Your guide to

Axial spondyloarthritis





Although there is no cure, axial spondyloarthritis can be managed in many ways.

What is axial spondyloarthritis?

Axial spondyloarthritis (ax-SpA) occurs when there is too much inflammation in parts of the body. Axial spondyloarthritis involves the spine. Doctors classify people as having a certain type of axial spondyloarthritis:

- Radiographic ax-SpA with characteristic damage or fusing seen on X-ray (also called ankylosing spondyloarthritis)
- Non-radiographic ax-SpA without characteristic damage or fusing seen on X-ray



Axial spondyloarthritis leads to pain and stiffness mainly in the spine, neck, and pelvis.

Although the spine is most commonly affected, joints in other areas such as the hips and the shoulders can also become painful and stiff.

Axial spondyloarthritis can also affect other areas of the body aside from joints, including the eyes, skin, the heart and lungs, or the bowels.

Although there is no cure, axial spondyloarthritis can be managed in many ways.

What are the symptoms of axial spondyloarthritis?

The symptoms of axial spondyloarthritis differ from person to person, though the most common symptoms are:

- pain and stiffness in the back, neck, pelvis or buttocks
- pain in tendons (which connect muscles to bones) and ligaments (which connect bones to each other) such as heels and shoulders
- pain that's worse in the morning and night time
- pain that doesn't improve or gets worse with rest

- pain that gets better with exercise
- pain and swelling in other joints, including the fingers, toes, back of the heel, or underneath the foot
- pain or tightness in the chest
- waking up during the night with a stiff and sore back
- painful, red eyes or blurry vision
- diarrhoea or bloating (caused by inflammation in the bowels).

It's important to remember that not everyone will experience all of these symptoms.

What causes axial spondyloarthritis?

Although the cause is not known, we do know that axial spondyloarthritis is an autoimmune disease, which means the immune system isn't working properly.

Genes are thought to play a role because the condition is more likely if you have a history of it in your family.



An overactive immune system

Our immune systems normally help keep us healthy by fighting harmful things like bacteria and viruses. But in autoimmune diseases, the immune system mistakenly attacks the body's own healthy tissues and triggers an increase in inflammation.



The immune system produces substances called cytokines, such as IL-17A and TNF-a, as part of the normal immune response. In people with an overactive immune system, increased levels of these cytokines are produced, which triggers an increase in inflammation.

More inflammation results in more severe symptoms.

For people with axial spondyloarthritis, an overactive immune system produces symptoms that affect the bone and joints in the neck, spine and pelvis.

Over time, this chronic (long-term) inflammation damages joints, causing pain and stiffness.

Left untreated, joints in the spine may fuse together, leading to permanent loss of mobility. However, there are treatments available that can effectively reduce the risk of long-term spinal and joint problems.

This is why it's important to reduce the level of inflammation in the body, and that's where biologic treatments come in.

See page 4 and 5 for more information about what treatments can help with axial spondyloarthritis.

How does axial spondyloarthritis progress over time?

Axial spondyloarthritis can be unpredictable. There may be times when your symptoms are worse (flare-ups) and other times when the symptoms almost disappear. For some people, the symptoms may slowly worsen over time and lead to increasing disability.

If left untreated, axial spondyloarthritis can lead to permanent stiffness in the spine as the vertebrae in the spine become fused together, so they can no longer move freely. Other joints and parts of the body can also become damaged.

Treatment can help reduce the signs and symptoms of axial spondyloarthritis and minimise loss of mobility due to spine and joint problems. In fact, the majority of people with axial spondyloarthritis are able to keep working and live full lives, but may need to make some lifestyle changes to allow for any symptoms or stiffness.

What treatments can help with axial spondyloarthritis?

There are a number of treatments that can help manage axial spondyloarthritis. Everyone is different, so your doctor will work closely with you to develop a tailored treatment plan that's best for you.

In general, the aims of treatment are to:

- reduce pain and stiffness
- keep your spine mobile
- limit spine or joint damage as much as possible
- minimise the impact of the condition on your day-to-day life.

Physiotherapy and exercise





A physiotherapist can give you advice about suitable exercises and create a tailored activity and stretching program for you (e.g. exercises in water – hydrotherapy – that are less stressful on sore or swollen joints).

Pain relievers and anti-inflammatory medicines

Your doctor may recommend medications to help relieve pain and inflammation. These medications may be useful if you have mild-to-moderate pain or mild symptoms between flare-ups.



- Paracetamol can help relieve pain but it doesn't treat other symptoms, like joint swelling or stiffness.
- Non-steroidal anti-inflammatory drugs (NSAIDs) help to relieve pain as well as joint swelling and stiffness.

Your doctor will work with you to find which pain relievers or anti-inflammatory medicines may help with your symptoms.

Biologic therapies

Biologic therapies are medications that are used when other treatments have not effectively controlled the condition.



They work by targeting specific substances in the body that cause inflammation and damage to the joints, bones and tissues affected by axial spondyloarthritis.



There are a number of different biologic therapies available to treat axial spondyloarthritis. The different biologic therapies target different substances causing joint inflammation and damage.



Biologic therapies are normally administered as an injection, or as an infusion into a vein.



Regular blood tests are usually required during treatment to make sure the biologic therapy is working and to check for any unwanted side effects.

You might also find it useful to speak with other people who have axial spondyloarthritis to hear about their experiences and learn practical ways to deal with the condition.

Ask your doctor or nurse if there's a support group in your area. If there isn't a group near you, online organisations and groups – such as Arthritis Australia (www.arthritisaustralia.com.au) – may be helpful.

Ask your healthcare team for more information.



Axial spondyloarthritis

Keep track of your symptoms and monitor your progress

This tracker allows you to keep track of your symptoms and monitor your progress over the next 9 months. Tracking how your symptoms change over time – and their impact on your moods, social life, and ability to work – can help you and your healthcare team check that you're getting the most out of treatment.

► START OF TREATMENT

Date: / /	
Mark on the diagram where y and what they are	ou have symptoms
(e.g. joint pain, stiffness, swelling, tenderness)	
Notes & questions	Front Back
Write down any notes, questions or colleg. triggers for joint pain/stiffness, how long	

current symptoms.	VERY SEV	ERE			NONE
Fatigue/tiredness My overall fatigue/tiredness today is:			<u>:</u>	\odot	
Morning stiffness My morning stiffness today is:	\odot	\odot	<u></u>	\odot	:
Pain My overall pain today is:	\odot	\odot	\odot	\odot	
Joint swelling/tenderness My overall joint swelling/tenderness today is:	\odot	\odot	\odot	\odot	

	VERY POO	VERY POOR			VERY GOOD		
Mood My mood today is:			<u></u>	\odot	(;)		
Sleep quality My sleep quality last night was:	\odot		<u>:</u>	\odot			
Social activity/relationships My ability to engage in social activities and relationships with friends and family is:	\odot		\odot	\odot	(i)		
Work life/daily activities My ability to work or carry out my daily activities today is:	\odot		<u>:</u>	\odot	(;)		

► AFTER 3 MONTHS

Date: /		
Mark on the diagram where y and what they are	ou have symptoms	
(e.g. joint pain, stiffness, swelling, tenderness)		
	Front	Back
Notes & questions Write down any notes, questions or of For example – what helped with your symptotyou noticed? Are there activities you can now	ms, or made things worse? Wh	

current symptoms.	VERY SEV	ERE			NONE
Fatigue/tiredness My overall fatigue/tiredness today is:	$ \odot $		<u></u>	\odot	
Morning stiffness My morning stiffness today is:	\odot	(;)	<u>:</u>	\odot	
Pain My overall pain today is:	\odot		\odot	\odot	
Joint swelling/tenderness My overall joint swelling/tenderness today is:	$ \odot $	\odot	\odot	\odot	

	VERY POOR			VERY GOOD		
Mood My mood today is:	\odot		<u>:</u>	\odot	(;)	
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Social activity/relationships My ability to engage in social activities and relationships with friends and family is:	⊗			\odot		
Work life/daily activities My ability to work or carry out my daily activities today is:	\odot		\odot	\odot	(1)	

► AFTER 6 MONTHS

Date: /		
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(e.g. joint pain, stiffness, swelling, tenderness)		
	Front	Back
Notes & questions Write down any notes, questions or of For example – what helped with your symptotyou noticed? Are there activities you can now	ms, or made things worse? Wh	

current symptoms.	VERY SEV	ERE			NONE
Fatigue/tiredness My overall fatigue/tiredness today is:	\odot	<u>:</u>	<u>:</u>	\odot	\(\text{\tin}\text{\tetx{\text{\tetx{\text{\text{\texi}\text{\texi}\text{\text{\text{\text{\text{\ti}\}\tittt{\text{\texi}\text{\texi}\text{\texit{\texi}\text{\texi}\til\titt{\text{\texi}\text{\text{\texi}\text{\text{\tet
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Pain My overall pain today is:	\odot		\odot	\odot	(i)
Joint swelling/tenderness My overall joint swelling/tenderness today is:	\odot		\odot	\odot	(i)

	VERY POOR			VERY GOOD		
Mood My mood today is:	\odot		<u>:</u>	\odot	(;)	
Sleep quality My sleep quality last night was:	\odot		<u>:</u>	\odot		
Social activity/relationships My ability to engage in social activities and relationships with friends and family is:	\odot			\odot	(;)	
Work life/daily activities My ability to work or carry out my daily activities today is:	\odot		\odot	\odot	(:)	

► AFTER 9 MONTHS

Date: / /		
Mark on the diagram where y and what they are (e.g. joint pain, stiffness, swelling, tenderness)		
	Front	Back
Notes & questions Write down any notes, questions or c For example – what helped with your sympto you noticed? Are there activities you can now	oms, or made things worse? What	

current symptoms.	VERY SEV	ERE			NONE
Fatigue/tiredness My overall fatigue/tiredness today is:		<u>:</u>	<u>:</u>	\odot	
Morning stiffness My morning stiffness today is:	$ \odot $	(;)	<u>:</u>	\odot	
Pain My overall pain today is:	\odot		\odot	\odot	
Joint swelling/tenderness My overall joint swelling/tenderness today is:		\odot	\odot	\odot	

	VERY POOR			VERY GOOD		
Mood My mood today is:	$ \odot $		<u>:</u>	\odot	(:)	
Sleep quality My sleep quality last night was:	\odot		<u>:</u>	\odot	(
Social activity/relationships My ability to engage in social activities and relationships with friends and family is:	\odot			\odot		
Work life/daily activities My ability to work or carry out my daily activities today is:	\odot		<u>:</u>	\odot	<u>(i)</u>	

Notes

Arthritis Australia. Non-radiographic axial spondyloarthritis. Arthritis information sheet. Available from: https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2019/01/ArthAus_infosheet_NonRadioAxialSpon_online.pdf [Accessed October 2020].

Yu TD and vanTubergen A. Patient education: Axial spondyloarthritis, including ankylosing spondylitis (beyond the basics). Up to date, January 2020.

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