

Living with axial SpA fatigue

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.

What is fatigue?

Fatigue is one of the major symptoms of axial SpA. Most people with axial SpA experience fatigue at some point. It is one of the most common and perhaps the most difficult symptom of axial SpA to live with.

Everyone gets tired or even exhausted at times, but after a few good nights' rest or a break away they usually feel refreshed. Chronic or long-term fatigue in axial SpA is not like tiredness. It can last for days or weeks at a time and no amount of sleep or rest will relieve it.

Some people describe it as overwhelming.

Fatigue is an overwhelming feeling of exhaustion, both physical and mental.

Fatigue can come on at any time of the day without warning. It can last from a few hours to several days at a time. For some it can persist for weeks or months. It tends to be worse during a flare.

“Fatigue is an overwhelming feeling of exhaustion.”

You may feel:

- It is a different type of tiredness from what you have experienced in the past.
- After sleeping you do not feel refreshed.
- Your fatigue is not due to physical or mental exhaustion.
- Your fatigue is not due to a loss of motivation, which people with depression often experience.
- Heaviness in your body or limbs.
- A lack of energy or feeling completely 'wiped out'. Small tasks can be very difficult.
- Inability to focus or concentrate. Some people call this 'brain fog' and you may find yourself being forgetful.

Here's how some people with axial SpA describe their fatigue.

"The closest thing to pain that doesn't hurt."

"Like all the electricity being turned off."

"I could sleep on the pavement when it hits."

"Just the thought of doing an activity can make me cry and stay curled up in bed."

It can be difficult for others to understand what it's like to live with fatigue. People who experience it often find that others may not be very understanding. Comments you hear might include:

"A good night's sleep will do you the world of good."

"I'm really tired today too. I had a really busy weekend!"

Unless you explain that fatigue is part of your axial SpA, others may not be aware that you have fatigue and what it's like to live with every day.

What we know about axial SpA fatigue

We know up to 75% of people with axial SpA say they experience severe fatigue.

The causes of fatigue in axial SpA are complex and little research has been carried out so it is poorly understood. NASS Members told us that increasing understanding of fatigue was a priority, so we funded a research study.

The research study was called 'WASTED - Understanding and Assessing Fatigue and Energy in Axial Spondyloarthritis'. We were trying to answer two key questions:

What is fatigue in Axial SpA?

How can we measure it?

People who took part in the study told us about the effects of living with fatigue.

They highlighted that fatigue is difficult to live with as it's hard to know how often it will happen, how long it will last and how severe it will be. Fatigue fluctuates and varies between days and weeks, so it is difficult to work around. It's unpredictable.

Fatigue can affect you physically.

It can make your body feel heavy and leaden.

Fatigue can challenge you mentally.

It can affect your ability to concentrate. People describe feeling 'drunk with tiredness'. You may be more forgetful than normal and even following conversations and finishing sentences can be a challenge.

Fatigue can affect you emotionally.

It can make you feel low in mood, worried, anxious and even guilty. It can also make you more snappy and irritable which can affect relationships.

Fatigue can affect your daily life.

It can make work feel more challenging and it can disrupt your social life. You may dread going out as you feel exhausted. You may feel that going out can be too demanding and can make you feel exhausted afterwards.



Fatigue is invisible. You can find it frustrating when people around you don't understand or get it.

This can make you feel isolated and alone. When people do understand and are able to support you it really helps. Having help with small tasks or chores, someone to take over when you are exhausted and someone who is there for you is really important.

Making sense of fatigue is difficult and it can be hard to talk about. But it is really important that you explain how fatigue is affecting your life. Remember people can't support you in living with fatigue unless they begin to understand your experience.

Causes of fatigue

A whole range of different factors can contribute to your fatigue.

Underlying disease process

Researchers and rheumatologists believe the underlying inflammatory process in axial SpA can lead to fatigue.

Researchers have discovered that chemicals called cytokines are found in inflamed tissue. These are similar to the type of chemicals released during viral illnesses such as colds and flu and can cause extreme fatigue.

Low red blood count

Anaemia is often found alongside inflammation. Anaemia is a condition in which you don't have enough red blood cells or haemoglobin to meet your body's needs. Your red blood cells use haemoglobin to carry oxygen around your body in your blood. If you have anaemia, the tissues and organs around your body may not be able to get enough oxygen. This can leave you feeling tired, weak and short of breath.

Pain

There is a strong link between levels of pain and fatigue. Being in constant pain is exhausting and over time it can really wear you down.

We know that, while treatments like NSAIDs and biologic therapy (anti TNF and anti IL 17A) can really help with pain, people are often still left with high levels of fatigue. So, dealing with the pain may well help but it may not be the full answer.

Poor sleep

If you are in pain throughout the night with your axial SpA your sleep is likely to be disturbed. Sleep helps the body recover and repair and restore energy levels. If you can't sleep properly or long enough you will lack energy for the day ahead and feel fatigued. When you're tired, it's easy to start napping during the day and that can make it even harder to sleep at night.

Medication

Some medications can make you feel drowsy and interfere with your concentration. This will make fatigue worse. Medications containing codeine or other opioids and medications such as amitriptyline are most likely to cause these side effects.

Muscles

When you are struggling with pain and stiffness you may find it difficult to exercise. That can lead to weakness of your muscles. This then adds to your fatigue as activity requires more effort and energy. If you aren't careful this can easily become a vicious circle.

Low mood

Living with a long-term condition can be distressing and cause uncertainty about the future. This can lead to low mood which is strongly linked with fatigue. Excessive tiredness can be a symptom of depression. And having axial SpA means you are at higher risk of developing depression in your lifetime.

“The underlying inflammatory process in axial SpA can lead to fatigue.”

Reducing your fatigue

There are no cures or simple treatments which will work to cure your fatigue. The causes of fatigue are complex and, unfortunately, there is currently no easy way to treat the issue.

However, there are plenty of things that can help reduce fatigue and to make it easier to manage.

Talking about it

It's really important to explain to your family, friends and work colleagues that fatigue is one of the symptoms of axial SpA and let them know how it affects you. Perhaps share copies of our guide.

There will always be people who won't understand, even after you have taken the time to explain, but others will take what you say on board and will empathise.

Do think about **when** would be a good time to discuss your fatigue. Many people tell us they tend to put off these conversations until they are struggling with high levels of fatigue and really need help. This may well not be a good time as it's hard to articulate how fatigue is part of your condition when you are exhausted, struggling to concentrate and feeling short tempered.

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

As well as describing your fatigue, do think about asking for help. Explain there's only so much you can do and ask family members to take on some of the jobs around the home. If you are working do talk to your manager about making some reasonable adjustments to your role. Check out our guide to Managing your axial SpA at Work for more information on your rights at work.

Our tips are:

- Don't be afraid to delegate.
- Don't take on any extra tasks that you know you won't be able to do that day.
- Do explain you already have enough to do and either someone else will have to do it or it will have to wait until another day.



Along with family and friends do make time to talk with others with axial SpA about your fatigue. You can chat online in the NASS Forum (www.nass.co.uk) or on our Facebook page. You can also meet with and chat to others at our local NASS branches and NASS events.

If you do feel that living with axial SpA is leaving you feeling anxious and depressed do try to share any worries you have with someone else. It often helps to acknowledge negative feelings and thoughts. We would also recommend going and talking to your GP about how you are feeling. Some people tell us they have benefitted from seeing a counsellor or a psychiatrist.

Medication review

Medications which help to control inflammation, resulting in reduced pain and stiffness, may also help to reduce the fatigue you are feeling. These medications include non-steroidal anti-inflammatory medications (NSAIDs) and biologic medications (anti TNF and anti IL 17A).

However, many people are left with some fatigue, even where the medications have made a significant difference to pain and stiffness.

Some pain medications cause drowsiness and loss of concentration. These tend to contain codeine or morphine.

Do speak to your GP or pharmacist about your medications and ask if any could be contributing to your fatigue.

Pain control

One of the main symptoms of axial SpA is pain and living with ongoing pain can be absolutely exhausting. It's important that your axial SpA is managed as well as possible so your symptoms are under control.

Everyone with axial SpA should be under the care of a rheumatologist. If you are only seeing your GP, do ask for a referral to a rheumatologist who are the experts in managing this condition. If you want more information on the axial SpA services in your area then do check out the 'In Your Area' section of the NASS website.

Your rheumatologist can prescribe a whole range of medications and give advice on managing your pain if your axial SpA flares. If you aren't sure how your axial SpA should best be treated do check out the 'Medications' section of the NASS Website or pick up a copy of the NASS Living Well with axial SpA Guidebook.



Exercise

The right exercise regime can improve strength, flexibility, wellbeing, energy levels and sleep. Ideally you should get advice from a specialist rheumatology physiotherapist.

You can find information on the NASS website about accessing physiotherapy under 'Exercise'. There are also lots of suggestions in this section for getting more active with axial SpA.

Don't forget NASS branches meet weekly for guided physiotherapy sessions. Enter your postcode in the 'In Your Area' section to see if there's a branch near you.

Diet

Both over-eating and under-eating can have an indirect impact on your fatigue.

Eating too much and becoming overweight puts more pressure on your joints and can make carrying out everyday tasks more tiring.

Eating too little (skipping meals, for example) and becoming underweight can reduce your energy. Being hungry is tiring. Having low blood sugar from not eating enough can make you feel tired and muddle-headed.

Keeping up your fluid intake is also important. Dehydration is tiring. Make sure you drink enough during the day.

People with axial SpA are also prone to low iron count (anaemia), which, among other things, causes tiredness and lack of energy. Anaemia is treated with iron supplements and by increasing iron-rich foods in the diet.

Iron rich foods include:

- Dark-green leafy vegetables such as watercress and curly kale.
- Dried fruit such as dried apricots.
- Pulses and beans.
- Nuts and seeds.
- Wholegrains such as brown rice.
- Fortified breakfast cereals.
- Meat.

You can ask your GP to check if you are anaemic. If you are anaemic your GP can prescribe an iron supplement to restore the iron that is missing from your body. Your GP can also advise you on how to include more iron in your diet and may wish to run tests to see why you are anaemic.

A high-angle photograph of a person with dark skin and short hair, wearing blue pajamas, sleeping peacefully on a bed with white pillows and linens. The bed is set on a wooden frame. The lighting is soft and natural, creating a calm atmosphere.

“If you don’t have enough sleep or your sleep is disturbed, it can make fatigue worse.”

A good nights sleep

If you don’t have enough sleep or your sleep is disturbed, it can make fatigue worse.

Sleep helps our bodies to recover, repair and restore our energy levels. Poor sleep will lead to you feeling less energetic and you won’t feel rested which may also affect your mood. Good ‘sleep hygiene’ includes:

- Only go to bed when you feel tired but get up at the same time every day, including weekends, in order to reset your body clock. Do not be tempted to stay longer in bed to ‘catch up’ with sleep.
- Create a relaxing bedtime routine
- Make sure that your sleeping environment is comfortable, not too hot, cold, noisy or light.
- Avoid ‘naps’ through the day if you can.
- Avoid caffeine, nicotine and alcohol late in the day.
- Avoid eating heavy meals late at night.
- Try not to use ‘blue light’ devices such as mobile phones and laptops for at least an hour before going to bed and no TV in the bedroom!

You may find the 15-minute rule helpful.

If you are not asleep within 15 minutes of getting into bed, or within 15 minutes of waking during the night...

- Get out of bed and go somewhere else until you are sleepy.
- Do something unstimulating.
- Return to bed only when sleepy.

You may find that your axial SpA wakes you during the second half of the night especially if you are experiencing a flare of your symptoms.

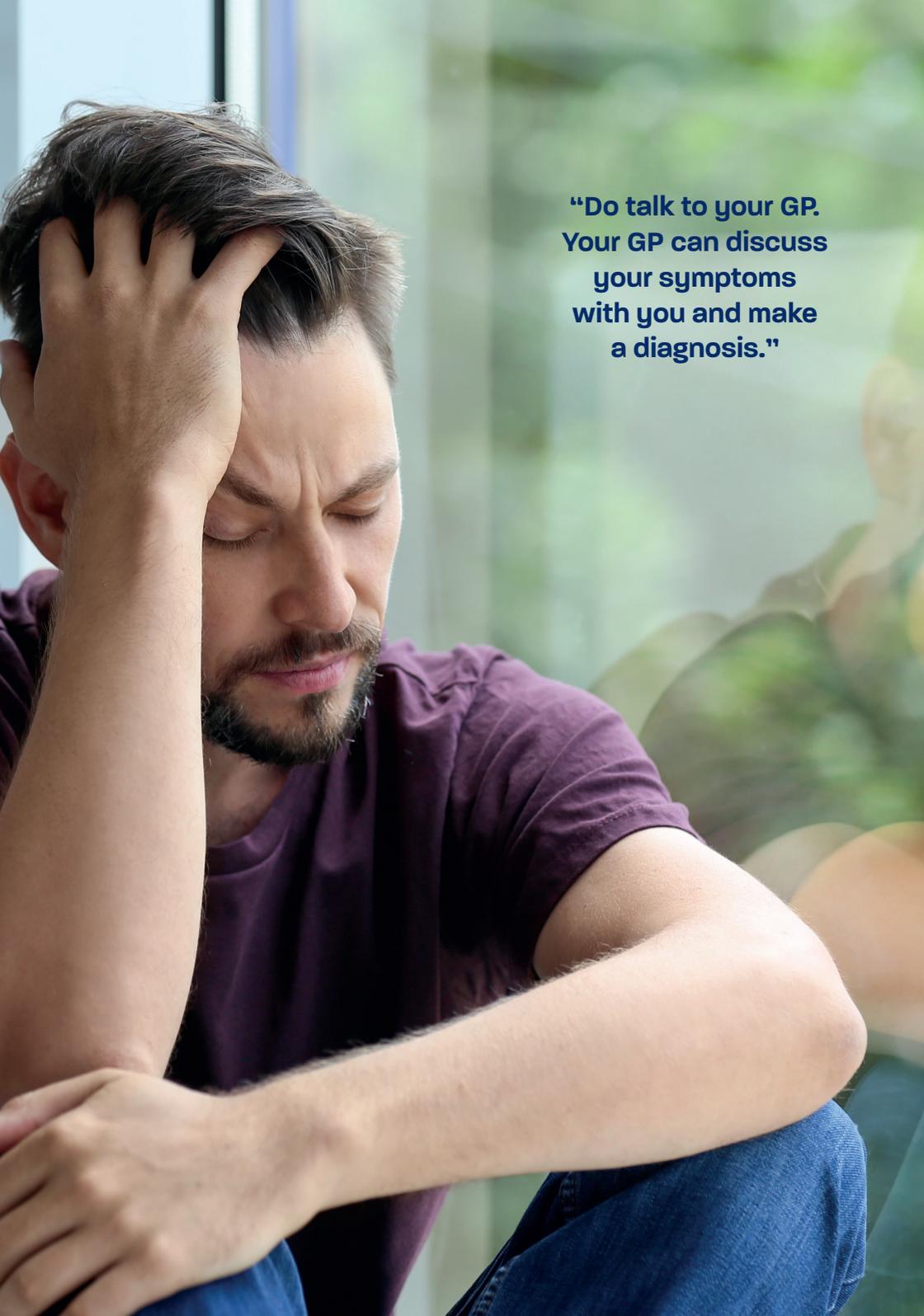
Try getting up and moving around.

Put the kettle on and while you wait for it to boil, do some simple stretches. You don’t even need to make a drink but movement during those few moments can help.

You could try taking a heat pack or hot water bottle back to bed with you to help soothe your muscles.

Talk to one of the health professionals involved in your care if you continue to have poor sleep.

“Sleep helps our bodies to recover, repair and restore our energy levels.”



**“Do talk to your GP.
Your GP can discuss
your symptoms
with you and make
a diagnosis.”**

Low mood

Managing everyday life with axial SpA can be very challenging. It can be hard to balance well-being and mood when you are experiencing pain, fatigue and disturbed sleep. This can make the stresses of daily life harder to deal with and lead to low mood.

Depression is a low mood that lasts for a long time and affects your everyday life.

Symptoms of depression can include:

- Low mood lasting two weeks or more.
- Not getting any enjoyment out of life.
- Feeling hopeless.
- Not being able to concentrate on everyday things.
- Comfort eating or losing your appetite.
- Sleeping more than usual or being unable to sleep.
- Feeling tired or lacking energy.

It's worth considering if some of your fatigue might be related to low mood or depression.

Do talk to your GP. Your GP can discuss your symptoms with you and make a diagnosis.

If you are diagnosed with depression, do make sure your GP discusses all the available treatment options with you, including anti-depressants. There are also many effective psychological approaches available including:

- Cognitive behavioural therapy.
- Mindfulness intervention.
- Relaxation/meditation.
- Exercise regimes prescribed by your physiotherapist.
- Stress management.
- Motivational interviewing.

Pacing and prioritising

Pacing is about balancing activity and rest to help learn to manage your fatigue.

Pacing yourself when you're struggling with fatigue might sound like common sense, but working towards an effective pacing programme isn't always easy. It requires a good understanding of the principles of pacing, combined with commitment to making them work for you.

You may be trying to cram in as much activity as you can in the morning then sleeping during the afternoon to recover. Pacing helps you to break this habit.

Pacing discourages you from resting too much through the day and then attempting a burst of activity later in the afternoon or evening.

Pacing can help you to take control of your axial SpA fatigue.

What is pacing?

Pacing means spreading out activity and alternating it with rest periods so that you are able to continue for longer.

It's not about doing less but spreading out the things you want to do in a day or week so you can achieve them more easily.

Getting started

Tracking your fatigue with a diary or an app can be helpful to start to recognise the pattern of how fatigue is affecting your life. It will help you to see when your fatigue is likely to affect you, and how long it tends to last.

You may recognise how a poor night's sleep or busy day make things worse and also see when your best time to rest and your best time to be active are.

Key elements

The key elements of pacing are:

- Taking regular rest periods.
- Spreading activities throughout the day.

Pacing is based around the 'Three P's'

Planning your activity in advance.

Prioritising your tasks for the day.

Pacing – breaking down your activity by having regular rest periods.

Little and often is key. Some examples of pacing include:

Cooking

- Planning meals means you can break down the task into manageable chunks.
- You can sit to prepare the meal, take a rest, cook the meal, then rest before clearing up.

Washing and dressing

- Think about sitting rather than standing when washing or shaving.
- Organise your toiletries so that everything is within easy reach.
- Consider a towelling dressing gown to save energy drying your body with a bath towel.
- Have your clothes within easy reach and get dressed while sitting.

Resting

Good quality rest periods are essential in pacing.

Everyone is different, so the time you need to rest will depend on what works for you. Some people find it works best to take frequent

10-minute breaks, while others prefer to take breaks of 30 minutes or an hour spread less frequently over the day.

How you prefer to spend your rest periods is also very individual.

You may find it useful to practice relaxation techniques or mindfulness. Find a quiet space where you can use breathing techniques to help you relax.

You may prefer to lie down and maybe have a short nap, or just want to sit quietly and read a book or magazine or listen to music or the radio.

There are no right and wrong answers to resting, it's about finding out what works for you.

Boom and Bust



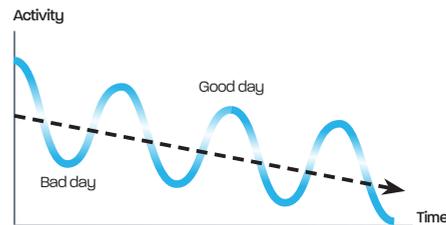
Peaks = a good day Troughs = a bad day

It's vital to avoid the cycle of boom and bust.

Peaks can happen when you are having a good day. When you have a good day, you might want to fit in all those jobs and activities you haven't been able to get around to. This can mean you overdo it and the next day you are left completely wiped out and exhausted.

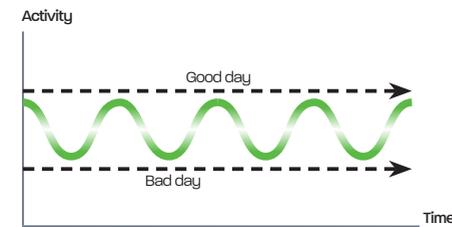
You will feel forced to rest, then the next day you are revitalised and want to catch up on everything you missed. That leads to another peak and so the cycle of boom and bust continues.

The cycle of this up and down is unhelpful. It's unpredictable and stops you being able to plan ahead. Having to always wait and see how you feel can undermine your morale and limit your ability to maintain activities that require a level of commitment.



This pattern of boom and bust also slowly reduces your fitness and energy reserves, meaning your problems of fatigue can gradually take over.

An even level of activity will help you restore control. It will allow you to plan ahead, build up fitness and energy reserves and boost your morale.



It's better to aim to **do less than you think you can on a good day** and **more than you think you can on a bad day**.

Remember it's about achieving a balance.

Planning

How you will get things done.

Prioritising

Deciding what's important, including rests and treats.

Positive

Mental attitude, you can control your thoughts and attitudes.

Patience

In trying to climb that mountain.

Persevere

When there are difficulties or setbacks.

Participate

And have a go, even when you don't really feel like it.

“Do less than you think you can on a good day and more than you think you can on a bad day.”

Megan's story

I find the consistent thing about having axial SpA, is the inconsistency. Every day is different and unpredictable, so it is important to learn and understand what your body best responds to.

When I have days where I am in a lot of pain or extremely fatigued, I call them Spoonie Days. This helps my family and friends understand what I am feeling.

Living with axial SpA can be extremely difficult, but I think it is really important to push through and not let it control what you want to achieve each day or throughout life - using the pain as your power.



Keeping a fatigue diary

Keeping a fatigue diary can be a very effective way of understanding your fatigue.

We have included some fatigue diaries to help you see how your week might be contributing to your fatigue and help you start to think about changes you can make.

Each diary covers a week and the idea is that you colour in the boxes over the week to indicate whether you mainly spend that hour in:

● High energy activity

This might include work, commuting or travelling, activity like walking, cycling or running and anything else you find especially tiring. This will vary from one person to another. You might find cooking a high level activity or it could be low level. It may also vary according to what you are cooking or who you are cooking for.

● Low energy activity

This might include reading, eating, games and puzzles or chatting.

● Rest and relaxation

This might include listening to music, relaxation techniques or anything that you find particularly restful in your day.

● Sleep

Once you have completed the first week, look back at your activity patterns. Do you have long periods of high energy activity? Is there a way you could start to break up your high energy activity with low energy activity or rest and relaxation?

If you find these diaries useful you can download and print more from www.nass.co.uk/resources.

Week One

Year	AM												PM											
	00	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Mon																								
Tues																								
Wed																								
Thurs																								
Fri																								
Sat																								
Sun																								

Week Two

Year	AM												PM											
	00	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Mon																								
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Sat																								
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● High energy activity ● Low energy activity ● Rest and relaxation ● Sleep

Week Three

Year	AM												PM											
	00	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
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Week Four

Year	AM												PM											
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Sat																								
Sun																								

● High energy activity ● Low energy activity ● Rest and relaxation ● Sleep



Axial SpA
works silently.
We don't.

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.

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!

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)

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

Acknowledgements

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