Royal Free London
NHS Foundation Trust

Axial spondyloarthritis

Information for patients

What is axial spondyloarthritis?

Axial Spondyloarthritis (ax-i-al spondy-loarthri-tis) or axial SpA was previously known as ankylosing spondylitis. It is a form of inflammatory arthritis where the main symptom is back pain. Over time it can cause some of the bones in the spine to fuse together, making it less flexible. It can also affect joints of the limbs (eg shoulders and knees), tendons and ligaments.

Symptoms often start when people are in their late teens and early twenties with intermittent symptoms gradually developing over months or years. Some people have few symptoms, some experience occasional increases in pain and stiffness, while others have significant pain and stiffness which has an impact on their quality of life.

Although there is no cure, most people with axial SpA can continue to lead an active life. The condition can often be successfully managed using a combination of exercise and education to support self-management and wellbeing, anti-inflammatory drugs, and biologic medications.

Individuals are now far less likely to experience severe disability due to newer treatment options.

How common is axial spondyloarthritis?

Axial SpA affects 1 in 200 of the adult population in the UK. It is unknown how many more people have symptoms but do not have a confirmed diagnosis.

Who might have axial spondyloarthritis?

Anyone can get axial SpA, although it affects more men than women. Symptoms usually appear in young people below the age of 45.

What causes axial spondyloarthritis?

The actual cause of axial SpA is unknown, although there is evidence of a genetic association with a gene called HLA B27. The HLA B27 gene is present in more than 85% of people with axial SpA, but just carrying the gene does not necessarily mean you have axial SpA or that you will go onto develop it. 15% of people with axial SpA do not have the HLA B27 gene. It is thought a series of genes are likely to be involved in the condition.

Having inflammatory bowel diseases such as Crohn’s or ulcerative colitis increases your chance of developing axial SpA, as does uveitis (a type of eye inflammation) and psoriasis (a skin disease).

What are the symptoms of axial spondyloarthritis?

The most common symptom is back pain. This pain is usually:

- gradual, causing stiffness that starts in the lower back or buttocks, which usually lasts more than three months.
- present at night which may wake you up.
- associated with stiffness in the lower spine when you wake up in the mornings, which tends to improve with movement and exercise during the day but worsens after periods of rest.
- associated with fatigue (tiredness).

Axial SpA can affect joints and tendons other than those in the spine. Approximately 50% of patients with axial SpA have inflammation in the joints of the limbs (arms and legs), most commonly in the hip and shoulder joints.

Symptoms in these joints include pain, stiffness, and sometimes swelling. Stiffness is typically worse first thing in the morning and can ease with movement. Sometimes a whole toe or finger can become swollen and painful which is called dactylitis.

You can experience tenderness under the heel or in the sole of the foot, known as plantar fasciitis, or pain at the back of the heel, called Achilles' tendinopathy. In some cases, axial SpA can lead to other problems:

Mental health

59% of people with axial SpA report experiencing mental health problems. The impact of axial SpA can affect how you think and feel about yourself and affect your work, relationships, activity levels and ability to exercise. As a result, people with axial SpA can experience stress, anxiety, depression, and other related disorders. Please discuss any mental health issues you have with your specialist team or GP as they will be able to suggest appropriate support.

Eye symptoms

About a quarter of people with axial SpA will experience uveitis which is an inflammation in the front of the eye between the cornea and the lens. If one or both of your eyes is painful, gritty and red and you are sensitive to light you should visit a walk-in eye clinic as soon as possible for treatment. To help you find a suitable walk-in clinic in your area, visit the eye accident and emergency service tool on the NHS website: www.nhs.uk/service-search/other-services/Eye-accident-and-emergency-services/LocationSearch/1858.

Bowel symptoms

On average about one in 14 people with axial SpA will have inflammatory bowel disease (Crohn’s disease or ulcerative colitis). Symptoms of inflammatory bowel disease include diarrhoea, abdominal pain, and weight loss. If you experience these symptoms mention it to your GP or rheumatology team so further investigations can be requested.

Skin psoriasis

On average roughly one in nine people with axial SpA will have psoriasis which causes scaly red patches on the skin. These patches can appear anywhere but are more common on the scalp, elbows and knees. Symptoms include itchiness, tenderness, burning and stinging which can be relieved with topical creams or medication. If you notice any flaky, red or itchy patches of skin mention it to your GP or rheumatology team.

Osteoporosis
Osteoporosis is more common in people with axial SpA due to local inflammation and reduced flexibility. Having osteoporosis means your bones break more easily and in people with axial SpA this typically affects the spine.

The risk of osteoporosis is greater in those who smoke, drink alcohol excessively, have a poor dairy intake or do not exercise regularly. Bone density is measured by having a DEXA scan. People with a higher risk of fracture are offered treatment.

Heart and circulation problems
The inflammation caused by axial SpA is estimated to affect the heart of between 2-10% of people diagnosed with the condition. The risk can be reduced by stopping smoking, regularly exercising, medication and regular check-ups. Some people develop a lack of red blood cells, which leads to general fatigue.

Breathing problems
You may notice tightness or stiffness around the rib cage, upper back and across the chest which is caused by inflammation of the rib joints or muscles attached to the ribs. Sneezing and taking deep breaths may become painful and stop you using your full lung capacity. The symptoms can be reduced by exercises and medication.

A small number of people develop scarring or fibrosis of the lungs due to inflammation which is usually detected by a chest x-ray or CT scan.

Discuss any intermittent pain across your chest with your GP to rule out other more serious causes.

How is my condition diagnosed?
Axial SpA is usually diagnosed by a rheumatologist, who will ask you about your symptoms, examine your joints and order investigations (tests).

These investigations include blood tests to check for inflammation (ESR and CRP) and the HLA B27 gene. Around a half of people with axial SpA will have normal inflammatory markers and over 85% are HLA-B27 positive. Therefore, it is still possible to have axial SpA if your inflammatory markers are normal, and you are HLA-B27 negative.

X-rays are useful for looking at your bones and will show us if there have been any changes such as extra bone growth or bones fusing together. Changes can be visible on an X-ray when inflammation has been present for a number of years.

Magnetic resonance imaging (MRI) is useful for visualising ligaments and tendons and can show inflammatory changes within bone.

In the very early stages of axial SpA, inflammation causes back pain and stiffness but damage to the sacroiliac joints which link your pelvis and lower spine is small and does not usually show up on an MRI scan or X-ray. In a small percentage of people axial SpA does not progress beyond this stage.

If inflammation is visible on an MRI but not on an X-ray, it is called **non-radiographic axial SpA.** MRI plays a significant role in the diagnosis of axial SpA by detecting early changes not yet visible on an X-ray

When inflammation has been present for some years, bone loss, calcification (a build-up of calcium in body tissue) and joints that have fused together can be seen on X-rays as well as MRI. The term used to describe this stage of the disease is **radiographic axial SpA** which was previously called ankylosing spondylitis.

Once diagnosed, you will continue to be under the care of the rheumatology department with access to a consultant rheumatologist, rheumatology advanced practice physiotherapist and rheumatology nurse specialist. In person or telephone follow up appointments will be arranged as required.

What treatments are available?

There is currently no cure for axial SpA, but it can be managed using a combination of medication, exercise, and education to support self-management and wellbeing. Looking after your health and establishing a treatment plan is essential to reduce the long-term effects of the disease.

What medicines can help?

There are a range of medications that can be used in the management of axial SpA:

Analgesics (painkillers)

Painkillers like paracetamol may be used in combination with other medicines. They can be useful in managing your pain, especially during a flare-up of axial SpA.

Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs such as ibuprofen, naproxen and etoricoxib are the first choice of treatment and help to reduce pain and inflammation caused by axial SpA.

You should discuss which NSAIDs to try and for how long with your GP or specialist as they have varying side effects and risks when taken for prolonged periods of time. NSAIDs are not recommended for those who have asthma, kidney or liver disease or have a previous history of stroke, gastrointestinal bleed, or heart problems.

Corticosteroids (steroids)

If you have a flare-up of peripheral (arm and leg) joint symptoms, injecting corticosteroids directly into the joint can be very effective. You may also be prescribed corticosteroid tablets (e.g prednisolone) or be given an injection in the muscle (e.g methylprednisolone). Due to their side effects, steroids are not offered for long-term treatment for axial SpA.

Disease-modifying anti-rheumatic drugs (DMARDs)

Drugs such as methotrexate, leflunomide or sulfasalazine are used to treat inflammation in peripheral (arm and leg) joints. They reduce inflammation therefore lessening joint pain, stiffness, and swelling. There is also evidence that they prevent joint damage but there is no evidence that these medications help with spine pain associated with axial SpA. Your blood will need to be monitored regularly if you have been prescribed one of these drugs.

Biologic drugs
Biologics have revolutionised the treatment of axial SpA. These drugs target specific cells in the immune system that cause inflammation. This type of medication may be offered to you if you have not responded to or are unable to tolerate NSAIDs and you have high levels of pain and stiffness. Currently there are two main types of biologic drugs used in the treatment of axial SpA; anti-TNF (infliximab, etanercept, adalimumab, certolizumab and golimumab) and anti-IL-17 medications (secukinumab and ixekizumab).

Biologic medications are generally given by injection via a prefilled syringe or auto-injector device. With education, most people learn how to give themselves these injections.

There are several biologic drugs available, and the main differences are in the frequency of injections and in the device used. Your rheumatologist will discuss the options with you.

Before starting biologic treatment, you need to have some screening tests to minimise the risk of side effects. This would include checking for previous known or unknown infections including viral hepatitis, HIV and tuberculosis (TB).

Examples of currently available biologics:

Biologic agent	**Method of delivery**	**Frequency once stabilised on treatment**	**Dose**
Infliximab (Remicade, Inflectra)	By infusion into a vein	Every six to eight weeks	5 mg/kg
Etanercept (Enbrel, Benepali)	Prefilled syringe or injection pen	One to two times every week	25mg - 50mg
Adalimumab (Humira, Amgevita, Hyrimoz, Imraldi)	Prefilled syringe or injection pen	Every two weeks	40mg
Certolizumab (Cimzia)	Prefilled syringe or injection pen	Every two to four weeks	200mg – 400mg
Golimumab (Simponi)	Prefilled syringe or injection pen	Every month	50mg
Secukinumab (Cosentyx)	Prefilled syringe or injection pen	Every month	150mg
Ixekizumab (Taltz)	Prefilled syringe or injection pen	Every month	80mg

What are the side effects of biologic drugs?
The most common side effects are skin injection site reactions and increased susceptibility to infections. If you develop signs of an infection whilst on this treatment you should contact your GP, rheumatology nurse or physiotherapy specialist for advice. You may need to stop your biologic medication until the infection is treated.

Are there any vaccinations I need to have if I am taking biologics?
We would suggest you have the flu vaccine every year, a pneumococcal vaccination once (a repeat vaccination may be recommended for some people) and any COVID-19 vaccinations. These can be arranged via your GP.

Can exercise help me?
Exercise has been shown to help patients with axial SpA at all stages, so it is a vital part of your treatment. Exercise improves cardiovascular (heart) health, flexibility, strength, posture, sleep and mental health and general wellbeing. It can have a significant impact on your quality of life. There will be times during your illness when pain and stiffness becomes worse and learning to pace your level of exercise is helpful during these times. The fitter and more flexible you are, will help you manage the flare-ups and have a more favourable outcome. People with axial SpA can find exercise such as swimming, pilates, yoga and HIIT (high intensity interval training) helpful.

Government guidelines suggest that adults should try to be active daily and undertake at least 20 minutes of moderate aerobic activity such as cycling, dancing or fast walking five times per week. Moderate activity raises your heart rate and makes you breathe faster. Chose an exercise that you enjoy as you will find it easier to keep it up.

Specific stretching and strengthening exercises are also important and should be included in your exercise programme to maintain flexibility and strength.

You can be referred to the physiotherapy team for further advice and guidance on exercise. You can also access regular exercise sessions tailor-made for people with axial SpA via NASS (National Axial Spondyloarthritis Society).

Do I need physiotherapy?
Physiotherapy enables individuals with axial SpA to lead an active and independent life. Physiotherapy sessions will help you to manage your condition and will include tips on exercise, managing flare-ups and fatigue (tiredness) and emotional wellbeing strategies. You can be referred to physiotherapy by your consultant rheumatologist, rheumatology advanced practice physiotherapist or rheumatology nurse specialist.

Will I need surgery?
The majority of people with axial SpA do not require surgical treatment. However, if inflammation in the joints causes significant damage, surgery such as joint replacements may be required.

How will my condition be monitored?
The healthcare professionals involved in your care will regularly monitor your disease activity and response to treatment. We ask you to complete a few measures to monitor your condition and the effect it is having on your life. The most common measures will be BASDAI and spinal VAS scores which you can calculate via the monitoring section of the My SpA app (see further information below). We will also review your spinal flexibility and the effect the symptoms are having on your daily life.

Blood tests will be carried out every three to four months if you are taking DMARD or biologic medications.

What can I do to help manage my condition?
Axial SpA is a long-term condition, so it is important to explore different strategies to help manage your symptoms. The disease will present different challenges and issues at different points in life so it useful to have a number of techniques to help you manage your symptoms.

The following can be helpful:

Relaxation, meditation, and mindfulness
Living with a long-term condition can present many challenges including increased levels of stress and issues with mental health such as depression. Stress and depression can have a negative effect on axial SpA symptoms therefore it is important to have strategies to promote relaxation and mental wellbeing. Relaxation, meditation and mindfulness techniques can help relax your body and mind, reduce stress, muscle spasms (cramps) and improve overall wellbeing. Your specialist team can suggest some resources if this is something you would like to explore. It is important to discuss any mental health difficulties you may be having with your GP or specialist team to access the right support.

Healthy diet
Eating a balanced diet and maintaining a healthy weight are important for your general health and to ensure you are not putting extra strain on your joints or increasing your risk of heart disease. There is very little scientific evidence that any particular foods help with axial SpA but omega 3 has been shown to reduce inflammation. Foods that are a good source of omega 3 include salmon, mackerel, sardines, cod liver oil and nuts.

Stop smoking
Axial SpA has been shown to be more aggressive in smokers. Talk to your healthcare team if you need help to stop smoking.

Alcohol
There is some evidence that drinking alcohol may cause axial SpA to worsen therefore it is suggested that people adhere to the national recommendations of drinking no more than 14 units of alcohol per week.

What about fatigue?
Fatigue (tiredness) is a really common symptom of axial SpA and often the most difficult to live with. People with axial SpA often experience difficultly getting to sleep and have disturbed sleep due to pain, which contribute to feeling tired. Getting the right amount of rest and relaxation, finding the right level of activity, and talking about the issues related to fatigue can make it easier to manage.

How do I manage my flare ups?
Even with treatment there may be times when you experience a flare-up of your axial SpA symptoms. Developing a personal flare-up management plan with your rheumatology consultant and specialist physiotherapist can help you to manage symptoms at this time.

Painkillers, NSAIDs and changing your level of activity and exercise can offer relief. Taking a hot bath or applying heat packs to painful areas of the body can be helpful.

You can contact the rheumatology advanced practice physiotherapist or rheumatology clinical nurse specialist if you need further guidance during a flare-up of symptoms by emailing: rf-tr.rheumnursesbarnet@nhs.net.

I am thinking of having a baby, is there anything I need to consider?
If you plan to start a family speak to your rheumatologist. Our general recommendation is to start trying for a baby once your axial SpA has been well controlled for at least three months.

Some of the drugs you have been prescribed may be stopped during pregnancy by your rheumatologist.

It is difficult to predict what will happen to your axial SpA symptoms during pregnancy. Some people experience a reduction in symptoms, but some have increased pain. Many pregnant women experience back pain during pregnancy, so it is important to continue to regularly exercise and include wellbeing strategies.

You can deliver a full-term healthy baby with a normal labour. Talk to your midwife in advance about pain relief during labour.

Other support available:

NASS (National Axial Spondyloarthritis Society)
For up-to-date information, support and advice.
Helpline: 020 8741 1515, Mondays to Fridays, 10am–4pm
Website: www.nass.co.uk

Versus Arthritis
For up-to-date information on rheumatology research and general advice.
Website: www.versusarthritis.org

MySpA app
The app is free to download to your smart device and provides information about axial SpA and its management and a library of exercises designed by experts. You can also record disease monitoring information.

More information

For more information about the inflammatory back pain service at the Royal Free London, please visit our website: www.royalfree.nhs.uk/services/services-a-z/rheumatology/

Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf.communications@nhs.net

Alternative formats

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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