

Managing your axial SpA at work

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.

Why is work important?

Staying in work is likely to be one of the most important goals for you and your family.

It is better financially if you can stay in work, but there are other important benefits in working. Research has shown that people who are able to work are more likely to have better self-esteem – leading to less depression, less pain and less isolation.

The support of your employer to stay in work also provides important benefits for them, such as retaining valuable staff, increasing productivity and creating a diverse workplace. This guide is designed to help you find a way to manage your axial SpA and your work.

Raj's story

I manage my axial SpA through NSAIDs and exercise, especially stretching, running and working out in the gym. My dog is my running partner and, even when I'm not feeling up for exercise, he gets me up and out.

When I was in my 20's I was working as a lawyer in New York but I realised that being office and desk bound wasn't working for me. I quit and headed back to the UK to work as a consultant so I could achieve the work life balance I need. This meant I could organise my day to include plenty of activity.

A few years ago I set up my own business and that's led to me being back in the office again. So I'm making adaptations to how I work. I use a curved keyboard and touch screen, I have an adjustable desk and often work while standing and I stretch while I'm at the coffee machine. Lots of small changes helps make a big difference.



How axial SpA can affect your work

The effects of axial SpA are different for everyone. Some people are more severely affected than others. You may find it more difficult to cope with work at some times than at others, because of your changing symptoms or the changing demands of your job.

The most common symptoms that affect whether you can continue to do your job normally are:

- Pain and stiffness in the mornings can make it hard to get going first thing and get to work on time.
- Sitting in one place or position can lead to pain and stiffness.
- Pain and inflammation can make it hard for you to get around.
- Not having the same amount of energy or stamina and getting tired easily or feeling a lot of fatigue.

Take your time

It is important to take your time when making any decisions about work.

It can be difficult if you don't have a definite diagnosis, if you haven't found an effective treatment or if you are having a particularly bad flare up.

Keep your work options open while you work through your options for managing your axial SpA.

"It is important to take your time when making any decisions about work."

Your rights at work

The Equality Act

You're considered to be disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do daily activities.

'Substantial' is more than minor or trivial. For example, it takes much longer than it usually would to complete a daily task like getting dressed.

'Long-term' means 12 months or more. For example, a diagnosis of axial spondyloarthritis including ankylosing spondylitis.

If you are unsure whether you are covered under the Equality Act then do contact the Equality and Human Rights Commission. You will find the contact details towards the back of this guide.

It's against the law for employers to discriminate against you because of a disability. The Equality Act 2010 protects you.

In Northern Ireland, you are protected by the Disabilities Discrimination Act (DDA). For more information on the DDA, please visit www.nidirect.gov.uk.

Recruitment

When recruiting staff an employer may make limited enquiries about your health or disability. You can only be asked about your health or disability:

- To help decide if you can carry out a task that is an essential part of the work.
- To help find out if you can take part in an interview or if the interviewers need to make reasonable adjustments for you in a selection process.
- If they want to increase the number of disabled people they employ.
- If they need to know for the purposes of national security checks

You may be asked whether you have a health condition or disability on an application form or in an interview. You need to think about whether the question is one that is allowed to be asked at that stage of recruitment.

Starting a new job

Your employer will be allowed to ask health-related questions once you have been offered a job. You have a duty to tell an employer about a health condition if it might present a health and safety risk to yourself or other work colleagues.

Signing a declaration saying you are not disabled if you are, may make things difficult later on.

Reasonable adjustments in the workplace

An employer has to make '**reasonable adjustments**' to avoid you being put at a disadvantage compared to non-disabled people in the workplace.

Some reasonable adjustments you may want to think about and discuss with your employer might include:

- Providing special equipment to help you work better, such as an adapted chair or desk.
- Allowing you to take short, regular breaks to stretch out.

- Rearranging your work hours to avoid the rush hour. It may even be possible for you to work from home occasionally, or part-time.
- Reallocating duties that you find difficult to perform because of your axial SpA.
- Provide opportunities to re-train for a different role.

It is in your employer's interests to consider these changes, as these should minimise the time you need to take off.

Initiatives such as Access to Work can help employers meet the costs of making reasonable adjustments.

Resolving conflict

If your employer is being unreasonable and the situation cannot be resolved informally, you can raise the matter as a formal grievance. It is vital to seek further support and guidance, for example from your local Citizen's Advice.



Time off work

You can find out more about Statutory Sick Pay from Citizens Advice.

Time off due to illness

If you are employed and off for four working days or more in a row and you earn more than £120 a week, you will be entitled to Statutory Sick Pay (SSP).

SSP is money paid by employers to employees who are away from work because they are sick. It is the minimum amount you can be paid when you are off work because you are sick. It's paid by your employer for up to 28 weeks.

Your contract of employment may give you extra rights to more sick pay than this (contractual sick pay). You should check your contract to see what you are entitled to.

Time off for medical appointments

Your employer may allow you time off work for medical appointments but they are not legally required to do so unless specified in your contract of employment. Your employer can, for example, insist that you make these visits outside work hours, that you take holiday leave or that you make the time up later on.

You should check your contract of employment to see what rights you have.

If you are covered under the Equality Act for your axial SpA and your employer will not let you take time off for a medical appointment connected with your axial SpA or your disability, they could be breaking the law.

If you are not covered by the Equality Act then do still bear in mind that your employer cannot treat you differently to other employees. If others are allowed time off work for medical appointments then you should be allowed time off too.

“You should check your contract of employment to see what rights you have.”



Talking about axial SpA at work

To your employer

There is no legal obligation for you to tell your employer that you have axial SpA unless your condition presents a health and safety risk. However, you must not mislead your employer and you have a duty to answer medical questions honestly.

Remember that you can only be guaranteed protection by the Equality Act if your employer is aware of your disability.

It's important to get the right advice and support at an early stage rather than battling on and feeling miserable. We recommend that you talk about it sooner rather than later. Do use the Employer's Guide at the back of this guide.

The Work Foundation conducted a survey of people with musculoskeletal conditions and found around three-quarters of those who had discussed their condition with their managers received a supportive response. Additionally around two thirds had received some form of adjustment to their working conditions in order to help them manage better.

To your union

If you are a member of a union do approach your union representative. They should be able to clarify your rights and can help with discussing your problems with your employer.

If you are not a member of a union, do consider joining before you encounter any problems as some unions may not provide support or legal advice for pre-existing problems.

To your work colleagues

Deciding on the right time to talk about your axial SpA to your work colleagues depends on the severity of your axial SpA and your personal feelings. Some people prefer to be upfront as soon as they are diagnosed, while others continue working for many years before they feel the need to tell their colleagues.

Many people tell us they tend to put off these conversations until they are struggling with their axial SpA and really need help. This may well not be a good time as it's hard to explain this complex disease when you are in pain, stiff and maybe experiencing high levels of fatigue.

Ensuring you have a conversation about your axial SpA on a better day can be easier to manage and be much more rewarding.

Whatever you decide, bear in mind that it's hard for people to understand your problems if you don't discuss them.

Staying well at work

All employers are legally required to protect the health and safety of their employees. This includes providing safe and suitable work equipment.

Workstation assessment

If you are office-based you can ask for a 'workstation assessment'. You will be advised on how to minimise discomfort at your workstation, and if necessary, provided with special equipment.

Your posture

Maintaining a good posture is essential to keep your back and spine healthy, and in turn, your muscles and joints. This is especially important for people who spend many hours sitting in an office chair. To ensure that you have a good posture:

- Keep your back aligned against the back of your chair and your shoulders straight – avoid slouching.
- The base of the chair is critically important. It should be firm and adjustable to the correct height from the floor.

- Take regular breaks away from the screen.
- Your knees should be even with your hips or slightly higher while seated, and your feet should be flat on the floor.
- Make sure your forearms are horizontal when you are sitting at your desk.
- Keep your wrists straight when typing and try not to overstretch your fingers.
- Your eyes should be the same height as the top of your computer screen.

7 easy ways to get moving at work

It's hard to make sure you are keeping active when you are working 9 to 5. We've put together some simple ways of getting moving during the day.

1. Walk or ride at least

part of the way to work

If you can cycle or walk to work, this can be an excellent way to fit more activity into your day and you'll arrive feeling fresh and energised, with a clear mind. Not everyone lives close enough for this to be a realistic option, but you can still find ways to make at least part of your trip more active.

If you use public transport get off a stop or two early and walk the rest of the way. If you drive see if you could park a bit further away. If it's a big car park try parking at the far side.

Experiment and try a few different things to see what works for you.

2. Take the stairs

Take the stairs rather than using the lift. If it's too much for you then think about taking the lift part of the way and walking just one or two floors. If you struggle to walk up the stairs then how about taking the lift a floor or two higher and then walking down the stairs?

3. Set a reminder to move

It's easy to get engrossed in your work and forget to move until you realise you are feeling stiff and in pain. Some wearable health devices will vibrate when you haven't moved for a while or you can set reminders to remind you to take a break. Then you could get up and go for a short walk around the building or up and down the stairs. You don't have to go for long.

Not only will it get you moving, it will help clear your head, so you go back to work feeling a bit more refreshed.

4. Try a standing desk

If it's possible in your office, standing up to work can be a great choice. Your desk needs to be easily adjustable so you can alternate between sitting and standing throughout the day.

5. Turn waiting time into moving time

Waiting for the printer, or the kettle to boil? Take the opportunity to do some stretching exercises.

Check out the NASS stretches for your daily life for some suggestions. Alternatively, ask your physiotherapist to show you some suitable exercises.

6. Use every opportunity you have to get up from your desk

Pretend it's the '80s – instead of emailing your colleague, walk across to their desk and have a chat with them face to face.

Encourage people to have standing or walking meetings rather than sitting around a table. Research shows standing meetings can also be a good way to increase efficiency, making sure things don't drag on unnecessarily.

For smaller groups or one-on-ones, a walking meeting can be a great way to get things done while getting in a little physical activity. A walking meeting can also help reduce tensions and encourage more creativity and free-flowing conversation.

7. Get moving at lunch time

Do take a lunchbreak and try not to take your break at your desk. Having a break during the day is beneficial for your mental health and wellbeing, and it's a good opportunity to get active.

Instead of eating at your desk or sitting down in the kitchen area for your whole lunchbreak, make a point to get up and move for at least part of the time. Maybe go outside for a walk and enjoy the change of scenery.



Managing your axial SpA

For more detailed information on managing your axial SpA, including some simple exercises, please ask for a copy of the NASS Guide to Living well with axial SpA.

Top tips for managing your axial SpA include:

Make sure you are under the care of a rheumatologist and see them at least once a year. If your condition changes and your axial SpA flares up ask for help rather than just putting up with it.

Have a clear understanding of what you need to do if your axial SpA flares up. You can find out more about the medications used to treat axial SpA in the Medications section of the NASS website (www.nass.co.uk).

Keep active and make sure you regularly stretch. Eat healthily and don't smoke - it can make your axial SpA worse.

Make sure your rheumatologist refers you to a specialist rheumatology physiotherapist. The NHS isn't usually able to offer ongoing physiotherapy which is why we set up our local NASS branches. Our branches offer regular group physiotherapy sessions supervised by qualified physiotherapists in over 90 locations across the UK.

People regularly attending NASS Branches benefit from improved mobility and flexibility and along with reduced stiffness as a result of accessing regular physiotherapy.

Our branches offer a place for people with axial SpA to go to seek advice and support from professionals and their peers. They are a place where friendships are built in a fun environment with those who will understand you best.

“Visit www.nass.co.uk and head to the In Your Area section to find your local branch.”



Some extra help

It might be the small things that make all the difference between staying in work and feeling it's too much to cope with.

Access to Work

Access to Work is a specialist disability service providing grants to help pay for practical support with your work.

Personal Independence Payment (PIP)

Do consider applying for Personal Independence Payment (PIP).

It is designed to help with some of the extra costs caused by long-term ill-health or a disability. How much you get is based on how your condition affects you. It's tax free and you can get it whether you're in or out of work.

Employment and Support Allowance

If you are unable to work due to your long-term sickness or disability, you may want to consider applying for Employment and Support Allowance (ESA).

Blue Badge Parking

Some people would find it easier if they could drive to work rather than using public transport. However, parking can be an issue.

If there is an office car park do make sure you discuss getting a parking space, particularly if your mobility is affected by your axial SpA. Alternatively do consider applying for a Blue Badge which will allow you to park on single yellow lines and in street spaces with pay and display machines free of charge.

Useful contacts

ACAS

The AcCAS helpline is for anyone who needs employment law or workplace advice, including employers and employees.

They give confidential, free advice on any work-related problem or question you have and will explain what the law says and how it relates to you.

www.acas.org.uk
0300 123 1100

Access to Work

Helps pay for practical support so you can do your job. You can apply for Access to Work online from the gov.UK website or by phone.

0800 121 7479

Citizens Advice

Free, independent and confidential advice and a range of factsheets.

www.citizensadvice.org.uk

Equality and Human Rights Commission (EHRC)

Advice and information.

www.equalityhumanrights.com
0808 800 0082

Gov.uk


UK government website covering a range of issues including employment and disability.

www.gov.uk

Scottish Government **scot.gov**

Northern Ireland Government **www.nidirect.gov.uk**

Welsh Government **Gov.Wales**



“Being a member makes you an essential part of the work we do.”



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 (twice a year)
- Access to our annual Members Day (free for a member and guest)
- 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!

How can your company support NASS?

NASS does not receive any government funding and relies solely on donations from its supporters to carry out our work for people affected by axial SpA.

Supporting NASS is a great way to motivate and engage staff through a range of fun and simple fundraising activities, whilst raising vital awareness of axial SpA. Your support can also help to meet your social responsibility objectives, increase engagement with new and existing customers, create positive PR opportunities and build relationships with colleagues.

Here are some ways that you and your company can help NASS to continue supporting all those affected by axial SpA.

Payroll Giving

Payroll Giving is an easy, tax-effective way to give to NASS. It enables employees to donate straight from their gross salary (before tax is deducted), and to receive immediate tax relief of up to £5 for every £10 donated, and it's easy to opt in and out of.

If you don't have a payroll giving programme, there is useful information on how to set one up on the Payroll Giving Centre website at www.payrollgivingcentre.org.uk

Employee fundraising

Bring colleagues together for fun events to support our work. From quiz nights to coffee mornings and bake sales, from sponsored silences to dress down days to organising a team step challenge or cycle, there's no limit to what you can do!

The fundraising team at NASS can help make your fundraising activity a success with t-shirts, fundraising packs, fundraising support and lots more! Please contact fundraising@nass.co.uk to find out more.

Matched funding

This is a really simple way to make a big difference to fundraising events that your employees take part in, potentially doubling their fundraising total.

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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Employers guide to axial SpA

Keep in touch!



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www.nass.co.uk



/NationalAxialSpondyloarthritisSociety



@NASSexercise and @NASS_ASone



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