

GUIDE TO AXIAL SPONDYLOARTHRITIS



An axSpA Fighter's Long Battle in Pain and Getting an Accurate Diagnosis

My journey with Axial Spondyloarthritis (AxSpA) has been long and arduous. My fight to get an accurate diagnosis and treatment for my condition started 13 years ago but I was only given an official diagnosis of axSpA 3 years ago after 10 years of misdiagnosis and seeing different specialists.

Looking back, I started experiencing bouts of joint pain and stiffness in my fingers where my fingers used to go numb or even became immobile. However, being an investment banker and a workaholic, I hid my hand under the table so that my co-workers or family members wouldn't notice it. I just ignored it or brushed it off, thinking it was just fatigue instead of a serious medical condition. Little did I know that it was actually much more. Over the years, my symptoms worsened with intensified joint pain and fatigue. I developed hematoma on my right thigh and had to be admitted to the hospital. They told me it could possibly be a tumor or cancer. I was then referred to the oncology orthopedic department where I was sent for further tests and prescribed with different medications for a while, but nothing worked. An orthopedic specialist I was referred to told me my hematoma could be rheumatoid arthritis (RA) and prescribed medication to treat RA, but the symptoms persisted.

It was only when I saw a rheumatologist later, I was officially diagnosed with AxSpA. My rheumatologist did a thorough clinical examinations and had me to take a HLA-B27 gene test that came up positive. The HLA-B27 gene test determines if the person carries the gene related to axSpA¹. I was so relieved to finally get a proper diagnosis, after living with pain for 9 years. One part of my fight was over, and I am grateful that I never gave up. However, my journey still continues as there is no cure for AxSpA. But, my lifestyle modification and the medications have helped me live better.

As an active person, I used to swim 75 laps a day, but I can't even do 2 laps now. It takes me longer to get up in the morning with the pain and joint stiffness all over my body. I am also unable to climb or descend the stairs, nor sit on the floor. I have now learned to adapt to my new life so I can be more independent with the help of kitchen aids, support bars, and home modifications due to my limited mobility. To help keep my joints moving, I try to get some exercise and play the piano.

Because axSpA is a condition that doesn't manifest physically, most people including my parents, do not understand why I was unable to take them to their medical appointments. My bosses had very little empathy and would not accommodate my frequent medical leave or doctors' appointments. As a result, I decided to retire early.

As a single mum with 2 grown children, my kids are more protective and constantly remind me to take care of myself better. They are also vigilant and help me on my bad days. My kids, a positive mindset, and a lot of faith have kept me going throughout my journey with axSpA.

My advice to fellow axSpA warriors is to have a bit of patience and faith, visit your rheumatologist regularly and let them know if you notice any progression or more symptoms so you can get an earlier treatment. If you have any back or joint pain, please do not ignore it, but visit a rheumatologist. As someone who has tried different treatments, always be patient and do not be afraid to go for treatment plans as prescribed by your rheumatologist. Don't stop fighting for yourself! You will definitely get better soon!

Fauzanita Rathi Ishak

*By True Complexion**



¹<https://mysporiasis.my/axspa-fighters-long-battle-pain-and-getting-accurate-diagnosis>

Reference: 1. <https://nass.co.uk/about-as/as-facts-and-figures>

What is Axial spondyloarthritis (axSpA)?

- Axial spondyloarthritis (axSpA) is an inflammatory form of arthritis that causes back and sacroiliac joint pain.
 - > Non-radiographic axial spondyloarthritis (nr-axSpA): Where x-ray changes are not present, but inflammation is visible on MRI or you have symptoms.
 - > Ankylosing spondylitis (AS, or radiographic AS): Where changes to the sacroiliac joints or the spine can be seen on x-ray.
- > Did you know?
 - ◆ 10-12% of nr-axSpA patients progress to AS in 2 years.

Here are typical symptoms in axSpA:



Chronic low back pain



Fatigue or tiredness



Back pain at night which wakes you up from sleep



Other disorders in eyes and bowel can be involved

What is associated with axSpA?



Heredity:

AxSpA rarely starts after the age of 45 years and is highly heritable.



Gene:

The major gene that is associated with this disease is human leukocyte antigen (HLA)-B27 gene.



Mechanical stress:

Mechanical strain may contribute both to enthesal inflammation and new bone formation in axSpA.



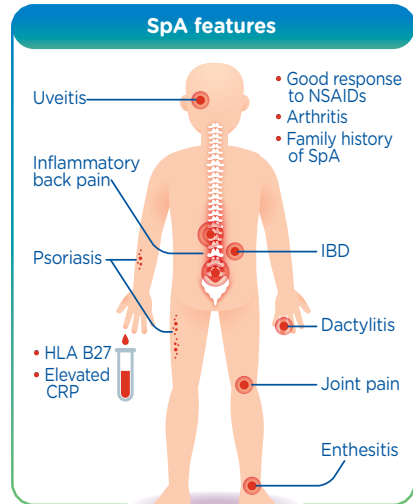
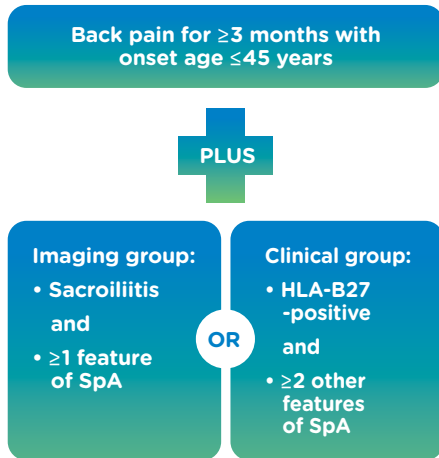
Smoking:

Smoking aggravates axSpA and can speed up the rate of spinal fusion.

How is axSpA diagnosed?

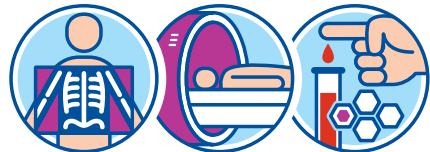
- Diagnosis of axSpA requires comprehensive assessment by a physician based on the patient's medical history, a physical exam, imaging and blood tests.
- Your doctor may refer to ASAS classification criteria for axSpA.

ENTRY CRITERIA



Investigations

- > X-ray or MRI imaging
- > Blood test for inflammatory markers and HLA-B27 gene



- **Self-check:** you may have inflammatory back pain, which is known to be highly associated with axSpA.

How many of inflammatory back pain symptoms would apply to you?

- > Insidious onset of back pain
- > Morning stiffness in the lower back of >30 minutes
- > Improvement of back pain with exercise
- > No improvement with rest
- > Awakening at night or in the early morning because of back pain
- > Alternating buttock pain

Clarrio IBP module



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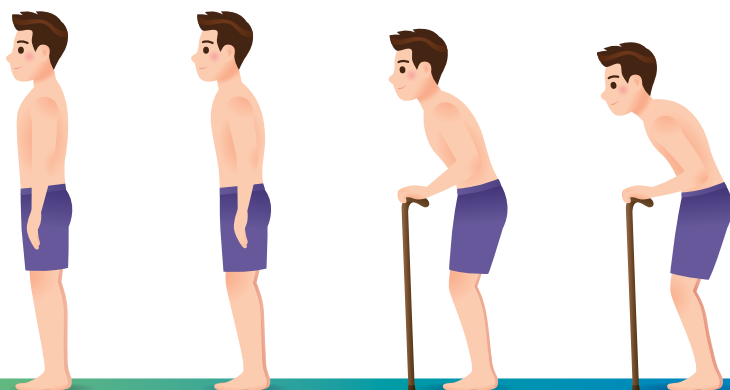
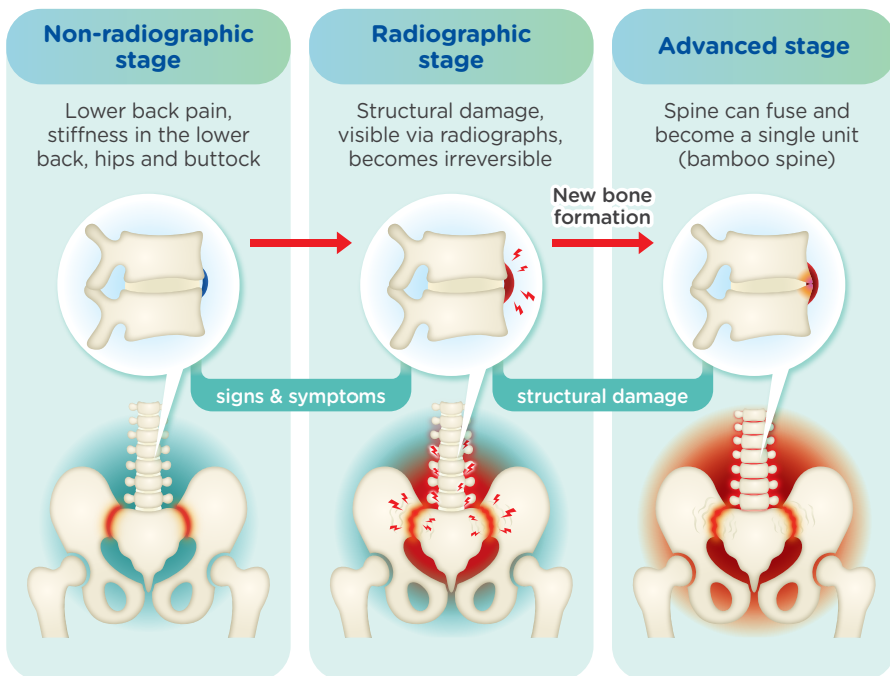
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What is happening in my body?

- Overactive immune system triggers axSpA progression, causing irreversible structural changes in the spine.



Changes in spinal posture usually begin in early disease, becoming more marked over time. In serious cases, small bones in your spine may fuse together. This leads to a stooped-over posture.

How is axSpA treated?

- For treatment goals in axSpA, ASAS recommendation takes a various aspects of the disease into consideration. The aims and outcomes of therapy are to minimize disease activity, pain and structural damage, as well as to maximize your quality of life and social participation such as work productivity.

Medications

There are many options for medications. Your doctor will check your disease activity and choose the medication(s) most suitable for your symptoms.



Non-steroidal anti-inflammatory drugs (NSAIDs)



Biologics

- TNF- α blocker
- IL-17 blocker

If you suffers from peripheral arthritis:



Local corticosteroid injection



Conventional synthetic disease modifying anti-rheumatic drugs (csDMARDs)

Non-pharmacologic management

- **Physiotherapy**
- **Regular exercise**
- **Surgical approach**
- **Change of your lifestyle**



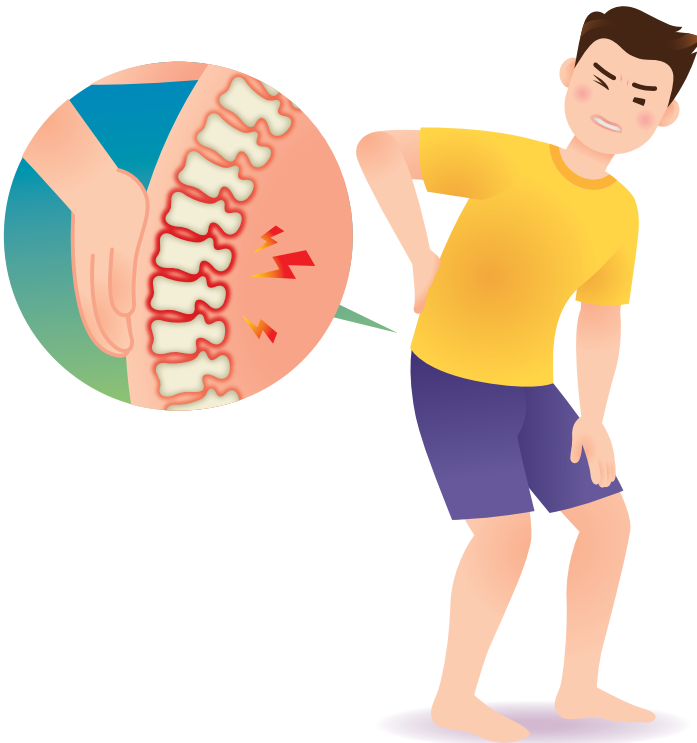
Who can be offered biologic treatment? How do they work?

Biologics are designed to block specific aspects of immune system that cause excessive inflammation.

Biologics may be required if...

- You have tried NSAIDs* but your symptoms are poorly controlled.
- You are not able to tolerate NSAIDs* due to certain medical conditions.
- You still feel pain and stiffness possibly caused by axSpA.
- Your symptoms affect your ability to work, enjoy your family life or have a good quality of life.

To avoid any safety risks, you may not be eligible if you have certain disorders or serious infections. Talk to your doctor for details.



* NSAIDs, non-steroidal anti-inflammatory drugs.

Identify your own treatment goals

- Identify your own treatment goals

- ✓ Discuss your symptoms and how it affects your life with your doctor
- ✓ Report all symptoms including troubles in eyes, bowel or skin if any
- ✓ Share your preference in lifestyle and treatment

For example



“I am experiencing (symptom/s) ”

“I find (symptom/s) most uncomfortable.”

“I have difficulties in (action/s in daily life) ”

“ (Symptom/s) make me feel (feelings) .”

“I would like to get (results) and/or to become able to (action/s) in (period of time) .”

Ask your doctor about your treatment

- What treatment options you would recommend?
- Are there any treatments that make my life easier at work, school and leisure?
- What are the aims, risks and benefits of the treatment?
- Is there something I can do to manage my symptoms?
- How long would you expect to see good effects?
- If the severity of my symptoms has changed, what happens next?
- Would you have any suggestions for resources that might help me?



Tips for your better life with axSpA



Regular exercise

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AS exercise video



Weight control



Stay active



Sleep
comfortably



Take a good rest



Avoid smoking



Avoid drinking



Healthy diet



Take your medications as
instructed by your doctor



Attend physiotherapy
sessions

In case you want to know more...



Ankylosing Spondylitis - An Inflammatory Back Pain Disease

Malaysian Society of Rheumatology (msr.my)

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5 exercise principles guide for Axial Spondyloarthritis & Ankylosing Spondylitis exercise video

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Axial Spondyloarthritis International Federation

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Managing your back pain

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