

Your SpAce resources



Welcome to Your SpAce. Here we build skills together to live life with axial SpA. This booklet contains resources you can use alongside our Your SpAce videos to create your personalised plans.

To watch the videos, scan the QR code or visit <https://nass.co.uk/about-as/your-space/>

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Join our free friendly online meetups to connect with other people with axial SpA, share ideas, and get support.

Visit <https://nass.co.uk/about-as/your-space/meetups> or scan the QR code for more information.

<https://nass.co.uk/about-as/your-space/>

My symptom diary

What is a symptom diary?

A symptom diary is a written record of how your axial SpA is affecting you. You can track your symptoms over time. The diary is also a place to record what affects your symptoms – any triggers or anything that helps.

Why should I keep a symptom diary?

A symptom diary can help you:

- Look back over time to understand how your axial SpA has been affecting you.
- Prepare for appointments with your healthcare professionals.
- Identify possible triggers for your symptoms.
- Understand what can help your symptoms – you can build this into your flare toolkit.
- Understand how your condition impacts your mood. You can develop a toolkit to look after your emotional wellbeing.

How do I complete a symptom diary?

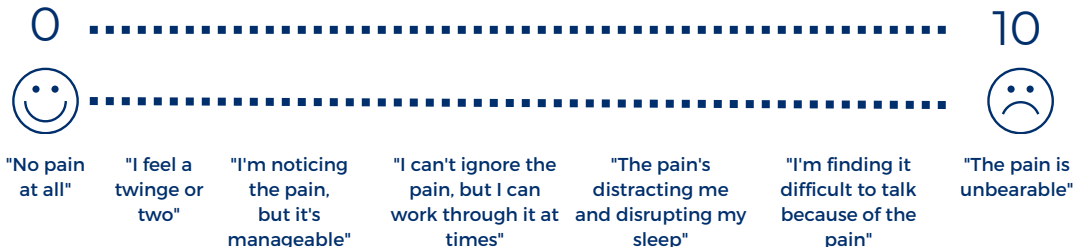
Fill in the symptom diary when you experience symptoms of your axial SpA. It can be helpful to do this daily for a few weeks to understand how your condition is affecting you. Only fill in the sections that apply to you at the time.

It can be helpful to keep a diary when starting a new treatment or activity. This can help you understand if the new treatment or activity is helping.

Severity scale

What is a severity scale?

The severity scale is to record how severe a symptom is. It's on a scale of 0 (none) to 10 (the worst ever). For example, for pain it may look like this:



My symptom diary

Date, day of the week and time	Symptom name/ location	What does it feel like?	Severity 0-10	How long did it last?	Any triggers?	Anything ease it?	How did it impact activities or sleep?	How did it make me feel emotionally?	What helped with the emotions?

My axial SpA flare toolkit

How should I use this sheet?

Keep this sheet somewhere you can easily access and remember. When you feel an increase in your axial SpA symptoms, you may be experiencing a flare. Use this sheet to remind you what can be helpful to manage your symptoms.

Where can I record my medication?

You can record medication you usually take and what you can take during a flare on our medication resource sheet.

Who can help me complete this sheet?

Ask your healthcare professionals to help you fill in this sheet. This can include your rheumatologist, rheumatology nurse, physiotherapist, occupational therapist, GP, or another healthcare professional you see for your axial SpA.

Ask your rheumatologist if they have a helpline that you can call for advice between appointments. Record the contact details and when you should contact them.

	Good day	Okay day	Bad day
<p>What self care techniques help me? E.g. heat, cold, massage, TENS...</p>			
<p>How can I better prepare for sleep? E.g. pain medication, hot bath, avoid screens, gentle stretches...</p>			
<p>What activities usually help me during a flare? E.g. walking, bed stretches, swimming, activity little and often...</p>			
<p>How can I look after my emotional wellbeing? E.g. reading, crafts, walking, breathing exercises, distraction...</p>			



Axial SpA
works silently.
We don't.

Who can I speak to for support?

E.g. friends and family, other people with axial SpA, mental health professionals for talking therapies...

When should I contact my healthcare professionals?

E.g. my self-care techniques aren't helping my flares, I have a question about my medication...

Name of healthcare professional:

Telephone number:

Notes:

Name of healthcare professional:

Telephone number:

Notes:

Notes:

Prioritising tasks

Why can it be helpful to prioritise tasks?

When you experience persistent pain or fatigue, it can be overwhelming trying to complete tasks. Prioritising tasks can help you plan how you will use your energy. It can also help you find tasks that you could remove, postpone, or ask for help with.

It's important to remember that almost everyone can benefit from prioritising tasks and planning how they spend their time – postponing or cancelling tasks can feel difficult, but it is important for your wellbeing.

How do I use this resource sheet?

Tasks can be split into different categories:

- Whether they need to be completed soon – are they urgent or not urgent?
- How important they are – are they important or not important?

Sit and think of one task at a time. As yourself, “how important is this task?” and choose which category. Then, ask yourself “how urgent is this task?”

Once you've decided, you can place it in the appropriate box. Repeat for all your tasks on your to do list or in your head. Once you've completed it, you can take action...

DO: Tasks that are important and urgent.

Prioritise these tasks first. You can still pace your energy by breaking them down into smaller steps and adding rest breaks.

DECIDE: Tasks that are important, but not urgent.

Can you plan these into your schedule for when you have more time and energy?

DELEGATE: Tasks that are urgent, but not important.

Who can you ask for help? Can someone else do this task for you?

DELETE: Tasks that are not important and not urgent.

Do they really need doing? Can you remove these from your list to take some pressure off yourself? If you do remove them, don't feel guilty – saying no is good self-care.

	Urgent	Not urgent
Important	Urgent and important = <u>do</u>	Important, not urgent = <u>decide</u>
Not important	Urgent, not important = <u>delegate</u>	Not important, not urgent = <u>delete</u>

My restful activities

Why should I use this sheet?

Stress causes our body to release hormones, such as cortisol. Stress hormones can cause muscle tension, create inflammation, and make us more sensitive to pain. Taking time to rest and relax can reduce stress and the physical impact it has.

Everyone can benefit from taking time to relax, but it's especially important for people who live with inflammatory conditions, such as axial SpA.

You can use this sheet alongside your flare toolkit.

When should I look at this sheet?

This sheet will remind you of different activities you enjoy that help you relax.

Look at this sheet:

- When you're experiencing a flare of pain or fatigue
- If you're experiencing low mood
- Regularly to check whether you have taken time for yourself recently



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What activities do I find relaxing?

E.g. gardening, cooking/baking, walking, swimming, being in nature...

What restful activities do I find relaxing?

E.g. reading, crafts, writing, speaking to friends, time with pets...

These are useful when you're experiencing fatigue.

How should I use this resource sheet?

This sheet helps you to make decisions about medications that are right for you. Use information provided by your healthcare professional to complete the sections, helping you to weigh up options.

It's important to list the potential benefits/pros and what the medication would be aiming to help.

Make a note of any questions for your healthcare professional. This may include:

- How long it takes to get an improvement
- Any monitoring tests required
- Potential side effects
- Anything you need before starting the medication (e.g. tests, vaccines)
- Potential considerations if you're planning to start a family

Who can help me complete this record?

Ask your healthcare professional to help you fill in this sheet. This could be your rheumatologist, rheumatology nurse, GP, pharmacist, or another healthcare professional you see for your axial SpA.

Where can I learn more about medications for axial SpA?



For detailed information about medications used to treat axial SpA, scan the QR code or visit <https://nass.co.uk/managing-my-as/medication/>

<https://nass.co.uk/about-as/your-space/>

Making medication decisions

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Use this resource sheet to help you make decisions about your medication options.

What issues(s) are you looking to improve?

What medications are under consideration?

Potential pros

Potential cons

What questions do you have? What do you need to ask your healthcare professional?

Tracking medication

Use this resource sheet to track when you take medication. Print copies as many times as needed.

Date	Time	Name of medication	Dose	Next due?	Any side effects	Notes

My medication record

How should I use this record?

This sheet can help you keep track of your medications. It's important to understand what each medication is for and how to take it.

You can use the second table to record medications prescribed to help you during flares. Keep this record to hand and use alongside the flare toolkit.

Who can help me complete this record?

Ask your healthcare professional to help you fill in this sheet. This could be your rheumatologist, rheumatology nurse, GP, pharmacist, or another healthcare professional you see for your axial SpA.

Healthcare professional contact details

Name and telephone number:

Notes:

Name and telephone number:

Notes:

My usual medication

Name of medication	Dose	How often can I take this?	How long can I take this for?	What is this medication for?	Who prescribes this?	Notes

Medications for my flares

Name of medication	Dose	How often can I take this?	How long can I take this for?	What is this medication for?	Any medications I <u>cannot</u> take at the same time?	Any medication I <u>should</u> take at the same time?	Who prescribes this?

Navigating appointments

With limited time in appointments, it's important to prepare for them to get the most out of them. Remember, medical appointments should be a two-way conversation with your healthcare professional. It's an opportunity to make decisions together to manage your axial SpA and the impact it has on your life.

How should I use these resource sheets?

Use the first sheet to prepare for an appointment. Take your time completing it, as thinking things through in advance can help you get the most out of your appointment.

Some things to remember:

- Have you completed any forms or questionnaires sent by your healthcare team?
- To help describe your symptoms, refer back to the pain scale in the symptom diary toolkit
- You're welcome to take a friend or family member with you to your appointment

Use the next resource sheet to keep a note of your priorities for the appointment, so you cover what you need. You can also take essential notes during the appointment, but your healthcare professional should send a summary of the appointment to you afterwards.

If you need to take time reflecting after an appointment, use the third sheet to help you do this.

It's helpful to reflect back on completed sheets to help you prepare for future appointments.

Preparing for an appointment - 1

Date and time
Name and title of healthcare professional (s)
List of current medication
How has your axial SpA been since your last appointment?
What's been going well? Any positive changes?
Any changes to your general health since your last appointment? (Scans, blood tests, operations, other symptoms?)

Preparing for an appointment - 2

What have you been doing to manage your symptoms?

How have your axial SpA flares been? (How often, how severe, improving/worsening, any triggers?)

Anything to consider? (E.g. planning to start a family, life changes coming up...)

If you could change one thing about your axial SpA today, what would it be?

Do you have any questions you would like to ask in your appointment?

Using your responses in the spaces above, what are your top 2-3 priorities for today's appointment? Put these into the 'during the appointment' worksheet

During an appointment -1

What are you hoping to get out of the appointment?

List your top 2-3 priorities to discuss in the appointment (share these with your healthcare professional at the beginning of the appointment)

Use this space to take notes during the appointment

During an appointment -2

What are the next steps for your management or treatment?

What things can you do between appointments to manage your condition/symptoms?

How long until your next appointment? Will it be face-to-face, virtual, or telephone?

Appointment reflection

Feel free to make general notes/reflections here

How do you feel the appointment went?

Is there anything you didn't cover that you wanted to?

Is there anything you'd like to discuss at your next appointment?

Are there other healthcare professionals it would be helpful to see? (E.g. physiotherapist, nurse, occupational therapist, talking therapies...)