

This is an eye condition caused by inflammation in the front part of the eye between the cornea (the clear window at the front of the eye) and the lens. It usually comes on suddenly and symptoms include:

- Pain and redness in the eye.
- Sensitivity to light. The brighter the light the more pain in the eye as the pupil gets smaller causing pain.
- Blurred vision.

If you have symptoms you should see an eye doctor (ophthalmologist) as soon as possible, ideally within 24 hours, to confirm it and start you on treatment. Early treatment reduces the risk of long-term damage to the eye which can affect your vision.

### Your gut

7% of people with axial SpA will also develop inflammatory bowel disease (IBD). If you develop symptoms which might indicate IBD you should be referred by your GP or rheumatologist to a gastroenterologist for tests, diagnosis and ongoing management.

The main symptoms of IBD include:

- Diarrhoea which is sometimes mixed with blood, mucus and pus.
- Cramping pains in the abdomen which can be very severe and often occur before passing a stool.
- Loss of appetite and loss of weight.
- Anaemia.
- Mouth ulcers.



Get a copy of  
**Managing my  
Uveitis from  
NASS.**

## Your skin

9% of people with axial SpA also develop psoriasis. This is an immune condition, which causes symptoms on the skin.

The skin replacement process speeds up in psoriasis, taking just a few days to replace skin cells that usually take 21-28 days. This accumulation of skin cells builds up to form raised 'plaques' on the skin, which can also be flaky, scaly, red and itchy.

Most people with psoriasis start their treatment under the guidance of a GP with creams or ointments (topical treatments). If your psoriasis is severe, or if various types of topical treatments don't work, you should be referred to a dermatologist who can offer treatments including:

- Ultraviolet light therapy.
- Medications such as methotrexate, ciclosporin, acitretin and apremilast.
- Biologic therapy. Some biologics used for axial SpA can also help psoriasis.

## Your feet

Just because you have axial SpA doesn't mean you will develop foot problems – but there are a few foot problems that seem to be more common. These include:

- Plantar fasciitis which causes inflammation at the site where the plantar fascia (a soft tissue structure under the foot) attaches to the heel bone.
- Insertional Achilles tendinitis which is inflammation where the Achilles tendon attaches to the back of the heel bone. Tight calf muscles can worsen the condition so gentle calf stretches will help.
- Cramping and toe clawing can occur if your posture has changed due to pain or fusion in the spine due to changes in the loading through your legs and feet. Muscles which are now being used more or just differently can be more prone to spasms.

A physiotherapist or podiatrist is the best source of help for foot problems.

## Your ribs

Your ribs can become inflamed where they attach to the spine. This is painful and can lead to stiffness and even fusion.

Inflammation of the ribs may cause pains that can be confused with the pain of cardiac or lung problems. Anyone experiencing symptoms of chest pain should seek medical attention to rule out a more serious condition.

In normal breathing the ribs move up and down with each breath. If the ribs become stiff, the ribs rise and fall less well. This means that breathing takes place using only the flat muscle below the lungs separating the lungs from the belly (diaphragm). You don't stop being able to breathe if the ribs fuse but tight clothing around the belly will be more uncomfortable as it will make it more difficult for you to breathe.

Breathing exercises encourage you to maintain your rib movements so you do not have to rely entirely on your diaphragm muscle.

## Your bones

People with axial SpA are at higher risk of osteoporosis, a condition that weakens bones, making them fragile and more likely to break.

Your GP can use an online programme to help assess your risk of fracture. They may also refer you for a bone mineral density scan, known as a DXA scan. There are medications that can help strengthen bones and you can lower your risk of osteoporosis and improve your bone health through:

- Weight-bearing exercise such as brisk walking.
- Muscle strengthening exercise.
- Including calcium and vitamin D in your diet.
- Stopping smoking.

## Your heart

Researchers believe that people with axial SpA may have a slightly raised risk of cardiovascular events. To lower your risk:

- Your axial SpA should be well controlled.
- Your GP should evaluate your cardiovascular risk.
- If necessary, medications including cholesterol lowering drugs and blood pressure lowering drugs should be used.
- You should not smoke.

**“Inflammation of the ribs may cause pains that can be confused with cardiac problems.”**



## Flares

There will be times when your axial SpA flares or worsens and times when it seems more manageable or settled. NASS have a guide to managing your flares but we've included some tips below. The best advice we can give is to plan ahead for a flare so you know just what to do if it happens.

### Medication

Talk to your rheumatologist or GP about how you can adjust your usual medications if your axial SpA flares. Find out the maximum dose to which you can safely increase your usual medications and ask which other medications you can safely add.

Write down the information you are given and keep it somewhere safe and convenient so you can easily refer to it when needed.

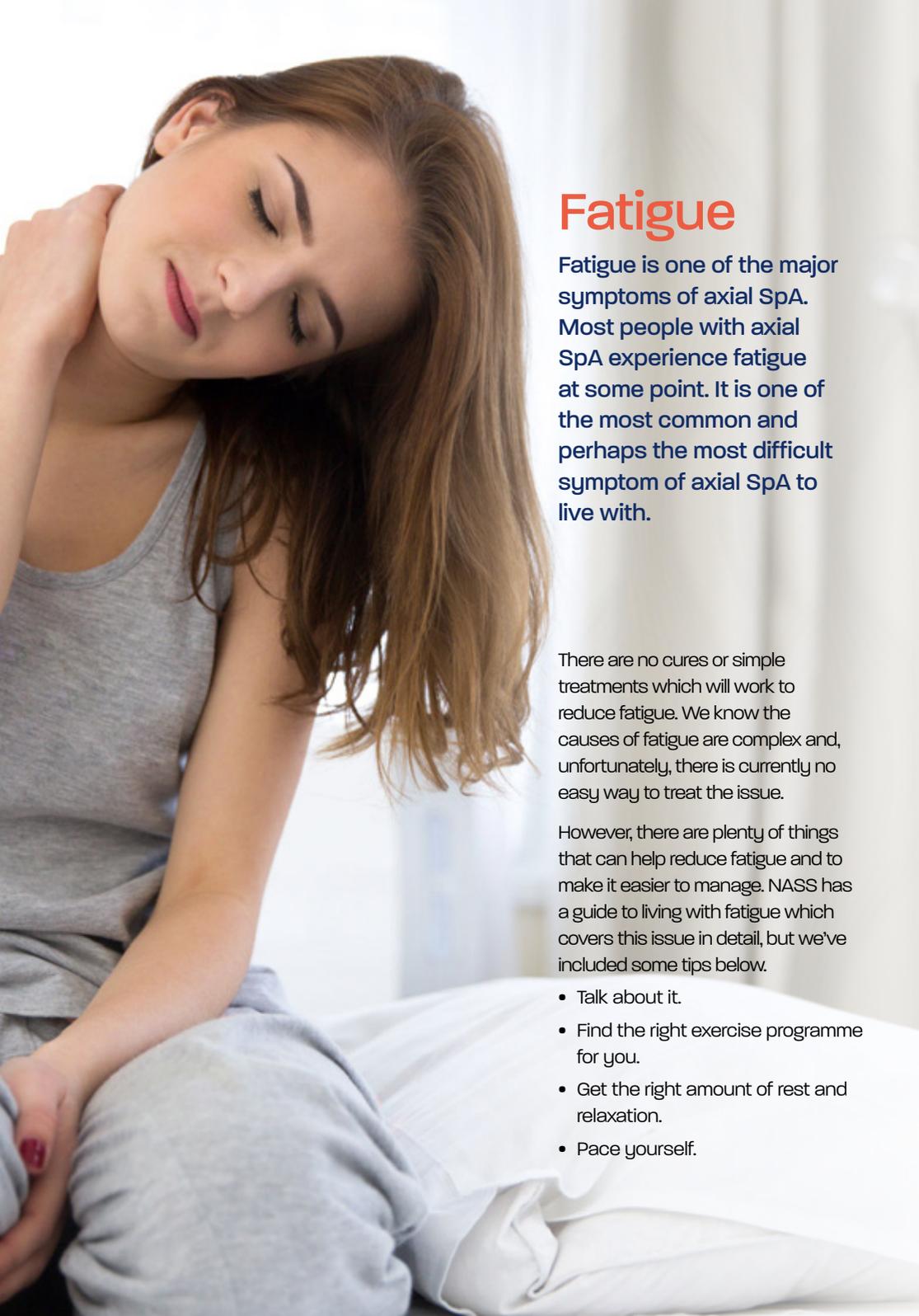
### Exercise

Consider avoiding high impact exercise such as running if you feel a flare coming on. Talk to your physiotherapist about the type of gentle stretching exercises that would be most suitable for you during a flare.

### Discover what helps you

Write a list of the things that you know make you feel better when your axial SpA is worse and pin it up somewhere in your home.

**“Plan ahead for a flare so you know what to do when it happens.”**



## Fatigue

Fatigue is one of the major symptoms of axial SpA. Most people with axial SpA experience fatigue at some point. It is one of the most common and perhaps the most difficult symptom of axial SpA to live with.

There are no cures or simple treatments which will work to reduce fatigue. We know the causes of fatigue are complex and, unfortunately, there is currently no easy way to treat the issue.

However, there are plenty of things that can help reduce fatigue and to make it easier to manage. NASS has a guide to living with fatigue which covers this issue in detail, but we've included some tips below.

- Talk about it.
- Find the right exercise programme for you.
- Get the right amount of rest and relaxation.
- Pace yourself.

## Your wellbeing

Living with a long-term, painful condition isn't always easy. It can affect how you think and feel about yourself and the world and it can affect your work, relationships and leisure activities. It can cause enormous challenges but you can also grow; developing resilience and wisdom.

When you first discover you have axial SpA you can feel robbed of the life you might have had. This can lead to a sense of anger which in some cases may lead to depression and a sense of fear and uncertainty about the future.

Relationships can suffer, with partners often at a loss to know how to help. Misunderstandings can easily arise from something as simple as the need of a person in pain to have a little space, being interpreted as rejection by their partner.

Difficulties with sexual activity may occur due to side effects of medication, pain through contact, fear of contact, tiredness and restricted movement. A cycle can develop where it is difficult to re-connect physically after a break in a sexual relationship. Talking with each other about this is important to keep your relationship strong.

### What can help?

#### **Acceptance.**

This transforms your experience of axial SpA from being at war with a part of yourself to recognising your needs as a whole person. It's about working with your condition. If you attend to its needs (rest and relaxation along with exercise) you are more likely to be able to get on with your life.

Incorporating this way of thinking into your life takes time and practice. This may mean paying attention to your emotional and psychological needs and for some that will involve acknowledging a struggle for which you may need professional help.

#### **Recognition.**

It is very important to see your GP and discuss treatment options if you feel you may be suffering from a depression that you can't manage on your own.

The Improving Access to Psychological Therapies (IAPT) programme provides NHS treatment for people living with anxiety and depression. You can search for the local service in your area. Local services vary but will typically offer talking therapies, guided self help and cognitive behavioural therapy. These can be used alone or in combination with medication. Some local services offer online self referral.

#### **Talking about it.**

Facing the condition directly and accepting your needs with it can help in all aspects of life. It can help in talking honestly with family, friends and your employer about some simple adjustments you might need to manage better. Talking with someone who understands can be very helpful. This may be someone you have met through NASS, an understanding partner or friend or a professional counsellor.

We have a forum for NASS members where you can chat to other people who will relate to what you are going through. Do also think about joining your local NASS branch where you'll meet other people with similar issues to you and will understand.

#### **Dealing with stress.**

Trying to prevent some of the worst effects of stress will reduce physical tension which has to be beneficial in managing your condition. Leaving space for time in your life for some form of relaxation can pay huge dividends. Learning and practising breathing exercises is a simple but effective form of stress management that you can use at any time.

#### **Preparing for the difficult times.**

It can help to have a list of what helps you to keep going through the difficult times. Knowing you have got through it before and reminding yourself what worked then is a good strategy.

Some things on the list may be practical things you can do and some could be more to do with the way you think about things – reminding yourself that you have limits and not to 'beat yourself up' about the things you feel you should be doing.

There are many, many people who live full, satisfying lives with axial SpA. Not everyone will experience the difficult emotional aspects and some will only experience them for a stage in their lives and will come through it.

**“Knowing that it is OK to ask for help can make a difference.”**



# Managing your axial SpA

**Axial SpA medications are used to improve your symptoms.**

Depending on the severity of your axial SpA your doctor may need to give you a combination of medications to help you with the pain, stiffness and inflammation.

If you are having a flare you may want to talk to your GP or rheumatologist about altering your medication.

Medicines used to treat axial SpA include:

## **Analgesics (painkillers)**

These reduce pain and are often used together with other medications.

## **Non-steroidal anti-inflammatory drugs (NSAIDs)**

When you are diagnosed with axial SpA it's very likely that you will be offered an NSAID as a starting point. NSAIDs help reduce the pain and stiffness caused by inflammation. They can be used in addition to simple painkillers such as paracetamol.

There are many different NSAIDs available in the UK. Some commonly used NSAIDs include ibuprofen, naproxen and diclofenac. Many are available to buy over the counter but stronger NSAIDs are only available on prescription.

It's important that you go back to your GP if the type and dose of NSAIDs that have been prescribed do not relieve your pain and stiffness after 2 to 4 weeks. A change in the type of NSAID or increased dose could make a big difference to your pain and stiffness.

NSAIDs work quickly, usually within a few hours. However, it can take up to 2 weeks to get the full benefit so do consider taking them regularly to get your symptoms under control.

If you develop any new symptoms you should stop taking the drug and tell your doctor as soon as possible.

NSAIDs can damage the lining of the stomach and cause bleeding, especially if you are taking high doses or using them over a long period of time. They should be used with caution and only continue to be used if they are controlling your symptoms. Drugs known as proton-pump inhibitors (PPIs) are commonly prescribed along with NSAIDs to help reduce the risk of side-effects on the stomach. Do discuss this with your doctor.

## **Corticosteroids (steroids)**

While steroids can be useful for pain and inflammation in peripheral joints like your knees, ankles and feet, they are not used for back pain. They can be effective in controlling inflammation in these peripheral areas but can cause side effects in the longer term. They can be used in the form of local injections into joints or in tablet form.

## **Disease modifying anti-rheumatic drugs (DMARDs)**

These can reduce pain, stiffness and swelling in people who have symptoms in peripheral areas such as the hips, knees, ankles or wrists. There is no evidence DMARDs will help with pain in the spine (axial disease).

## **Nerve pain medication.**

These medications specifically help people who suffer from long term nerve pain. This type of pain is caused by damage to or pressure on nerves. Nerve pain is often described by people as being like 'shooting pains', 'electric shocks', 'tingling' or 'the sensation of crawling under the skin'. Amitriptyline is the most commonly used medication in this group.

## **Biologic therapy**

NICE (National Institute for Health and Care Excellence) say biologic therapy is an option for treating severe active axial SpA in people who haven't responded adequately to, or who cannot tolerate, NSAIDs.

Most biologics are designed to block specific aspects of the immune system and can be thought of as 'targeted therapies'. Because these therapies are proteins, they do not work as tablets and have to be given as injections.

There are currently two types of biologic therapy which have been licensed to treat axial SpA and are approved by NICE. We know there are more currently in development and going through clinical trials. Both types work by reducing the inflammation produced by the body.

### Anti TNF therapy

Anti TNF therapy is used to treat a range of inflammatory conditions including non radiographic axial SpA (no changes on x-ray) and ankylosing spondylitis (changes on x-ray), as well as other conditions such as inflammatory bowel disease, rheumatoid arthritis and psoriasis.

These treatments interfere with the action of a protein called tumour necrosis factor (TNF) which is over-active in people with inflammatory arthritis, including axial SpA.

Too much TNF can cause inflammation and damage to bones, cartilage and tissue. Anti TNF therapy blocks the action of TNF and can reduce the amount of inflammation present in your body and joints.

### Anti IL 17A

Anti IL-17A therapy is currently licensed to treat ankylosing spondylitis and non radiographic spondyloarthritis, as well as psoriasis and psoriatic arthritis.

It works by neutralising the activity of a protein in the body called IL-17A.

IL-17A is a key protein in the skin inflammation in psoriasis. Research has shown that people with axial SpA have very high levels of IL-17A in their body and that IL-17A plays a very important role in causing the inflammation associated with axial SpA. By decreasing the IL-17A, this biologic reduces inflammation in your body and joints.

**“Read more in our guide to biologic therapy and on the NASS website.”**

## Physiotherapy and exercise

**Exercise is the single most important thing you can do to help yourself.**

Axial SpA is a condition for life and during its course it may affect you differently at different times. The fitter and more flexible you are, the better able you will be to deal with your symptoms.

Research has shown that to manage your axial SpA well it's not enough to rely on medication. You also have to exercise.

A physiotherapist can teach you a daily exercise and stretching routine and will remind you to be aware of your posture. You should learn how to increase the range of movement of your joints, particularly your spine and hips.

It's important to keep your muscles strong as lack of movement can weaken them and it may take a long time to build them up again. You also need to learn how to stretch muscles that become shortened.

Cardiovascular exercise can help improve chest expansion, decrease fatigue and improve sleep. Swimming is a great choice – you can wear a snorkel if it helps – but do find a physical activity you enjoy and which fits into your lifestyle, you're more likely to keep it up in the long term.

### Benefits of exercise

#### **Increased flexibility.**

The more flexible you are the easier it is to do everyday tasks.

#### **Increased range of movement.**

The more mobility you have the easier it is to do things.

#### **Improved posture.**

Better posture makes you feel better in yourself and reduces feelings of self consciousness.

#### **Improved sleep.**

Exercise is physically tiring which improves sleep quality, ensuring you wake feeling refreshed.

#### **Reduction in stiffness and pain.**

Exercise can result in less pain at night and improved sleep quality.

## Posture

It's important to keep a good posture. Think tall all day. Stand sideways in front of a full-length mirror. Imagine dropping a weighted string from the top of your head to your feet. Stand so it passes straight down, through your earlobe, shoulder, centre of your hip, behind your kneecap, and in front of your anklebone. NASS have a video showing you how to check your posture. You can find it on our YouTube Channel.

NASS can also help with your exercise needs through:

## Exercise section on the NASS website

There's a whole section on the NASS website covering everything you need to know about exercising with axial SpA.

## My AS My Life

The new My AS My Life section on the NASS website has a whole section on exercise with videos and downloadable resources. It includes session on Pilates, Tai Chi, yoga, HIIT and Somatics along with a great finding on finding your motivation to exercise.

## Back to Action guide Parts 1 and 2

Back to Action is an exercise programme specifically designed for people with AS who want to exercise safely in the gym. Back to Action Part 2 covers free weight exercises and gym ball exercises. You can download Back to Action free from the NASS website or order your guides from the NASS Shop.

## NASS Branches

We offer regular physiotherapy and hydrotherapy sessions under the guidance of experienced physiotherapists through our network of branches across the UK. To find out if there is a NASS branch near you please visit the 'In Your Area' section of the website and put in your postcode and a distance.

# Patricia's story

**I started getting symptoms of low back pain, rib pain and stiffness in my teens but wasn't diagnosed until I was in my 50's. Even though the diagnosis made sense of all my symptoms I felt really down after being diagnosed.**

I joined my local branch, NASS Tooting, and the friendly community of people and the great physiotherapists really helped me come to terms with things. I go every week for hydrotherapy and a stretch session.

Swimming, cycling and walking have really helped too. I see my rheumatologist at least once a year and I'm being treated with NSAIDs and biologic medication.



# Living well with your axial SpA

## Working

NASS have a guide to managing at work. It includes information on your rights at work, simple ways you can manage your axial SpA in the workplace and how your employer can support you.

It's important to get the right advice and support at an early stage rather than battling on so start talking about it sooner rather than later. Make sure you keep channels of communication open with your employer. It's hard for people to understand your problems if you don't discuss them.

Some problems people with axial SpA experience in the workplace include:

- Pain and stiffness in the mornings means it is hard to get going first thing and get to work on time.
- Sitting in one place or position can lead to pain and stiffness.

- Problems with carrying out heavy manual work.
- Not having the energy or stamina to work like you used to and getting fatigued easily.

Think about asking your employer for a workplace assessment with an occupational therapist or an Access to Work Advisor. They may be able to make some simple suggestions that make a lot of difference to your work.

If you are a member of a union at work do approach your union representative to discuss your problems. They should be able to find out your rights for you.

Bear in mind that the Equality Act requires employers to make reasonable changes to working practices or premises to overcome disadvantage caused by disability.

**“If you have fusion your spine is more vulnerable to injury.”**

## Driving

You may have increased pain and stiffness during long drives so do stop to stretch.

Make sure your vehicle is fitted with correctly adjusted head-restraints as even a relatively small impact can be serious for people with neck problems.

The law requires you to tell the Driver and Vehicle Licensing Agency (DVLA) about any condition that may affect your ability to drive safely.

The advice given by the DVLA is that:

- If it **does not** affect your safe driving you do not need to tell the DVLA.
- If it **affects** your safe driving you will need to tell the DVLA.
- If you are **unsure** whether it affects your safe driving you will need to check with your GP or rheumatologist who will be able to advise you.

The DVLA might consider that axial SpA was affecting your safe driving if you need adaptations to your car to be able to drive safely such as extra mirrors, or if you felt you could only safely drive a car with automatic transmission.

This does not mean that you would lose your license. Often the DVLA will simply note that you are using adaptations or they may send you to the Forum of Mobility Centres for advice and assessment.

The Forum of Mobility Centres website has some useful recommendations for extra mirrors for those with stiff or rigid necks.

## Accidents

If you have fusion your spine is more vulnerable to injury. If you have an accident or fall it's important to take any new symptoms seriously.

Go to A&E if you have an accident and have:

- New neck pain, or neck pain which is different to usual.
- New back pain, or back pain which is different to usual.
- Shoulder pain or injury.
- Tingling, pain or “pins and needles” in your limbs.
- Weakness in your limbs.

Do highlight that you have fusion in your back due to your axial SpA and ensure staff fully investigate.

## Travelling

Always tell your airline, travel agent or tour operator when you book if you are going to need assistance when you travel.

If you are on biologic therapy and need vaccinations for the countries you are planning to visit, do highlight this to the nurse and stress that you should not have live vaccines.

If you are travelling with your biologic therapy, do plan to keep it at the correct temperature during the journey and at your destination. Keep it in your hand luggage and do not put it into the hold of a plane.

Be aware that some prescription medications, including codeine based medications, are illegal in some other countries. Check with the Foreign Office, embassy or consulate of the countries you are travelling to and find out if it is legal to bring your medications into the country.

If your flight is not direct and you have a transfer do check for every country on your journey. For example, quite a few long-haul flights stop in Dubai where it is not legal to be in possession of codeine based medication.

Carrying copies of your prescriptions in your hand luggage is important in case you are stopped and questioned about the medications you are carrying.

### **Pregnancy**

The single most important piece of advice that we can give about planning a family is to discuss it with your rheumatology team in advance.

Having axial SpA will not affect your ability to conceive or have a harmful effect on the course of pregnancy or on the wellbeing of your unborn child. Women with axial SpA generally have healthy babies and they carry them to full term.

There is no pattern to women's axial SpA symptoms during pregnancy. Some find their symptoms improve, some find they stay more or less the same and others find they get worse.

It's important for you to keep exercising for as long as possible during your pregnancy. This will help both with your general health and with your axial SpA. As your pregnancy advances and you gain weight you may find it easier to exercise in the swimming pool where the water will help to support your weight.

We know some women hope that they will be medication free during their pregnancy and while they are breast feeding.

The reality for some women is that you may need either to stay on your medication during your pregnancy or know what medications you can safely add in during flares.

Everyone has different needs and that's why it's so important to discuss this with your rheumatology team, ideally in advance, so that you know what the best approach options are going to be available to you.



**“Check out the NASS website for the most up to date information on medication during pregnancy.”**

# Practical advice

## Get a suitable chair

The ideal chair has a firm seat and a high, upright, firm back. A chair with arms will help relieve weight from the spine. The seat shouldn't be too long, as you may have difficulty in placing your lower spine into the back of the chair. It should be a height that allows you to keep a right angle with the knee and hip joints.

Office chairs should be adjustable.

Do avoid low, soft chairs and sofas as they will encourage bad posture and increase pain.

## Watch how you sit

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

## Sleep comfortably

Take care with your bed, mattress and pillow. The ideal mattress should be firm and not saggy, but not too hard. Remember there's no single right bed to help your pain and everyone is different. Take time to choose what you personally find supportive and comfortable.

Try to use as few pillows as possible. Choose a pillow that can be moulded to suit any position and still give your neck good support.

## Try heat or cold

Many people find a hot bath or shower first thing in the morning or before bed reduces pain and stiffness, especially if you do some stretching exercises at the same time. Hot water bottles, cherry stone bags, wheat bags or electric blankets can be useful.

If you have an inflamed area, an ice-pack may help. But do take care as ice can burn. Do not leave an ice pack in place for more than 10 minutes.

## Eat well

It is important to make sure you maintain a healthy weight as being overweight increases the burden on weight-bearing joints and can increase pain. Try to eat at least 4 portions of vegetables (including at least 1 leafy green vegetable) every day, along with 2 portions of fruit.

Add in protein in the form of fish, beans, pulses, nuts, eggs and meat (not too much). Calcium is important for bone health and you need around 700mg a day - equivalent to 200ml semi-skimmed milk, a 150g pot of low-fat yogurt and a small matchbox sized piece of cheese.

Omega-3 fatty acids have been shown to help some people with inflammatory arthritis. You can find these in oily fish (pilchards, sardines, mackerel and salmon), rapeseed oil, flaxseed oil and walnuts.

## Don't smoke

Axial SpA can reduce the capacity of the lungs. Smoking can make this even worse, making you more prone to lung infections and shortness of breath.

Research shows that smoking is associated with earlier onset of inflammatory back pain, higher disease activity, increased inflammation on MRI, increased structural damage on MRI and x-ray, poorer function and worse quality of life.

If you smoke, the best thing you can do for your health is to stop.

**“If you smoke, the best thing you can do for your health is to stop.”**

# Useful exercises

Regular exercise will help you manage your axial SpA better.

You should have an assessment from a physiotherapist who will teach you some stretches.

In this section of the guide we've included some stretches you may find useful. If you have any doubts about your ability to carry out any of the exercises do check with your doctor or physiotherapist first. NASS cannot take any responsibility for any problems arising from the exercises shown.

## Warming up

Always warm up before exercising. A warm up increases the blood flow to your muscles - warming you up. This prepares your body to exercise and makes it less likely that you will injure yourself.

A warm up could be marching on the spot or using a bottom stair for step ups.



## Neck rotation

- 1 Sit upright in good posture and with both feet flat on the floor. Hold the sides of your chair seat.
  - 2 Turn your head to the right as far as possible without letting your shoulders turn. Repeat to the left.
- Repeat 3 times.

This is an exercise we'd recommend you try and do everyday, especially if you sit at a desk.



## Trunk rotation

- 1 Sit sideways on an armless chair in good posture.
  - 2 Keeping your feet firmly planted on the floor, twist your upper body towards the back of the chair and place both hands on the chair back.
  - 3 Repeat on the opposite side.
- Use your hands to help your rotate a little further around, keeping your good posture throughout.



## Pelvic tilting

- 1 Lie down with your knees bent and with your head supported if required.
  - 1 Tighten your stomach muscles, pushing your back down into the floor.
- Hold for a count of 5 and repeat 5 times.

Remember, this is a very small movement.





1



2



### Back and hip rotation

- 1 Lie on your back with your knees bent and your arms out to the side.
- 2 Keeping your knees together, slowly lower your knees to the right, back to the centre and then down to the left.

Try to keep your knees together and both shoulders on the floor.

Repeat 5 times.

### Trunk side stretch

- 1 Stand with your back to a wall, with your shoulders, buttocks and heels as close to the wall as you can manage.
- 2 Slowly stretch your right arm down the outside of your leg as far as you can. You should feel a comfortable stretch.

Repeat on the left.

Repeat 3 times.



1



2

### Hamstring stretch

Move forwards so that you are sitting towards the front of your chair but still feel safe. Straighten out your left leg with the heel resting on the floor.

Keeping your back straight, slide your hands gently down the front of your thigh. You should feel a good stretch in the back of your thigh.

Try to hold the position for 10 seconds. Repeat on the right leg.

Our top tip for this exercise is to make sure you are keeping your back straight and not rounding down over the leg.



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### Cat stretch

- 1 Kneel on all fours. Keep your hands shoulder width apart and directly under your shoulders. Keep your knees hip width apart and directly under your hips.
- 2 Keeping your elbows straight, tuck your head down between your arms and slowly arch your back as high as possible.
- 3 Now lengthen your neck keeping your nose parallel to the floor and hollow your back as much as possible.

Repeat 5 times.

## Posture stretch

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

Stretch as tall as possible without lifting your heels.

- 2 Slowly raise both arms sideways, keeping the backs of your hands against the wall.

Try to keep your bottom in contact with the wall.

Slowly lower and repeat 5 times.



## Superman stretch

- 1 Go back to your starting position for the cat stretch.
- 2 Keeping your head in the same position, raise your right arm and your left leg.

You are aiming to make a straight line with your body from your right hand to your left foot.

Hold for 5 seconds.

Return, with control, to the starting position and change to raising your left leg and right arm.

Repeat 3 times.

## Hip flexor stretch

- 1 Stand up facing the side of an armless chair and hold the chair back with your right hand.
- 2 Bend your right knee and place your right shin on the seat. Move your left foot as far forwards as possible.
- 3 Bend your left knee as much as possible, keeping a good posture and straight back. You should feel a good stretch at the front of your right hip.

Hold it for a count of 10. Relax and then repeat twice, trying to stretch a little further each time.

Turn around the face the other side of the chair and repeat with the opposite leg.





Axial SpA  
works silently.  
We don't.

## Become a NASS member today!

Join us. Become part of the biggest network of people living with axial SpA in the UK.

We know living with axial SpA can be tough. We know living with the condition can be isolating.

When you join NASS, you will become part of a community of people who understand what it's like to live with the condition. Our members tell us that when they join us they feel less alone.

But importantly, you'll be helping us to help others. Your voice will help us transform the diagnosis and care of people with axial SpA. And your support will help us ensure that no one is locked out of life because of the condition.

Raise your voice. Join NASS today and help ensure that everyone can live well with axial SpA.

Simply call 020 8741 1515, or visit [www.nass.co.uk/get-involved/become-a-member/](http://www.nass.co.uk/get-involved/become-a-member/) to become a member today!



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## Information for your friends and family

One in 200 people in the UK have axial spondyloarthritis (axial SpA) including ankylosing spondylitis. Symptoms usually begin in early adult life, with the average age of diagnosis being 24.

Axial SpA is an inflammatory arthritis which mainly affects the spine. Inflammation occurs around the spine where the ligaments or tendons attach to the bone. It often starts at the bottom of the spine in the sacroiliac joints but can happen anywhere within the spine. Over time this repeated inflammation can lead to further bone formation, causing vertebrae to fuse together.

This inflammation causes pain, stiffness and high levels of fatigue.

Symptoms can vary a lot from one day to another. Sometimes the inflammation will die down meaning less pain and more energy. Other days it will flare up causing more pain and stiffness. On those days it's much harder to get on with daily life.



Axial SpA isn't just back pain. It can cause pain and inflammation outside the spine including the hips, knees, shoulders and ribs. Problems with the feet, including plantar fasciitis and Achilles tendonitis are more common in people with axial SpA.

Around a quarter of people with axial SpA will develop uveitis at some point in their life. This is an eye condition caused by inflammation in the front part of the eye. Symptoms include eye pain, redness and sensitivity to light. Anyone developing symptoms of uveitis should see an ophthalmologist at an eye clinic as soon as possible to confirm and treat it. Early treatment with steroid eye drops reduces the risk of damage to the eye.

Axial SpA is also linked to inflammatory bowel disease, including ulcerative colitis and Crohn's disease and skin conditions such as psoriasis.

Medications to reduce inflammation and stretching exercises are the main way axial SpA is managed. There is currently no cure.

Axial SpA, especially in its early stages, can be an invisible condition. People with axial SpA are often battling on a daily basis against pain, stiffness and fatigue. This can lead to feelings of isolation, particularly just after diagnosis.

Living with axial SpA often generates feelings of frustration, anger, depression and fear. It does make all the difference to have the understanding, support and encouragement of family and friends.

You can read in more detail about axial SpA in this guide and we'd also recommend reading our guide to living with axial SpA fatigue and our flares guide.

**“Contact NASS if you would like more copies of this guidebook for friends, family or your employer.”**



## Thank you for your support

Did you know that NASS doesn't receive any statutory funding? We rely on the kindness of our supporters to fund our work.

Every donation helps us provide vital support to those who need us, raise awareness of axial SpA, and transform the diagnosis and care of people living with the condition.

### **Can you help us help more people live well with axial SpA?**

To donate please visit: [www.nass.co.uk/donate](http://www.nass.co.uk/donate)

## Acknowledgements

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## Keep in touch!



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