

Living with Ankylosing Spondylitis

My Personal Care Plan

Facts and self management actions

Working in partnership with:

Solent NHS Trust

and

Portsmouth National Ankylosing Spondylitis Society Group

A "Personal Care Plan" is way of empowering people with a Long Term Conditions such as Ankylosing Spondylitis to be able to take greater ownership and responsibility for their care and have more control over the management of their Ankylosing Spondylitis.

Personal Care Plans can be described as a journey over time, involving contact with a number of professionals and non-professionals (e.g. advocates and carers). During this journey people develop a greater understanding of themselves, their own needs and wishes, as well as the range of services they can access to improve their long term conditions, their health and most importantly, their quality of life.

This Personal Care Plan ideally would be used with the personal profile document which can be obtained from the "Say It Once" group

For More Information:

Say It Once, 9 Love Lane, Romsey, Hampshire, SO51 8DE.

Telephone: 01794 519 495

Email: contact@sayitonce.info

Website: www.sayitonce.info/

What is Ankylosing Spondylitis

What is Ankylosing Spondylitis

- An inflammatory condition (that is different to Rheumatoid Arthritis or Osteoarthritis).
- The condition varies between individuals. In some it only affects the spine, whilst in others it can also affect other joints too.
- Over time the pattern of musculoskeletal involvement may change and often the condition may be associated with skin problems, eye problems and bowel problems.
- There may be systemic features such as fatigue and lethargy.
- People with Ankylosing Spondylitis can experience repeated episodes or flares of inflammation at different sites in the spine (or elsewhere in the body where soft tissue inserts into the bone ie: the heel, breast bone).
- With repeated episodes of inflammation and recovery, extra bone or “ankylosis” may form where the inflammation has occurred. In some cases boney bridges form across vertebral bodies (the bones in your spine) causing fusion of the spine.
- The condition can be managed with regular exercises and anti-inflammatory medication. For those that do not respond there are now “biologic” therapies.
- Over recent years, the outlook of this condition has improved significantly and many patients can hope to maintain their employment and quality of life.

What is Ankylosing Spondylitis

Ankylosing Spondylitis is different to “mechanical low back pain “and different to general wear/tear of the spine that is seen in osteoarthritis

If you are diagnosed with Ankylosing Spondylitis it does not mean that you will become disabled or wheelchair bound

Remember – not all people with Ankylosing Spondylitis have the same level of symptoms – you are all different and individual

Over a course of days, weeks or months it is common for you to have varying levels of pain, fatigue and stiffness

What is Ankylosing Spondylitis

Key facts and Self-Management actions

Recognise your symptoms

Remember your symptoms can vary from day to day or week to week – listen to your body and respond accordingly. Monitor the following to determine if you think you are heading for a flare:

Early morning stiffness in your joints – Is it taking you longer to get up and move around than it would do normally?

Pain levels – Are you experiencing more pain than normal but for no obvious reason?

Levels of fatigue – Is your sleep less refreshing than normal? Do you feel overwhelmingly more tired than normal but for no obvious reason?

If you answer **YES** to the points above then consider the following options:

- Increase your medication (if you have been previously advised to by your GP or Rheumatology Consultant)
- Seek medical review with your GP or Rheumatology Consultant

Activity and exercise

Exercise and activity remains the corner stone of managing your condition – it needs to be part of your every day life – try to exercise daily. Exercise regimes need to include work for:

- | | |
|--|----------------------------------|
| - Cardiovascular fitness | - Posture control |
| - Breathing / lung expansion | - Balance |
| - Stretching / flexibility for muscles | - Mobility for joints |
| - Specific muscle strengthening | - Weight bearing for bone health |

An ideal programme of exercise for people with Ankylosing Spondylitis should include exercise you can perform on land and exercise in water (to allow you to exercise when you are in flare)

Try to exercise daily

If you are having a flare, you still need to exercise but:

- cut down on the amount of exercise you are doing
- ensure you have adequate rest
- consider exercising in water only as you may experience less pain

If you are new to exercise you should seek professional guidance on what exercise is right for you from a Chartered Physiotherapist

Pacing

Trying to do too much all in one go can result in you feeling more fatigued, have more pain and at worse cause your condition to flare.

Pacing can help you to ensure you have the energy to focus on fun activities that you enjoy and the exercise management needed for your condition

Pacing means spreading out tasks and activities that you would like to do into more manageable parts – setting achievable goals of activity intensity or time rather than trying to get everything done all on the same day.

Pacing can be an **essential tool if you are having a flare** to enable you to complete basic tasks and work without you feeling worse.

Basic principles to follow:

- Look at your jobs/activities for the day / week – which ones are essential and which ones can be left for another day
- Can you give a job to somebody else to do
- Have rest breaks whilst doing, and in between activities
- Only do activities for 30 – 40 minutes
- Consider doing an activity across 2 days i.e.: mow half of the lawn on one day and half the next day

Posture control

Maintaining a good posture is an essential element of managing your condition make it part of your every day life: home, work, driving.

Pain experienced in the spine from your condition can result in you rounding your shoulders and upper back. This in turn can then lead you to lose the natural inward curve at the lower part of your back and cause your hips to become more flexed – poor posture.

Poor posture can result in:

- Increased pain
- Loss of movement i.e.: the ability to raise your arm up to a high shelf, to look over your shoulder, to take a deep breath in

To ensure you are maintaining a good posture:

- Ensure you are keeping good posture of the spine when you are sitting, walking, standing and lying
- If you work at a computer, ensure it is positioned at the correct place and level – request an ergonomic assessment from your employer
- Exercise regularly to strengthen postural muscles and prevent shortening in muscles that may encourage a rounded posture

Know your Cardiovascular risk

Research has shown that patients with Ankylosing Spondylitis have an increased risk of developing Cardiovascular disease and having incidents such as heart attacks or strokes.

Attending annual Cardiovascular risk assessment (with your GP or at your annual Rheumatology review) is important.

As you already have increased risk, reducing all of your Cardiovascular risks is essential. The following Self-Management actions need to be considered:

- Maintaining a healthy blood pressure level
- Eating a healthy diet
- Maintaining a healthy weight
- Exercising regularly to improve your Cardiovascular fitness
- Stopping smoking (if applicable)
- Controlling / reducing stress levels

Blood Pressure

This result tells how hard the heart has to work to move the blood around your body

Healthy Range 140/80 or less

The following actions can help you to maintain a healthy blood pressure:

- Regular Cardiovascular exercising
- Healthy Eating – less salt, less saturated fat, 4-5 portions of fruit and vegetables a day
- Limiting alcohol intake: 3-4 units for men and 2-3 units for women per day
- Stop smoking

Cholesterol levels	Smoking
<p>Raised levels of some lipids (“bad fats”) in the blood are seen in people with Ankylosing Spondylitis.</p> <p>Key actions that you can take to reduce your cholesterol levels include:</p> <ul style="list-style-type: none"> • Eating a healthy diet • Remaining physically fit • Reducing your weight (if you are over weight) • Stopping smoking • Reducing your alcohol intake <p>Assessment of your cholesterol levels should be undertaken by your GP. If your levels are outside of the normal ranges in some cases medications may be prescribed and should be taken in conjunction with the Self-Management actions stated above. Regular review of your cholesterol levels with you GP should be organised.</p>	<p>Smoking increases cardiovascular risk. Smoking when you have Ankylosing Spondylitis can result in worse disease activity, poor functional ability, worse pain and poor quality of life.</p> <p>When giving up smoking people have more success when they use supplementary interventions i.e.: chewing gum, inhalers, patches or prescribed medicines. This success is enhanced further by accessing a support programme at the same time.</p> <p>To help you stop smoking: Contact your GP to ask about products to reduce nicotine cravings</p> <p>Contact sources of support: NHS smoking helpline 0800 169 0169 www.NHS.UK/GOSMOKEFREE</p>

Cardiovascular Exercise

Current recommendations state that adults should be completing the following level of exercise to maintain a good healthy cardiovascular system ie: efficient working heart and lungs

Moderately intense exercise - 30 minutes, 5 times a week

Moderately intense exercise means working at a level that makes your heart rate increase slightly or makes you slightly short of breath.

Considering you do not want to make any pain from your Ankylosing Spondylitis any worse, some exercises you might consider are: swimming, fast or power walking, cycling, stair climbing

IF YOU FEEL UNWELL WHILST EXERCISING - STOP AND SEEK MEDICAL ADVICE

Diet & weight

No robust research has been produced to say that certain foods can effect Ankylosing Spondylitis.

If you feel your food does affect your symptoms for better or for worse try keeping a food diary to record how you feel when you have eaten certain foods and see if there is a pattern to your symptoms

Overall advice for patients with Ankylosing Spondylitis remains the same:

- Eat a healthy balanced diet
- Reduce foods high in fat / sugar
- Eat more fruit, vegetables, pasta, rice and bread (wholegrain is best)

Maintaining a healthy weight is essential to ensure that you are not putting extra burden on joints which may lead to you experiencing more pain.

If you are over weight discuss this with your doctor or nurse as they will be able to advise you about safe ways to lose weight

Calculating your Body Mass Index (BMI) (the amount of fat in your body relative to your height) is another way of measuring if you have a healthy weight

Medication

The medications prescribed for Ankylosing Spondylitis varies from person to person depending on the severity of their condition, the presenting symptoms and other medical conditions that they may have – what works for one does not always work for another.

Medication is not an alternative to exercise – often medication is used to reduce your pain which in turn will enable you to exercise.

Medications for your condition can include:

- Analgesia
- Non steroidal anti-inflammatories
- Anti-TNF therapy

Take your medications only as directed by your doctor or nurse.

Ensure that you have medications in case you have a flare

Request your repeat prescriptions in plenty of time – never allow your medication to run out.

Have a supply of medication to cover any holidays.

If you have any questions about your medications, contact your GP, Rheumatology Nurse or Pharmacist.

Pain

Not all people with Ankylosing Spondylitis present with the same location, frequency, intensity or duration of pain. Some have mild ongoing pain, some have gradually increasing pain, others will have episodes of intense pain and then be relatively pain free for a period of time – everybody is different. It is not possible to predict who will experience what pain levels.

Self-Management actions to reduce or control your pain levels include:

- Taking your medication as prescribed (if applicable)
- Keeping a good posture
- Exercising regularly
- Pacing your activities / work
- Minimising stress levels

Have a dedicated time to practice relaxation techniques each day.

Use of TENS machines and ice or heat packs can prove effective.– if you have not used these before you should seek guidance from a Physiotherapist prior to use.

It is essential to remember that not all pain is “harmful”. A level of discomfort as you exercise is expected but this will not be causing you physical harm if you are performing the correct exercise in the right way and at the correct level.

Anxiety and Low mood/ Depression

Having a raised level of anxiety or depression is a common feature of inflammatory conditions such as Ankylosing Spondylitis.

Many factors can contribute to the symptoms of anxiety and depression including:

- Having a diagnosis of a long term condition
- Pain levels
- Fatigue levels / reduced sleep
- Loss of functional independence
- Reduced ability to work / remain productive at work

Actions can be taken to reduce the symptoms you may be feeling:

- Consider counselling to help you to come to terms with your diagnosis / current state
- Contact your GP for advise on effective medications
- Exercise regularly – this can help the body produce its own painkilling chemicals and give you a sense of well being
- Talk to family and friends – let them know how you are feeling and that it can be part of your condition

Eye Involvement

As you have Ankylosing Spondylitis you are at more at risk of developing inflammation of the eye – this is most commonly referred to a Uveitis or Iritis.

As all people are different you may never experience an episode of inflammation of the eye, whilst others have repeated episodes of the condition.

Being able to recognise the signs and symptoms of Uveitis / Iritis is essential as repeated episodes of the condition can lead to permanent eye damage including cataract or glaucoma.

Signs and symptoms:

- Sudden onset of pain
- Sensitivity to light
- Redness of the eye
- Blurred vision

Urgent medical attention is required if you have any of the above symptoms:

Contact the emergency eye department – inform them of your diagnosis and your symptoms.

Bowel Involvement

Inflammation of the bowel – Colitis or Crohn's Disease has a strong link with Ankylosing Spondylitis.

It is important to remember that not all people with Ankylosing Spondylitis develop either of these inflammatory bowel conditions. However recognising the signs and symptoms of the conditions is essential to allow early diagnosis and treatment.

Signs and symptoms of Crohn's Disease:

- Diarrhoea
- Abdominal pain
- Fatigue

Signs and Symptoms of Colitis:

- Bloody diarrhoea
- Abdominal pain
- A frequent need to go to toilet
- Weight loss

If you display any of the above symptoms you must seek medical review with your GP or Rheumatologist.

Referral to the Gastroenterology team may be required (a medical team who deal with your bodies digestive system)

Skin Involvement

In some cases people with Ankylosing Spondylitis may develop Psoriasis – a condition that sees abnormally rapid production of skin cells. This condition causes red flaky skin to appear as well as crusty patches or silvery scaly patches of skin. Some people also experience some level of itching or burning sensation.

This condition is not infectious i.e.: can not be passed onto anybody through contact and is not life threatening. People can have varying levels of the condition.

Common places to develop Psoriasis include: elbows, knees, scalp and low back.

If you display symptoms of Psoriasis seek medical review with your GP. A referral to the Dermatology team may be required (a medical team who deal with your bodies skin)

Bone Health

People with Ankylosing Spondylitis tend to have more fragile bones than those of the same sex and age who do not have the condition. This lower bone mineral density can develop into Osteoporosis meaning you are more susceptible to breaking a bone (a fracture).

To reduce your risk of Osteoporosis:

- Eat a healthy diet including foods high in calcium
- Reduce your alcohol intake
- Stop smoking
- Ensure you remain active and include low impact weight bearing or specific strengthening exercises in your weekly regime

Common sites of fracture in people with low bone density or Osteoporosis include the spine, wrist and hip.

Even if you experience no pain at the time, if you are involved in a minor car accident (i.e.: somebody shunts your car) or you have a fall even from a low height i.e.: from standing – **you must seek medical review as you may have a fracture of the spine.**

Living with Ankylosing Spondylitis

Exercising with Ankylosing Spondylitis

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Exercising with Ankylosing Spondylitis

Exercise

Exercise is a key element of managing your condition.

Its benefits include:

- Increased strength in postural and core that will help you keep an upright posture
- Increased mobility in joints that will enable you for example to reach your arm up high or look over your shoulder
- Maintenance of good balance, reducing your risk of falling
- Decreased pain levels
- Improved fatigue levels
- Improved cardiovascular fitness

Start slowly and build up - remember you may vary from week to week on what you can tolerate

Try to exercise daily but remember you can use some activities of your normal day as exercise i.e.: take the stairs instead of the lift

Ensure over the course of a week your exercise regime covers all the elements below:

- Stretching / flexibility for your muscles
- Strengthening for extensor muscle groups
- Mobility for your joints
- Postural / core strengthening
- Breathing exercises
- Cardiovascular fitness
- Weight-bearing exercise for bone health
- Balance exercise

Exercising with Ankylosing Spondylitis

If I had to choose one exercise?

Swimming

It gives you a good cardiovascular work out, moves your joints and strengthens you all in one exercise. It works you hard without the weight bearing that may irritate your condition when performed to the same level on land

BUT

Good technique is essential to ensure you do not swim with your neck in an extended position

NEW TO EXERCISE? ENSURE YOU SEEK ADVICE FROM A PHYSIOTHERAPIST BEFORE COMMENCING ANY EXERCISE

One piece of recommended exercise equipment?

Gym ball / Fit ball

- Relatively cheap
- Idea for use at home
- Can be accessed daily
- Can help to move your joints, strengthen, work your postural control / core and stretch you.

Ensure you are measured for the right sized gym ball before you buy it

Always look for "anti-burst" logos before you buy a ball

Can I do "normal" gym and community classes? **YES!**

Classes / exercises to consider:

- Yoga
- Pilates
- Tai chi
- Spinning
- Water aerobics
- Nordic walking
- Body balance
- Body pump.....

The only sports to avoid are contact sports i.e.: rugby, kick boxing etc. Some caution should be taken with rackets sports as they involve bending and twisting at speed

My Exercise and Activity record for Ankylosing Spondylitis

Week beginning	Exercise forms completed (walking, yoga class, spinning class, swimming, stretching at home)	Length of time exercise performed	Enjoyment rating (score 0 – 10) 0 = not enjoyable 10 = extremely enjoyable

Living with Ankylosing Spondylitis

Monitoring your Ankylosing Spondylitis

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Monitoring your Ankylosing Spondylitis

BASMI – A measure of spinal and hip movement. Scored out of 10. The closer to 10 the more restricted you are due to your condition.

BASDAI - A measure of disease activity. Scored out of 10. The closer to 10 the more active your condition is.

BASFI – A measure of functional ability. Scored out of 10. The closer to 10 the more functionally restricted you are due to your condition.

BASG – A measure of overall coping ability. Scored out of 10. The closer to 10 the greater impact your condition is having on your ability to cope.

ASQOL – A measure of quality of life. Scored out of 18. The closer to 18 the less quality of life you have due to your condition

Work Instability – A measure to assess your ability to remain at work and be productive at work. Scored out of 20. Scores above 12 may require further investigation or access to support to enable you to remain working

ESR – A measure of inflammation in the body which can indicate your disease is more active.

CRP – A measure of inflammation in the body which can indicate your disease is more active.

Date and time							
BASMI							
BASDAI							
BASFI							
BASG							
ASQOL							
Work instability							
ESR							
CRP							
Weight							
BMI							
BP							

Date and time						
BASMI						
BASDAI						
BASFI						
BASG						
ASQOL						
Work instability						
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Weight						
BMI						
BP						

Date and time						
BASMI						
BASDAI						
BASFI						
BASG						
ASQOL						
Work instability						
ESR						
CRP						
Weight						
BMI						
BP						

My clinic visits - general notes

Date:	Comments:

My clinic visits - general notes

Date:	Comments:

Monitoring your Ankylosing Spondylitis

Ankylosing Spondylitis drug:		Start date:
Review date	Dose taken	Overall effectiveness of drug (score 0 – 10) 0 = not effective 10 = extremely effective

Ankylosing Spondylitis drug:		Start date:
Review date	Dose taken	Overall effectiveness of drug (score 0 – 10) 0 = not effective 10 = extremely effective

Ankylosing Spondylitis drug:		Start date:
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Living with Ankylosing Spondylitis

Sources of Support and Resources

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Solent NHS Trust

and

Portsmouth National Ankylosing Spondylitis Society Group

Sources of Support and Resources



National Ankylosing Spondylitis Society

Unit 0.2, One Victoria Villas, Richmond Surrey TW9 2GW

Helpline - 0208 948 9117

Fax - 020 8940 7736

Email - admin@nass.co.uk

Web page- www.nass.co.uk

Where is my local NASS branch?

Portsmouth NASS Group

Activities: Hydrotherapy and gym sessions

Day: Tuesday 18:00 - 19:45 (with 15 minute break)

Venue: Rehabilitation Centre, Queen Alexandra Hospital, Portsmouth, PO6 3LY

Contact: For details on contacting Portsmouth NASS Group, tel 020 9049 117

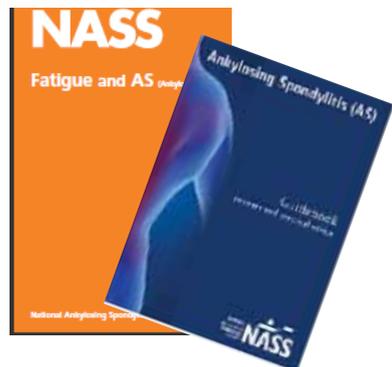
Some of the leaflets / DVD / Phone apps available from NASS include:

Exercise

- Exercise and ASA (leaflet)
- Pilates
- Tai Chi
- back to action (book)
- Back to action (phone app)
- Fight back (DVD)

Symptom Management

- Fatigue and AS
- Uveitis and AS
- TENS machines



Everyday living

- Anaesthesia and AS
- Driving and AS

Sources of Support and Resources



Arthritis Research UK

Write to Arthritis Research UK
Copeman House, St Mary's Gate
Chesterfield. Derbyshire, S41 7TD

Tel: 0300 790 0400

Fax: 0300 790 0401

Web page - www.arthritisresearchuk.org/

Email - enquiries@arthritisresearchuk.org



Arthritis Care

Arthritis Care, 18 Stephenson Way,
London, NW1 2HD

Webpage- www.arthritiscare.org.uk

Telephone- Helpline: 0808 800 4050
(Mon - Fri, 10.00am - 4.00pm)

Other useful websites

www.painconcern.org.uk	Pain
www.action-on-pain.co.uk	Pain
www.bhf.org.uk	British Heart Foundation
www.eatwell.gov.uk	Healthy eating
www.nacc.org.uk	Crohn's and Colitis
www.psoriasisassociation.org.uk	Psoriasis