

# A Simple Guide to Understanding and Managing Axial Spondyloarthritis (axSpA)



## What is Axial Spondyloarthritis (axSpA)?

AxSpA is a long-term condition that causes swelling and pain in your spine and the joints where your spine meets your pelvis (called sacroiliac joints). It's part of a group of diseases that includes arthritis linked to psoriasis (a skin condition), infections, or bowel problems like Crohn's disease. In the past, when axSpA caused visible spine damage on X-rays, it was called ankylosing spondylitis. Now, we know some people have inflammation that shows up on MRI scans but not X-rays—this is called non-radiographic axSpA.

AxSpA can also cause:

- Swollen fingers or toes (like sausages).
- Pain in your heels or other joints.
- Skin problems (scaly patches from psoriasis).
- Eye inflammation (red, painful eyes, called uveitis).
- Bowel issues (like diarrhea from Crohn's or colitis).

It's more common in people with a gene called HLA-B27, especially in some parts of Africa, but not everyone with this gene gets axSpA. It often runs in families.

## Why is Catching it Early Important?

Finding axSpA early helps prevent permanent damage to your spine, reduces pain, and improves your life. Without treatment, it can make daily activities harder, affect your job, and lower your quality of life. Sometimes, axSpA is missed or mistaken for other issues like fibromyalgia (body-wide pain), back injuries, or even infections like tuberculosis. Doctors need to carefully check to get it right.

## How Do Doctors Figure Out If You Have axSpA?

If you've had lower back pain for more than 3 months, especially if it started before you were 40, your doctor may suspect axSpA. Here's what they do:

**Check for special back pain signs** (called inflammatory back pain):

- It starts slowly, not from an injury.
- It's worse when you rest or sleep but feels better when you move or exercise.
- It wakes you up at night but gets better when you get out of bed.

**Look for other clues:**

- Swollen joints, heel pain, or sausage-like fingers/toes.
- Skin psoriasis, bowel problems, or eye inflammation.

- Family members with axSpA, psoriasis, or similar conditions.
- Back pain that goes away quickly (in 1–2 days) after taking medicines like ibuprofen.

**Run tests:**

- **Blood tests:** To check for the HLA-B27 gene or signs of inflammation (like C-reactive protein, or CRP).
- **X-rays:** To look for damage in the pelvic joints (this might not show up early).
- **MRI scans:** To spot inflammation in the pelvic joints, which is better for catching axSpA early.

Doctors use a checklist (called ASAS criteria) to confirm axSpA. For example, they might diagnose it if you have inflammation on an MRI plus one other clue, or if you have the HLA-B27 gene plus two other clues. They also make sure it's not something else, like a back injury from sports or an infection.

## How Do Doctors Know How Bad Your axSpA Is?

To see how active your axSpA is, doctors use simple tools:

- **ASDAS Score:** Combines your pain, stiffness, and blood test results. It shows if your axSpA is:
  - Inactive (under control, score below 1.3).
  - Low (score below 2.1).
  - High or very high (needs stronger treatment).
  - You can check this score online at: [ASAS Calculator](#).
- **BASDAI Score:** A survey about your pain, stiffness, and tiredness. A score of 4 or higher means your axSpA is active.
- **BASFI Score:** Checks how hard it is to do things like bending or dressing, using a 0–10 scale.

These scores help your doctor decide if your treatment is working.

## How is axSpA Treated?

The goal is to stop pain and swelling, keep you moving, and help you live well. Ideally, your axSpA should be “inactive” (ASDAS below 1.3) or at least “low activity” (ASDAS below 2.1). Here's the plan:

### 1. Team Up with Your Doctors

- **See a rheumatologist:** A doctor who knows axSpA best. They'll guide your treatment and may bring in:
  - Skin, eye, or bowel specialists for related problems.
  - Physical therapists to help you move better.
  - Counselors or social workers for emotional support.
- **Make a plan together:** You and your doctor will choose treatments that fit your life, health, and goals.
- **Learn about axSpA:** A nurse can explain the condition, treatments, and how to stick with them. This helps you feel more in control.

### 2. Live Healthy

- **Exercise:** Moving your body—like stretching, swimming, or walking—reduces stiffness and pain. It's as important as medicine.
- **Stop smoking:** Smoking makes axSpA worse and hurts your health.
- **Join a support group:** Talking to others with axSpA can give you tips and encouragement.
- **Keep working:** If you can, staying at work or doing activities you enjoy is good for your health.

### 3. Medicines

Medicines are tried one step at a time, starting with milder ones:

#### STEP 1: Anti-Inflammatory Medicines (NSAIDs)

- **Examples:** Ibuprofen, naproxen, or similar drugs.
- **What they do:** Reduce pain and swelling. Most people feel better in a few days.
- **How they're used:** You take the highest safe dose for 2–4 weeks. If it doesn't help, you try a different one.
- **Watch out:** These can upset your stomach, raise blood pressure, or affect your heart or kidneys. Your doctor might give you a stomach-protecting pill or choose a safer option. If you can't take NSAIDs, painkillers like paracetamol might be used.

#### STEP 2: For Arm or Leg Joint Pain

- If you have swollen joints outside your spine (like in your knees or hands), a medicine called sulfasalazine can help.
- Other drugs like methotrexate are rarely used unless nothing else works.
- For skin, eye, or bowel problems, different medicines might be needed (ask about peripheral arthritis guidelines).

#### STEP 3 & 4: Stronger Medicines (Biologics or Targeted Drugs)

- **What they are:** Medicines that calm your immune system to stop inflammation. Examples include:
  - **TNF inhibitors** (like adalimumab or etanercept): Help with spine, joint, eye, and bowel issues.
  - **IL-17 inhibitors** (like secukinumab): Good for spine and skin but not bowels.
  - **JAK inhibitors** (like tofacitinib): Newer pills for spine and joints.
- **When you need them:** If NSAIDs don't work, and you have:
  - Active axSpA (ASDAS above 2.1 or bad pain for at least 4 weeks).
  - Inflammation shown by high CRP, MRI, or ultrasound.
  - Tried at least two NSAIDs without success.
- **How they're chosen:** Your doctor picks based on your symptoms, other health issues (like infection risks), and whether you prefer shots or pills. For example, some drugs are better if you have eye or bowel problems.
- **Before starting:** You'll get tested for infections like tuberculosis, hepatitis, or HIV. Your doctor will also check your vaccinations and discuss pregnancy plans.
- **Checking if they work:** After 3 months, your doctor sees if your symptoms are better (e.g., ASDAS drops by 1.1 or more). If not, they might try a different drug.
- **Easing off:** If you're symptom-free for 6 months (ASDAS below 1.3 and normal blood tests), your doctor might lower the dose slowly. Stopping completely often causes symptoms to come back.

#### Steroids

- Steroid pills aren't used long-term because they can cause problems.
- Steroid shots into swollen joints might help, but they're avoided in some spots (like heel tendons) to prevent injury.

## 4. Keep an Eye on Other Health Problems

AxSpA can raise your risk for:

- **Heart problems:** Inflammation and NSAIDs can affect your heart. Your doctor will check your blood pressure and cholesterol.
- **Weak bones (osteoporosis):** AxSpA can make your bones fragile, especially in the spine. Bone scans (DEXA) can check this, but spine scans can be tricky, so wrist or hip scans might be used.
- **Spine fractures:** If your back pain feels different (more like an injury than inflammation), tell your doctor—it could be a fracture.
- **Infections:** You'll be tested for tuberculosis, hepatitis, or HIV before starting strong medicines.
- **Mental health:** Feeling tired, sad, or anxious is common. Tell your doctor if you need help.
- **Other issues:** Weight gain, high blood pressure, or fibromyalgia (extra pain) may need attention.

This guide is based on the South African Rheumatism and Arthritis Association's 2024 recommendations. Talk to your doctor or a rheumatology nurse for more details and ask about patient support groups in your area.

### Key Things to Remember

- **Get checked early:** If you have back pain before age 40 that's worse at night or better with exercise, see a rheumatologist.
- **Work with experts:** A rheumatologist and support team can make a plan just for you.
- **Move your body:** Exercise is a must to stay flexible and reduce pain.
- **Stick with medicines:** Taking your medicines as prescribed keeps axSpA under control.
- **Watch your health:** Regular checkups catch heart, bone, or other problems early.
- **Find support:** Join a group to connect with others who understand axSpA.