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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.

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.

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 at work 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.

Useful AS facts

Some AS facts you might find helpful to give to your employers or work colleagues include:

- Ankylosing spondylitis is pronounced an-ki-low-sing spon-de-lie-tis and is called AS for short.
- Ankylosing means fusing together. Spondylitis means inflammation of the spine. Both words come from ancient Greek. Ankylosing spondylitis describes the condition where some or all of the joints and bones of the spine fuse together.
- AS is a painful, progressive form of inflammatory arthritis. It mainly affects the spine but can also affect other joints, tendons and ligaments. Other areas such as the eyes, bowel, lungs and heart can also sometimes be involved in AS.
- AS affects an estimated 200,000 in the UK.
- Symptoms usually begin in early adult life, with the average age at diagnosis being 24.
- AS is a lifelong condition and there's currently no cure.
- It is managed by a combination of pain relief and stretching exercises.
- In the past decade newer therapies, called anti TNF have been developed for those who don't respond to standard forms of treatment.
- AS, especially in its early stages, can be an invisible condition. People with AS are often battling on a daily basis against pain, stiffness and fatigue.
- Some common problems for people with include:
 - Pain and stiffness in the mornings make it hard to get going
 - Sitting in one place can lead to pain and stiffness
 - People with AS often don't have the same amount of energy or stamina and get tired easily.



Staying well at work

Are you sitting comfortably?

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.



Join **NASS** now!

10 reasons to join NASS today

1. Twice yearly magazine packed with news and information
2. Resources to help you understand and manage your AS
3. Helpline where you can talk in confidence
4. Regular physiotherapy and hydrotherapy sessions at NASS branches
5. Meet healthcare professionals and get the most up to date views at our annual Members' Day
6. Share your experiences with others on the Members' Forum
7. Influence the future by getting involved in research
8. Get your voice heard by taking part in our influential surveys
9. Support NASS in campaigning for greater awareness of AS among healthcare professionals, decision makers and the general public
10. Help yourself and others affected by AS throughout the UK



giftaid it

If you are a UK taxpayer, Gift Aid is a great way to make your membership subscription and any donations you make go further. NASS can receive an extra 25p for every £1 you give through tax relief. Please complete the Gift Aid Declaration on the membership form, or for online membership application tick the box, if you are able to support NASS in this way.



– the smart way to pay

Direct debit is the simplest and most convenient way to pay for your NASS membership. Not only does it save you time in renewing every year, it also saves NASS time and money on processing your payment which can be spent on improving the services that NASS provides.

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Membership and donation form

Thank you for joining NASS. Please tick the subscription rate you wish to pay and return this form to:

NASS UNIT 0.2, ONE VICTORIA VILLAS, RICHMOND, SURREY, TW9 2GW

ANNUAL SUBSCRIPTION RATES

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(Cheque online or direct debit) | £10 |
| <input type="checkbox"/> UK Standard by Direct Debit | £18 | <input type="checkbox"/> Overseas Membership | £25 |
| <input type="checkbox"/> UK Concession (Cheque online or direct debit) | £6 | <input type="checkbox"/> Life Membership | £250 |

Membership	£	
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Total	£	Please pay by cheque or direct debit.

GIFT AID DECLARATION

I am a UK tax payer and would like the charity to treat all donations I make from the date of this declaration until I notify you otherwise to be tax effective under the Gift Aid scheme. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give.

Tick to apply

MEMBER DETAILS: Please complete in BLOCK CAPITALS

Title First name(s) Surname

Home Address

.....

..... Post code

Telephone number: Home Mobile

Email address

Have you been diagnosed with ankylosing spondylitis? D.O.B



Your rights at work

Instruction to your Bank or Building Society to pay by Direct Debit

Please send this completed instruction to:

Service User No.

CAF, Kings Hill, West Malling, Kent, ME19 4TA

CAF Ref No. **FS 1016**

NASS
Unit 0.2, One Victoria Villas
Richmond, Surrey, TW9 3GW

Name(s) and address of account holder(s)

Mr/Mrs/Miss/Ms

Address

Post Code

FOR CAF OFFICIAL USE ONLY – This is not part of the instruction to your Bank/Building Society.

Date of first payment on or after;

/ /

Bank/Building Society account number

Branch Sort Code

- -

Name and full postal address of your Bank/Building Society

To: The Manager

Address:

Postcode

Instruction to your Bank or Building Society.

Please pay CAF Re NASS debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with CAF Re NASS and if so, details will be passed electronically to my Bank/Building Society.

Signature:

Date:

/ /

Banks and Building Societies may not accept Direct Debit Instructions for some type of accounts.

This guarantee should be detached and retained by the Payer



The Direct Debit Guarantee

- This guarantee is offered by all Banks and Building Societies that accept instructions to pay Direct Debits
- If there are any changes to the amount, date or frequency of your Direct Debit, CharityDonation will notify you ten working days in advance of your account being debited or as otherwise agreed. If you request CharityDonation to collect a payment, confirmation of the amount and date will be given to you at the time of the request
- If an error is made in the payment of your Direct Debit, by CharityDonation or your Bank or Building Society, you are entitled to a full and immediate refund of the amount paid from your bank or building society - If you receive a refund you are not entitled to, you must pay it back when CharityDonation asks you to
- You can cancel a Direct Debit at any time by writing to your Bank or Building Society. Written confirmation may be required. Please also send a copy of your letter to us.

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 12.

As a disabled person, you have rights to protect you from discrimination.

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

- application forms, interviews and job offers
- terms of employment
- promotion, transfer and training opportunities
- dismissal or redundancy and discipline and grievances

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 to help decide if the interviewers need to make reasonable adjustments for you in a selection process
- to help monitoring
- 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 when in fact 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, wrist rests or voice-activated software. These can often be fully funded through the Access to Work scheme (see page 12).
- 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
- Having reasonable time off for treatment, assessment or rehabilitation

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

There are also organisations and schemes to help employers meet the costs of making reasonable adjustments.

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.



Time off due to illness

If you are off for four days or more days in a row and you earn more than £107 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.



Managing your AS

For more detailed information on managing your AS 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. A rheumatologist is the specialist in this area and will be better able to manage you than your GP and will have a bigger range of management options.
- You should be seeing 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
- Be proactive at your rheumatology appointments. Call the NASS Helpline for a chat before you go along to see if there's anything you might want to discuss with your rheumatologist.
- Have a clear understanding of what you need to do if your AS flares up
- Make sure your rheumatologist refers you to the specialist rheumatology physiotherapist. A physiotherapist can help with pain management and simple exercises, such as stretching and keeping mobile at work
- Join a local NASS group for regular exercise sessions lead by a physiotherapist
- A podiatrist can help with problems with your feet or ankles
- Whenever you see your GP, rheumatologist or physiotherapist make sure you ask about managing your condition at work. They may well have some useful hints and tips.

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.

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.

NASS have a guide to making PIP claims.

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

ACAS

Provides up to date information, independent advice and can help employers and employees to solve problems and improve performance.

08457 474 747
www.acas.org.uk

Access to Work

Helps pay for practical support so you can do your job

Contact your local
Jobcentre Plus

Citizens Advice Bureau

Providing free, independent and confidential advice and a range of factsheets

www.citizensadvice.org.uk

Equality and Human Rights Commission (EHRC)

Provides advice and information

www.equalityhumanrights.com

Gov.uk

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

www.gov.uk

NASS Resources



Guidebook

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

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, iPod touches and iPads which you can download completely free of charge from the Apple Shop

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 over 85 NASS branches providing regular physiotherapy and hydrotherapy sessions throughout the UK. Call NASS or check on our website under NASS Near You.

AS News

A twice yearly newsletter for people with AS providing the latest information on the research, treatment and management of AS.