# Ankylosing Spondylitis (Axial Spondyloarthritis) (AS)

### Managing your AS Flares



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### Who is this guide for?

It's for anyone with ankylosing spondylitis (axial spondyloarthritis) (AS) who wants to find out more about managing flares.

# **Understanding your AS**

Educating yourself about ankylosing spondylitis (axial spondyloarthritis) (AS) empowers empowers you to manage your condition more effectively.

Get good, well-informed information and always ask questions at your appointments. There's a list of NASS resources at the back of this guide.

Don't forget the NASS website www.nass.co.uk

Listen to your body and keep a note here of how your AS changes, what helps and what seems to make it worse. Try the Talking AS website if you want to monitor how your AS affects you over a few months **www.talkingas.co.uk**.



You can write down any information you are given here so you can refer to it when needed.

## **Understanding flares**

AS seems to have times of flare and episodes when it is more manageable or settled.

A flare can include pain, stiffness, and fatigue. Understanding all 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 / 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.

### **STIFFNESS** can be due to:

- Joints fusing or formation of bony bridges restricting movement.
- Muscles and tendons shortening and tightening.

#### FATIGUE can be due to:

- The inflammation and healing cycle.
- Muscle spasms as a response to pain.
- Poor quality sleep due to pain.
- Loss of deep sleep so energy levels are not adequately replenished.
- Stress from living with a chronic inflammatory condition.

## **Medication**

You may need the help of medicine to live with a chronic, inflammatory, and painful condition and to help 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.

The whole procedure of getting out of bed can be painful – so get help from painkillers as soon as possible.

Keep an emergency pack of your medication, water, and a biscuit 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 feeling "muzzy-headed" and sleep-deprived.

Remember to replace your emergency pack of medicine ready for the next time it is needed. Ask your Rheumatologist, Rheumatology Nurse or GP to help you write down how you can safely increase your medications during a flare.





## **Breathing Techniques**

During the 20 minutes that you are waiting for your medication to work, the best and most effective thing to do to alleviate the flare symptoms is to BREATHE.

Research shows that just three good diaphragmatic breaths correctly learned when you are not experiencing a flare can greatly reduce pain levels by: Slowing your breathing techniques avoids the fast panicky upper chest breathing associated with flares and will help to flood your system with oxygen and nutrients which in turn will help to break the build-up of pain.

Controlling feelings of panic.

Relaxing muscles.

- Lowering your stress hormone levels.
- Giving you a feeling of being in control.

# Mind / Body Link

# Never underestimate the strong relationship between your mind and body.

Your head will always influence your pain and conversely your pain will always affect your head and mind. Your pain signals are received in your brain and that is what controls your response. So:

- PLAN a strategy where you make sure that you are in control of your AS and not the other way around. Your aim at this stage is to not allow the pain to build up to a level where it takes over your life; this is what is known as the cycle of pain.
- During a flare people can sometimes feel panicky, tearful and out of control. AS feeds off this stress.
- Acceptance. It is useful and helpful to think about your condition at this time, accept that you have it and then find a way to make it part of who you are but not what defines you.

## **Gentle Stretches in Bed**

Whilst you are waiting in bed for your medication to take effect, don't forget that your bed is a soft, safe and gentle environment.

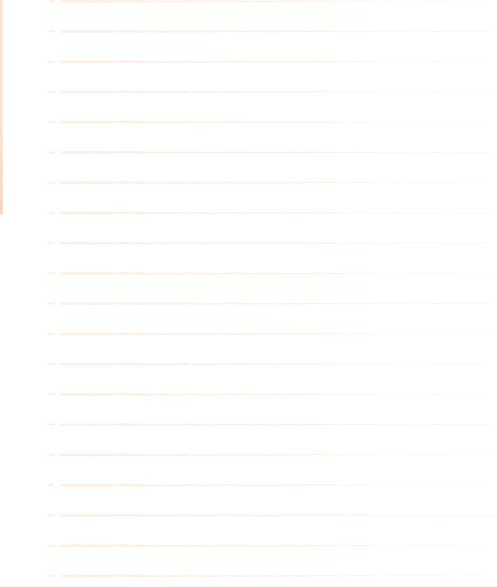
Your spine, joints and muscles are feeling warm and unaffected by the pull of gravity.

The key word here is GENTLE, a few simple stretches that you know well without aggravating your pain.

The worst thing to do is to keep still, even though it is the one thing that you most want to do. our modication

Ask your physiotherapist to help you write down some gentle stretches you can do in bed.





# **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.
- Let your body adjust to each position before moving to the next one.
- Move on the out breath do not hold your breath while bracing yourself.

## **Taking a 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 power 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.

## **Stretches and Movement**

The important thing to remember is that you won't hurt yourself if you have been taught the correct stretches by your physio.

Gently stretch the areas that stiffen up and tighten up with your AS even if this feels as though it might be harmful and counterproductive. It is one of the main strategies for limiting the duration and intensity of your flare.

Try to go out for a short walk; natural daylight helps to lift the mood by releasing endorphins which in turn help you to cope with your pain.

Ask your physiotherapist to help you write down some gentle stretches vou can do safely during a flare.



# **Pain Relieving Techniques**

During a flare it is useful to sit quietly and take stock of the situation. Then try some of these recommendations in combination with your medication.

**Heat:** Wheat or cherry stone packs or thermal heat stick-on packs,(useful if you need to be on the move). Sometimes an alternating combination of heat and ice can stimulate blood supply locally to the painful area.

**Hot bath/shower:** A combination of Epsom salts and/or your favourite aromatherapy oils can relax and help to lift your mood.

**TENS machine/pain pen:** Learn the correct way to use them, the pulsed programme of impulses is better.

**Learn acupressure points** and then use them on yourself.

Learn relaxation and or meditation techniques.

Don't forget that even when you are in flare it is safe to attend your local NASS group especially if there is access to a hydrotherapy pool where you can do some gentle stretches. 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 AS when you are feeling unwell, miserable, grumpy 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. You can get extra guidebooks from NASS and a guide to managing AS at work which gives advice on talking to your managers and work colleagues.

Some people have a code word for a bad AS day so the whole family can understand how they are feeling, and this helps to decrease tension for everyone.

### Finally

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.

**DO NOT SUFFER IN SILENCE.** There is help out there.

### **NASS resources**

#### 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 YOUR AS AT WORK

Includes how AS can affect your work, communicating about your condition, staying well at work and your rights.

**GUIDE TO ANTI TNF THERAPY** Everything you need to know about anti TNF therapy for AS.

### LEAFLETS

Axial spondyloarthritis An understanding of axial spondyloarthritis and how it fits with ankylosing spondylitis.

#### **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 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 NASS Near You.

### NASS

### NASS is a charity which provides support, advice and information for people with AS and their families.

Membership of NASS can go a long way towards improving your health and your life.

You'll benefit from up-to-date information on treatment, as well as support with information on benefits and work. You'll also connect with others in a similar situation.

Not only will you feel less alone, you'll be able to share solutions.

Here are some reasons why you should become a NASS member today!

- Access to our 90 regional branches offering regular physiotherapy and hydrotherapy sessions.
- Use our Exclusive NASS members' forum.
- Twice-yearly magazine, AS News.
- Free entry to our annual Members' Day.

### GET INVOLVED AND SUPPORT RESEARCH INTO AS

Support other people affected by AS.

 Support our five year plan to focus on early diagnosis, patient empowerment and self management, access to physiotherapy and exercise and awareness.

### **TO JOIN NASS**

If you'd like to join online please go to our website at **www.nass.co.uk** and choose your membership in the NASS Shop.

If you'd like to pay by credit card and over the telephone please call **020 8741 1515**.

#### **ABOUT THE AUTHORS**

Brisa France and Ingrid Hill are two senior physiotherapists who have specialised in AS for over 10 years. They are based at the Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath, working on the AS Rehabilitation course under Dr Raj Sengupta. The two week course aims to give patients an increased understanding of their AS and promotes self management of the condition. Patients can be referred to the course by their rheumatologist or their GP.



NATIONAL ANKYLOSING SPONDYLITIS SOCIETY

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