

## How does axial SpA (AS) affect you?

Axial SpA (AS) affects every person differently. Use this sheet to help you work out what your school, college or university may be able to offer to help you study while managing your axial SpA (AS). It can be useful to ask your family and medical team to help with this.

What do you find difficult due to axial SpA (AS)? E.g. mornings, sitting, standing long periods, lifting/carrying, concentration/fatigue, particular movements/positions, walking between classrooms, certain sports...

What can you do to limit the effects? E.g. specific seating, moving often (how often?), mobility aids, extra time to change lessons...

What can your educational institution do to help? E.g. different seating, disabled parking, passes to use a lift...

What would you like your teachers/lecturers to know?

How would you like to communicate with your teachers/lecturers about how they're feeling? E.g. regular meetings, email contact, you approach them when you need, one main contact for a 'bad' day...

You can share as much or as little information about your axial SpA (AS) with other students as you wish. What information would you like other students to know (if any)? Who would you like to discuss this with them (if needed)?

Are there any medical professionals you would like to speak to your school/university? E.g. rheumatologist, rheumatology nurse, occupational therapist, physiotherapist...

Now you can fill in the following sheet to give to your school/university, to help you access any assistance you need. There is a simple explanation of axial SpA (AS) for your teachers/lecturers, but it's important they understand how your condition affects you personally.

# **Axial Spondyloarthritis (axial SpA), including Ankylosing Spondylitis (AS)**

## **Information for Educational Institutions**



### **What is Axial Spondyloarthritis?**

Axial Spondyloarthritis (axial SpA) is an inflammatory arthritis, where the main symptom is back pain. Axial SpA is an umbrella term to include Ankylosing Spondylitis (AS), which is when changes to the sacroiliac joints or spine are visible on an x-ray.

Symptoms of axial SpA (AS) usually start late teens to early twenties, with the average age of diagnosis being 24 years of age.

### **Axial SpA (AS) can cause:**

- Back and/or joint pain
- Joint stiffness in the morning, easing with movement
- Fatigue (an overwhelming feeling of exhaustion)
- Inflammation and pain where ligaments attach to bones
- Sometimes it can affect the eyes, causing uveitis
- Sometimes it can affect the bowels, causing Ulcerative Colitis or Crohn's disease

People with Axial SpA (AS) may experience a sudden increase in symptoms, called a 'flare'. Flares can be unpredictable and can occur without any known trigger.

For many people, axial SpA (AS) is an 'invisible illness', which means you can't tell from looking at them that they have this condition or how they are feeling each day.

Management of axial SpA (AS) requires a medical team including a rheumatologist, rheumatology nurse and physiotherapist. This requires frequent hospital appointments for check ups and sometimes treatment.

**For more information about axial SpA (AS), please visit [www.nass.co.uk](http://www.nass.co.uk).**

Student name:

I find these things challenging:

To limit the effect, these things are helpful:

I would like my teachers/lecturers to know:

The best way for me to communicate with my teachers/lecturers about how I'm feeling is:

How much I want other students to know about my condition and who may discuss this with them:

Are there any passes I need that will enable me to access assistance I need without having to repeatedly ask?