

Managing my axial SpA flares

For anyone living with
axial spondyloarthritis



Axial SpA
works silently.
We don't.

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Who is this guide for?

This guide is for anyone with axial spondyloarthritis (axial SpA) including people with ankylosing spondylitis.

What is axial spondyloarthritis?

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

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.

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 your blood tests and clinical picture fit the diagnosis.

To keep things simple in this guide we have tried to just refer to axial SpA throughout unless we need to highlight a difference between non-radiographic axial spondyloarthritis and ankylosing spondylitis.

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.

Understanding your axial SpA

Educating yourself about axial SpA empowers you to manage your condition more effectively.

Get good, well-informed information and always ask questions at your appointments.

Check out our full range of guides and don't forget the NASS website

www.nass.co.uk

Experiencing a flare, especially if it's for the first time can be a stressful and even frightening experience. Knowing a few basic steps that will help you manage these symptoms should help you feel more in control and reduce the impact of the flare on yourself and your family.

“Always ask questions at your appointments.”

James's story

I find regular exercise most valuable in controlling my axial SpA stiffness. I like swimming which improves the flexibility of my neck and lower back. The day after a swim, it takes me far less time to get going in the morning. I try to get to the pool three times a week.

I have an office job, so I do seated stretches at my desk and make sure I go for a walk at lunch. A work station assessment was helpful in making sure I was correctly set up at my desk.

If my symptoms flare up suddenly and intensely, I do 10 - 15 minutes of Pilates and yoga exercises that I learnt at my local NASS branch. This often reduces my pain levels.

Overall, I've tried to work out a sustainable exercise programme based on enjoyable activities that can be maintained, if possible, for life. If the exercise is fun and enjoyable, my brain benefits from the associated release of endorphins which elevates my mood and acts as a natural painkiller.



Understanding your axial SpA flares

Axial SpA seems to have times of flare and times when it is more manageable or settled. A flare can include pain, stiffness, and fatigue. Understanding these features can help you to manage them.

Pain

Can be due to:

- Active inflammation in the tissues around the joints and tendons. This can be a very intense, raw type of pain.
- Shortening or tightening of muscles or tendons. This can lead to a dull, achy type of pain.
- Protective muscle spasms. This pain can be intense and sharp.

Fatigue

Can be due to:

- Chemicals released by the body during the inflammation and healing cycle.
- Muscle tightness and imbalance.
- Disrupted sleep.
- Stress from living with a chronic inflammatory condition.
- Low mood and anxiety.

Stiffness

Can be due to:

- Muscles and tendons shortening and tightening.
- In some cases, new bone growth between the joints of the spine and in the pelvis.

“A flare can include pain, stiffness and fatigue.”

Medication

You may need the help of medicine to deal with a flare. These include anti-inflammatories and painkillers. We advise you take your medication, especially painkillers, as soon as you wake up and realise that you're having a flare.

A severe flare may prevent you getting out of bed initially so it is a good idea to keep an emergency pack of your medication and a glass of water next to your bed. Remember it can take a little time for your medication to start to work.

It's important to know the maximum dosage you can take in 24 hours for all your medications.

It is easy to lose track of the number of doses taken, especially if you are sleep-deprived and taken some medication over the night.

Remember to replace your emergency pack of medicine ready for the next time it is needed and to keep it securely out of the reach of young children.

Breathe

Feelings of panic are common with the onset of a flare and can in turn cause more muscle tension and pain.

Slowing your breathing allows more air through your lungs and will help you relax. It is a good idea to be familiar with some breathing exercises before you need them. Regularly practicing some breathing exercises can be great for your lung health and stress levels.

Diaphragmatic breathing for relaxation

Place one hand on your chest and the other on your stomach, just above your belly button. Relax your shoulders, allowing them to fall away from your ears.

1. Keeping your shoulders relaxed, take a slow, deep breath in through your nose, try to keep your chest and top-hand still but allow your belly and lower-hand to gently rise.
2. Gently breathe out through your mouth, allowing your stomach and lower hand fall.
3. Repeat for 3 breaths then return to normal breathing.



Getting out of bed

If you know it is going to be painful getting out of bed, then:

- Try to move in stages so you do not pull on muscles that are already in spasm.
- Move on the out breath - do not hold your breath while bracing yourself.
- Let your body adjust to each position before moving to the next one.
- Try rolling onto your side, taking your legs off the bed and pushing yourself up into a sitting position.
- Check out the everyday stretch - getting out of bed on the NASS website or YouTube Channel.

Take a warm shower or bath

Warm water helps to relax tight muscles and release the stiffness in joints. It is also pain relieving.

You may find the jet of warm water from a shower helps to soothe sore areas, like a massaging effect.

Soaking in a bath can also be soothing – if you can get in and out safely without causing more pain.

Try using a combination of Epsom salts and your favourite aromatherapy oils to help you relax and lift your mood.

If you are not able to get in a shower or bath, a heat pack or hot water bottle is a good substitute.

“Try using a combination of Epsom salts and your favourite aromatherapy oils.”



Make a plan

Accept that you may not be able to do everything you had planned today but do make smaller goals for the day and perhaps the days ahead.

What is essential for you to do today and what can wait until tomorrow?

Make a list and prioritise your tasks.

Move

Keeping moving is one of the main strategies for limiting the duration and intensity of your flare.

Try to go out for a short walk, even if it's just to the front gate! Natural daylight helps to lift the mood by releasing endorphins which in turn help you to cope with your pain.

Gently stretch the areas that tend to tighten up with your axial SpA even if this feels uncomfortable. It should not be agonising or intensely painful but will likely be out of your "comfort zone".

The aim is to maintain muscle length as during a flare muscles can become shortened and tight.

Ask your physiotherapist to help you write down some gentle stretches you can do safely during a flare or to modify the ones you do already. Check out the everyday stretch videos on the NASS website or YouTube channel for some simple ideas.

Exercises in a hydrotherapy pool can be a particularly effective way of staying active and flexible when in a flare. Do look to see if there's a NASS branch in your area offering hydrotherapy.

Look to gradually build up your activity levels over days and weeks back to your pre-flare levels.



Posture

During a flare your body will naturally want to curl-up and protect the areas that are painful.

If the flare is prolonged this can be a key time that postural changes occur as the muscles become shortened into this position. You may not realise this as after a while your brain readjusts to this more flexed posture normal. It will then feel strange to stand tall again.

Regular, gentle posture-checks against the wall at least once a day are a must. Lying flat on your back on the floor or bed can be an alternative as gravity is helping you... just make sure your head is supported and you are able to get up again.

Posture check

- Stand with your feet hip-width apart and your heels as close to the wall as you can while maintaining your balance.
- Tighten and straighten your knees.
- Place your bottom against the wall and gently draw your shoulders back and down, keeping your arms relaxed.
- Now keeping this position, draw your head back towards the wall, keeping your chin in as you do so.
- Try to feel as if you are growing tall through to the top of your head.
- Remember to breath and hold this position for at least 30 seconds.

Pain relieving techniques

There are things aside from medication that can help keep your pain at a manageable level.

Heat and cold

Wheat or cherry stone packs or thermal heat stick-on packs can really help. Sometimes an alternating combination of heat and ice can stimulate blood supply locally to the painful area.

Tens machine and pain pen

Learn the correct way to use them, the pulsed programme of impulses is better.

Massage

You could learn acupressure points and then use them on yourself or invest in a soft tissue massage. Be sure to inform the practitioner of your condition and request they use gentle techniques aimed at relaxation.

Meditation or mindfulness techniques

There are guided meditation apps, CDs and podcasts available to help. Alternatively you can use the breathing exercises described earlier in the guide.

NASS branch

Don't forget that even when you are in flare it is safe to attend your local NASS branch especially if there is access to a hydrotherapy pool where you can do some gentle exercises.

“Even when you are in flare it is safe to attend your local NASS branch.”

Prioritise your sleep

Sleep can suffer during a flare-up. This in turn can affect your levels of pain and fatigue.

- Try to stick to a regular sleep routine, taking pain medication before bed if needed.
- Have a “digital sundown” for an hour before bed; lower the light levels and avoid screen-time.
- Avoid caffeine and stimulants in the second-half of the day.
- If you are lying in bed awake for more than 30 minutes, get up, keep the lights low and come back to bed when you are feeling sleepy.



Make a note here of some of the things you have found have helped during previous flares.



Educating family, friends and colleagues

It is best to explain your condition when you are feeling well. There is nothing worse than having to explain the challenges you experience when you are feeling unwell, miserable and tearful.

People close to you can become anxious and worried when they see you in pain. It can help to reassure them if they understand your condition.

Some people have a code word for a bad axial SpA day so the whole family can understand how they are feeling. A visual indicator such as a colour-coded wrist band can help children in particular understand how you feel.

NASS do have packs of mood bands in our shop. Each pack comprises 3 different wristbands. The green wristband says 'Today is a good day'. The orange wristband says, 'Today is OK'. The red wristband says, 'Today is a bad day'.

Finally

It may be good to keep a record of how frequently you are experiencing flares and how long they last. This can be done as a note on paper or electronic diary, or using a smartphone tracking app.

This can help you provide more accurate information to your healthcare professionals as to how your condition is progressing or responding to treatment.

It can also help give you an insight into the things that may trigger or alleviate a flare-up.

If your flares increase in number or intensity, seek advice from your rheumatology team or GP as your medication or its dosage might need changing.



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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.

As a NASS member, you will receive:

- AS News Magazine
- Access to our Members Day (free for a member and guest)
- Invitations to our Members-only webinars
- Access to the Members only resources on our website
- Access to our Members Forum
- Voting rights at our AGM
- Chance to contribute to cutting-edge research and campaigns
- Exclusive guides to claiming disability benefits (on request)
- Members Pack (including membership card)

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/ to become a member today!

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

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Keep in touch!



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