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The information in this booklet is a guide only. It is not intended to replace individual guidance from appropriate agencies. Every effort has been made to ensure this information is accurate at the time of going to press - however, please be aware that details can change. We strongly recommend seeking advice according to your individual circumstances, as we cannot be held responsible for any consequences arising from reliance on the information in this booklet.

# 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 AS and your work.



## How AS can affect your work

The effects of AS 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 makes 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
- Problems with getting around due to pain and inflammation
- Not having the same amount of energy or stamina and getting tired easily or feeling a lot of fatigue

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 AS.

# 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 – e.g. it takes much longer than it usually would to complete a daily task like getting dressed
- 'long-term' means 12 months or more – e.g. a diagnosis of 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 on page 13.

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](http://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 AS
- 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 Bureau (see page 13 for useful contacts).



### Time off due to illness

If you are off for four days or more in a row and you earn more than £112 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 you when you are off work because you are sick.

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.

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

### 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 AS and your employer will not let you take time off for a medical appointment connected with your AS 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.

# Talking about your AS at work

## To your employer

There is no legal obligation for you to tell your employer that you have AS 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.

NASS believe 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.

The Work Foundation conducted a survey of 809 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 AS to your work colleagues depends on the severity of your AS 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.

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

Use the Employer's Guide to educate your colleagues.



# 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

## Keeping active

Rather than sitting in one position for a long time, try to find a mix of duties which allow you to sit, stand and walk around.

Take some time out to do some stretching. Have a look at the NASS Back to Action guide (available as a hard copy and an App for iPhones and android phones) for some guidance. Alternatively ask your physiotherapist to show you some suitable exercises.

Make sure you take proper breaks throughout the day. Get outside at lunchtime for some fresh air or even a short walk rather than eating lunch at your desk.

Make time for some activity after work. It might be walking to the local pub with some friends, going swimming, taking part in a yoga or Pilates class or even going to your local NASS group.

## **Prioritise your tasks**

Fatigue is common among people with AS and it is important to recognise it as part of your AS.

Fatigue in AS is not just an ordinary tiredness, like you might get at the end of a hard day's work. It's an overwhelming sense of tiredness that often occurs after very little activity. It may also be present from the beginning of the day.

Prioritising work needs can mean you save energy for the things you really need to do. It can help you plan your tasks and your time to rest and recuperate.

You might find it useful to make a list of all the tasks you do in a typical day or week. Can they be done in a more energy-efficient way, or at different times of the day, to make them easier? Can you get help with any of these tasks?

Whatever your priorities are, try to be realistic about how much you can get done - don't try to take on too much.

## **Pacing techniques**

When you are living daily with pain, you can become less and less active as you start to fear triggering off your pain and making it worse.

Pacing involves learning to space your activities throughout the day and week to avoid flare ups. Important elements of pacing are to take regular short breaks before the pain becomes very strong and alternating between tasks and activities.

The logic behind pacing is that if you manage your energy wisely, it will gradually increase. Ultimately, pacing aims to help you increase your overall level of activity.

If you could benefit from learning pacing techniques, then talk to your GP or rheumatologist who will be able to refer you on to an occupational therapist or physiotherapist.

# Managing your AS

For more detailed information on managing your AS, including some simple exercises like the ones below, please ask for a copy of the NASS Guidebook.

Top tips for managing your AS include:

- Make sure you are under the care of a rheumatologist for your AS.
- See your rheumatologist at least once a year – if your condition changes and your AS flares up ask for help rather than just putting up with it
- Have a clear understanding of what you need to do if your AS flares up
- Make sure your rheumatologist refers you to a specialist rheumatology physiotherapist.
- Stretch at least once a day and stay active
- Eat healthily and don't smoke



# 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.

## **Fit for Work**

Fit for Work is a free service providing occupational health assessment and general health and work advice to employees, employers and GPs.

## **Access to Work**

Access to Work is a specialist disability service providing financial support beyond the reasonable adjustments an employer is legally obliged to provide.

## **Personal Independence Payment (PIP)**

Think about applying for Personal Independence Payment (PIP). This benefit replaced Disability Living Allowance (DLA).

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 not based on your condition, but 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). This benefit has replaced Incapacity Benefit (IB).

## **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 AS. 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

<b>ACAS</b> Provides up to date information, independent advice and can help employers and employees to solve problems and improve performance.	08457 474 747 <a href="http://www.acas.org.uk">www.acas.org.uk</a>
<b>Access to Work</b> Helps pay for practical support so you can do your job	Contact your local Jobcentre Plus
<b>Fit for Work</b>	<a href="http://www.fitforwork.org">www.fitforwork.org</a> 0800 032 6235
<b>Citizens Advice Bureau</b> Providing free, independent and confidential advice and a range of factsheets	<a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a>
<b>Equality and Human Rights Commission (EHRC)</b> Provides advice and information	0808 800 0082 <a href="http://www.equalityhumanrights.com">www.equalityhumanrights.com</a>
<b>Gov.uk</b> UK government website covering a range of issues including employment and disability	<a href="http://www.gov.uk">www.gov.uk</a>
<b>NI Direct</b> The Northern Ireland government website	<a href="http://www.nidirect.gov.uk">www.nidirect.gov.uk</a>



# Become a **NASS** member today!

***Join thousands of others and become a NASS member to receive a host of benefits:***

- Twice yearly magazine packed with news and information
- Meet healthcare professionals to discuss the latest treatments and meet others affected by AS at our annual Member's Day
- Share your experiences with thousands of other NASS members on our exclusive Members' Forum
- Support NASS in campaigning for greater awareness of AS among healthcare professionals, decision makers and the general public
- Help yourself and others affected by AS throughout the UK

NASS relies on the support of its members to continue providing the vital services that people with AS deserve.

To sign up now, simply call **020 8741 1515**, or visit **[www.nass.co.uk](http://www.nass.co.uk)**

Thank you for your support.

# How can your company support NASS?

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

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 AS. Your support will also help your company to meet its social responsibility objectives, increase engagement with new and existing customers, and create positive PR opportunities.

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

## Payroll Giving

Payroll Giving is an easy, tax-effective way to give to NASS. It enables you to donate straight from your 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.



Ask your payroll supervisor or accounts department if your organisation has set up a payroll giving programme. If they don't have one, there is useful information on how to set one up on the Payroll Giving Centre website at [www.payrollgivingcentre.org.uk](http://www.payrollgivingcentre.org.uk).

## Matched Funding

If your company offers matched funding schemes, it can match pound for pound the money you raise through any fundraising events that you organise, such as cake sales and sporting events – doubling your fundraising total!

## Charity of the year

Some companies give their employees the chance to select a charity that will be the focus of the company's fundraising efforts for an extended period of time. Why not nominate NASS to be considered as your company's Charity of the Year? Our team will support you with all the information you need.

## Fundraise with colleagues

You can get colleagues involved to support NASS by organising a fun and simple activity at work. For example, these could be cake sales, quiz nights or dress down days, with all donations coming to NASS. Alternatively, you can take part in a team challenge, such as a sponsored run or cycle. It's a great opportunity to help raise awareness of AS amongst colleagues, whilst raising vital funds for NASS.

# NASS Resources

## **EXERCISE FOR AS**

Exercise is not just a useful addition to the management of AS. It is one of the cornerstones of treatment. Exercise helps in the maintenance of flexibility and good posture and also assists with pain management and wellbeing.

### **Back to Action**

A guide to exercising safely in the gym (pdf version). You can also buy a printed, spiral bound version in the NASS shop.

### **Back to Action App**

We have now been able to produce an App for iPhones and android phones which you can download completely free of charge from iTunes and Google Play.

### **Fight Back**

Our exercise DVD aimed at people with more advanced AS who want to exercise at home. It includes 6 exercise programmes with 35 individual exercises and contains hip safe exercises.

## **NASS BRANCH NETWORK FOR HYDROTHERAPY AND PHYSIOTHERAPY**

There are 90 NASS branches providing regular physiotherapy and hydrotherapy sessions throughout the UK. Call NASS or check on our website under 'In Your Area'.

## **NASS guidebook**

A practical introduction to the treatment and management of ankylosing spondylitis with useful advice on living and working with AS.

### **Guide to Managing Flares**

Practical guide to understanding your AS flares.

### **GUIDE to biologic therapy**

Everything you need to know about biologic therapy for AS.

## **LEAFLETS**

### **Driving and AS**

Safe driving, the DVLA, Forum of Mobility Centres, the Motability scheme and the Blue Badge scheme.

### **Fatigue and AS**

What causes fatigue in AS and how it can be managed.

### **Uveitis and AS**

Symptoms of uveitis and treatments.

For more information and support, please get in touch.

**020 8741 1515**

**[asknass@nass.co.uk](mailto:asknass@nass.co.uk)**