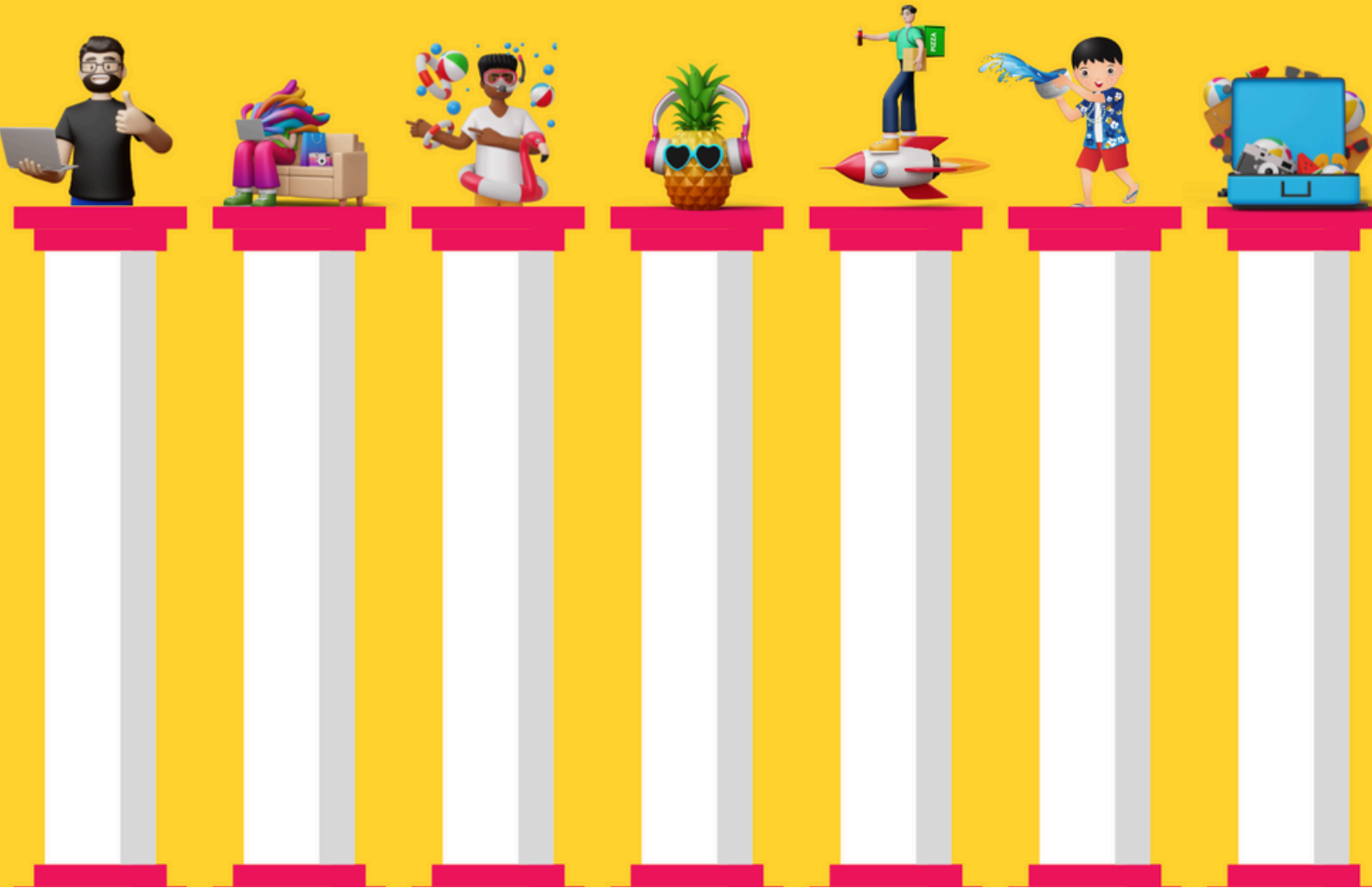




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# AXIAL SPONDYLOARTHRITIS (AXSPA) SELF-CARE PLAN

A plan to help you understand, manage  
and live well with axSpA



# Axial spondyloarthritis (axSpA) Self-care plan

A plan to help you understand, manage and live well  
with axSpA

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Including ankylosing spondylitis (AS) and  
non-radiographic axial spondyloarthritis (nr-axSpA)



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# What is a self-care plan and how can it help me?

Learning that you have axial spondyloarthritis (axSpA) is the beginning of a long expedition into unfamiliar territory and you're sure to have dozens of questions swimming around in your head.

You've no doubt had lots of tests, seen many doctors, and have possibly already started treatment. But where do you fit into this plan? What are the steps that you can take every day to help yourself live an active, healthy and fulfilling life, while managing your pain and other symptoms?

That's exactly where this self-care plan comes in. With the collective wisdom and experience of other people living with axSpA, and guided by the latest research, our medical advisors and Musculoskeletal Australia (MSK) staff, we've created a plan that puts you at the centre of managing axSpA.

We've designed this plan to put you back in the driver's seat, providing you with the information, tools and support systems you need to become actively involved in managing your arthritis. Years of research and experience have shown that the more involved you can be in managing your health, the less pain and greater quality of life you will experience.

This plan will guide you through understanding your condition and its treatments, through to the vital role of exercise and healthy eating, and practical ways to manage your pain. You'll learn new skills to care for your mental health and wellbeing – helping you to build resilience no matter what axSpA and life in general throws at you – and you'll learn how to manage many everyday risks to your health.

While this plan is designed to be a practical resource that puts you at the centre of your care, remember that it doesn't mean all the responsibility for managing axSpA rests with you. Your healthcare team and MSK are always here for you, ready to provide you with information, guidance and support whenever you need it.

Using your self-care plan: The self-care plan isn't intended to be read from front to back – although you could certainly do that. We think the most helpful way to use it is to dip in, scan the contents and choose where you'd like to start. Each section is its own unique guide with information, hints, tips and links for more information.

Make notes and add your own thoughts, insights and experiences. This is your journey and self-care plan – make it your own. And if you have feedback on how we can improve this plan for others, please let us know.

# 1. Learning about axSpA

## Things to remember

- axSpA is the umbrella term for two different types of inflammatory arthritis that affect the spine: ankylosing spondylitis (AS) and non-radiographic axial spondyloarthritis (nr-axSpA)
- axSpA is a chronic (ongoing), inflammatory health condition that causes pain, stiffness and reduced mobility in your spine. It can also cause symptoms in other parts of your body.
- Other symptoms can include inflammation of tendons and ligaments, inflammatory bowel disease, psoriasis and inflammation of the eye.
- Learning as much as you can about axSpA is one of the main steps to managing your condition as well as you can.
- It's normal to experience a wide range of different thoughts and feelings when you're diagnosed with axSpA. These will usually soften over time, but there's always help available if you need it.
- There's no one test that can diagnose axSpA - it's diagnosed based on a combination of your symptoms, a physical examination, blood tests and scans.
- Learning about what each member of your healthcare team does, asking questions, and keeping track of your test results and your symptoms helps you to be more actively involved in your healthcare.

## Knowledge helps put you in control

Living with and managing axSpA well begins with learning as much as you can about it - because the better you understand your condition and what is happening in your body, the better you can manage it.

With the right knowledge, you'll be able to ask your healthcare professionals clearer questions, become more involved in decisions about your treatment, understand how your lifestyle affects your symptoms, and therefore play a more active role in managing your axSpA daily and over the longer-term.

## A note about different types of axial spondyloarthritis (axSpA)

Axial spondyloarthritis, which is often shortened to axSpA and pronounced 'axe-spa', is an umbrella term that includes two different types of inflammatory arthritis that mainly affect the spine:

- **ankylosing spondylitis** (often shortened to AS) - where changes to the spine or sacroiliac joints that connect the lower spine to the pelvis, are visible on x-ray
- **non-radiographic axial spondyloarthritis** (often shortened to nr-axSpA) - where these changes aren't yet visible on x-ray, but may be seen on an MRI. For some people, nr-axSpA will never progress to the stage where joint changes are seen on x-ray. For others, these changes will eventually be seen on x-ray, and their diagnosis will be changed to AS.

The information in this self-care plan will help you understand and manage either type of axSpA. To make things easier, we'll use this general term in the plan from now on.

You may notice that some organisations use the abbreviation AS an umbrella term to mean the same thing as axSpA. So, when you're looking at resources from National Axial Spondyloarthritis Society UK or Spondyloarthritis Association of America, it helps to be aware that when they refer to AS, they usually mean both of the conditions we're covering in this self-care plan.

## **Finding out you have axSpA**

If you've recently found out that you have axSpA, you're probably experiencing a whole range of thoughts and feelings.

You may be feeling shock, confusion and anger – and possibly fear about what the future holds. Some people have a sense of disbelief or denial, especially if it wasn't a diagnosis they were expecting.

Because axSpA is more common in younger people, you may feel a sense of loss and grief about how your life will change and the potential impact of your condition on your career, relationships, parenting, playing sport and your social life.

It's common for it to take a long time for axSpA to be diagnosed, so receiving your diagnosis may give you a sense of relief, especially if you've had pain and other symptoms for some time. With a clear diagnosis, you may feel that you have a way forward with a treatment plan. Or, you may still be feeling that you have more questions than answers.

It's helpful to know all of these thoughts and feelings are normal. Sharing how you feel and building a support network around you can help you to cope – now and in the future.

Over time, your emotions will change and will usually soften. Life won't be the same again, but you'll begin to adapt and experience a new way of living and managing your health.

## **Where to get help**

For some people, the intense emotions at the time of diagnosis don't go away. Or you may find that living with axSpA continues to cause challenges that affect your mental wellbeing.

The Mental and physical wellbeing section of this self-care plan includes lots of information and links to support your mental wellbeing at any stage of living with axSpA.

## **What is axSpA and who does it affect?**

axSpA is an ongoing (chronic), inflammatory health condition that causes pain, stiffness and reduced mobility in your spine. It's the result of your immune system working in a faulty way, which is called having an autoimmune condition.

Our immune systems are designed to look out for and attack foreign bodies – like bacteria and viruses – that can make us sick. For reasons that we don't fully understand, when you have axSpA, your immune system gets confused and targets your joints and healthy tissues as if they were foreign bodies. This causes ongoing inflammation and pain.

axSpA is a condition that affects young people, with symptoms usually developing in people aged between 15 and 45 years. People often have symptoms for many years before being diagnosed. We used to think that axSpA affected more men than women, but recent research suggests men and women are affected relatively equally.

The cause of axSpA is unknown, but genes are thought to play a role.

Most people with axSpA have the gene called HLA-B27. But this gene can also be found in people who don't have axSpA. Since the presence of this gene doesn't automatically lead to axSpA developing, there are most likely other factors involved as well.

While there's currently no cure for axSpA, there are many things you can do to help manage the inflammation, pain and potential for joint damage– which is what this self-care plan is all about.

## **What are the symptoms of axSpA?**

The symptoms of axSpA vary from person to person.

The most common symptoms are pain and stiffness in the back, often the lower back and into the buttocks that:

- comes on gradually over weeks or months (rather than coming on suddenly like back pain that's the result of an injury or strain)
- is worse in the second half of the night and wakes you up
- is worse first thing in the morning, with early morning stiffness that lasts 30–45 minutes or more
- is worse after rest and feels better after activity and exercise
- has been present for 3 months or more (rather than having short periods of discomfort)
- may involve pain deep in the buttock that can swap from one side to the other over time, especially in the early stages (doctors call this 'alternating buttock pain').

Other symptoms can include:

- fatigue (extreme tiredness) – which is a common symptom for most people
- inflammation and pain in tendons (which connect muscles to bones) and ligaments (which connect bones to each other), which you may feel as pain at the front of your chest, back of your heel or underneath your foot
- arthritis in one or more of your peripheral joints – such as the joints in your hands, feet, arms or legs

- inflammation in your eye (called uveitis)
- inflammatory bowel disease
- psoriasis
- feeling feverish and having night sweats
- losing your appetite and losing weight.

It's important to remember that symptoms vary from person to person, and can change daily.

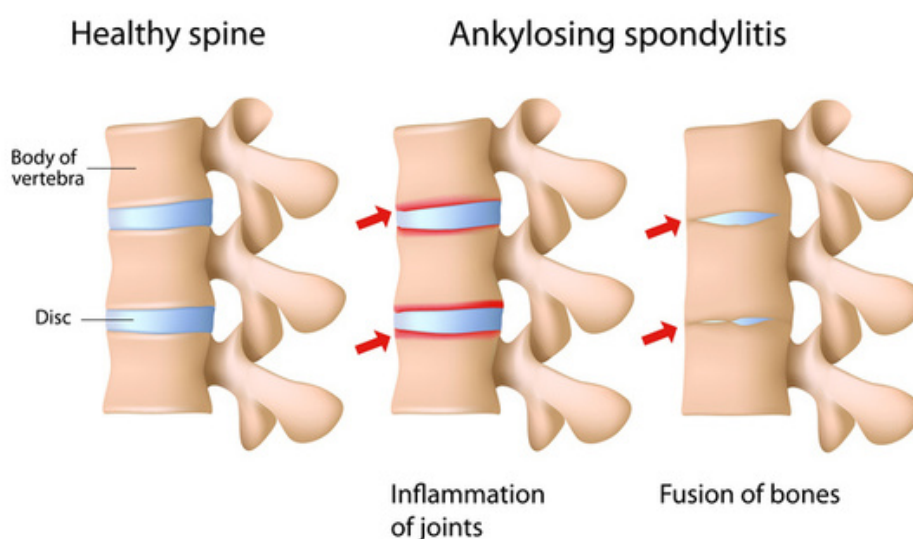
Depending on your daily physical activity you may find some symptoms ease more quickly. This is because movement is a key tool in your treatment strategy to managing axSpA. Read more about exercise in Section 3.

At times, your symptoms can become more intense, which is known as a flare. Flares can be unpredictable and seem to come out of nowhere. Learning more about flares and how to manage them is an important part of your self-care plan.

### More to explore

- National Axial Spondyloarthritis Society (UK) has lots of [detailed information about axSpA](#), including helpful videos and information about how axSpA can affect different parts of your body.
- Creaky Joints Australia's booklet [A patient's guide to living with axial spondyloarthritis in Australia](#) covers all stages of living with axSpA, including detailed information on symptoms, diagnosis, accessing treatments, navigating the Australian healthcare system, daily living, and much more.
- Spondylitis Association of America (SAA) has a [booklet on non-radiographic axial spondyloarthritis \(nr-axSpA\)](#) where you can read more about how it is different from ankylosing spondylitis (AS).

Note: As exercise is a key tool for managing axSpA, it's important to find the best routines. All of these websites contain downloadable exercise programs, videos and apps for you to access.





## What happens to your body in axSpA?

- When you have axSpA, an inflammatory process occurs that causes pain and stiffness:
- Inflammation develops in the tissues (or entheses) that connects your ligaments or tendons to the bone. This inflammation is called enthesitis.
- As a result of this inflammation, some changes can occur in the bone where ligaments and tendons attach, which can sometimes be seen on x-rays or other scans.
- As the inflammation reduces, the area begins to heal and new bone grows around the joints in the spine and other areas such as the Achilles tendon. When bone replaces the stretchy tissue of ligaments or tendons, this can lead to permanent stiffness, which restricts movement.
- When this inflammatory process is repeated many times, the extra bone that grows can fuse the bones of the spine (vertebrae) together. Starting the right treatment as early as possible, including specific axSpA exercises, can help to prevent spinal fusion.

## How is axSpA diagnosed?

The key symptom that a medical professional is looking for to diagnose axSpA is changes to your sacroiliac joints – the joints that connect the base of your spine to your pelvis.

Because it can take many years for x-rays to show joint damage and inflammation, there are other key factors that your doctor looks for when diagnosing axSpA. They include your age, the ongoing nature of your pain, if the back pain wakes you up at night, if you have a family history of axSpA and whether pain and stiffness eases with exercise.

There isn't one single test that can be used to diagnose axSpA, and your doctor will usually use a combination of tests to confirm your diagnosis, including:

- a physical examination to assess joint tenderness, flexibility, and stiffness
- blood tests to check for inflammation associated with axSpA
- genetic testing to check for the HLA-B27 gene which is present in most people who have axSpA
- scans such as x-ray and MRI (magnetic resonance imaging) to check for joint inflammation and damage.

Symptoms of axSpA often improve within a day or two of taking non-steroidal anti-inflammatory drugs (called NSAIDs for short). When the NSAIDs are stopped, symptoms usually become worse again. Your doctor may therefore try you on a NSAID to help make a diagnosis.

If you visit your family doctor (GP) with symptoms that suggest you might have axSpA, they'll usually order some of these tests and refer you to a rheumatologist (a doctor who specialises in conditions that affect muscles, bones and joints, or musculoskeletal conditions). The rheumatologist will usually order more tests to help them make a diagnosis.

Unfortunately, diagnosis of axSpA can sometimes take many years. People may spend a lot of time and energy seeing physical therapists and specialists looking for relief and a clear diagnosis. As our awareness and understanding of axSpA increases, diagnosis is beginning to happen sooner.

If you have ongoing back pain and stiffness or other symptoms of axSpA, but haven't been diagnosed, then it's really important to see your GP as soon as possible.

The earlier axSpA is diagnosed, the earlier you can start treatment to help control inflammation, better manage your pain, and reduce the risk of long-term damage to your joints.

### **More to explore**

- [National Axial Spondyloarthritis Society \(UK\)](#) has more information about the tests used to diagnose axSpA.

### **Keeping track of your test results**

When you're first diagnosed with axSpA, your GP and rheumatologist will order quite a few different tests and you'll quickly start to learn a whole new language!

Your rheumatologist will continue to order many of these tests to keep an eye on your axSpA, how it develops over time and how you respond to treatment. It's important to remember that everyone responds to medicines differently, so this needs close monitoring, especially when you're prescribed new medicines.

As well as these tests, your rheumatologist may ask you to complete questionnaires called disease activity scores (DAS) and patient-reported outcomes (PROs). These questionnaires have been specifically designed for people with axSpA and will help monitor your progress and response to medicines.

One of the ways that you can be actively involved in managing your condition is by asking for copies of test and questionnaire results and keeping them in a safe place. This can help you to:

- see how your axSpA changes over time
- understand how your axSpA responds to different treatments and lifestyle changes
- have test results at your fingertips to share with other healthcare professionals.

## Tips for keeping track of test results

- At each doctor's or specialists' appointment where you receive blood test results or you complete a questionnaire, ask if you can have a copy of these. Don't be shy about asking – it's your body and your right to have a copy.
- Keep your blood tests and completed questionnaires in date order where they are easy to find: a clear plastic folder works well. Or you may prefer to scan and upload your results to an app (see the tips box about health tracking tools later in this section).
- Most scans are now stored electronically, but you may be given physical copies of your scans to keep. These can be quite large, so a large clear plastic bag that's used to carry artwork or a large plastic storage box can be handy for storing these.
- Remember to take these test and questionnaire results and images along to any new healthcare appointment – such as when you see a physio or exercise physiologist for the first time.
- And ask your healthcare practitioner to always copy in your rheumatologist or GP on scans and tests to ensure they're sent the report. This way you can discuss the outcomes at your next visit.

### Keeping track of your symptoms

When you go to your medical appointments, do you find it difficult to accurately answer questions about how you've been since your last visit? How you've been sleeping, how your symptoms have been, how often you've been exercising, or how many flares you've had?

When you try to remember, it's very easy to get things wrong. Our memories aren't always reliable, and can be influenced by many other factors, including our emotions.

To help provide your doctor with a clearer picture of what's been happening – and so your treatment plan is based on facts – it can be very helpful to keep track of your symptoms.

Tracking your symptoms is also a good way for you to see how your daily activities and feelings might be affecting them, and to pick up on any trends. For example, you might notice that you consistently sleep well on Wednesday nights and have less pain on Thursdays – and you can track this to the swimming you do every Wednesday. This can provide you with good motivation to keep up your swimming – and possibly to look at increasing the amount of water-based exercise you enjoy.

Or, you may notice you have increased pain on Saturday mornings when you try to have a sleep-in and take your time to get up and moving. Perhaps you can try having an extra-long warm shower on weekend mornings as a trade-off for sleeping in?

To get started with tracking symptoms, you can simply grab a notebook and start jotting things down, try one of the apps suggested, or download a blank template. It doesn't matter what you use for your tracking: the most important thing is to keep it up so the information is relevant and useful for you and your healthcare team.

## Tips for tracking health records

You might like to try a smartphone app or online tool to keep track of test results, exercise, eating, medicines, symptoms and more:

- Versus Arthritis (UK) has a [free Arthritis Tracker app](#) for iPhone and Android. It was originally designed for teens and young adults, but it's popular with adults too.
- You can also track symptoms simply by adding them to the free 'Notes' app on your smartphone – where you can also upload and save copies of test results.
- If you'd prefer to keep track of your symptoms on your computer or with pen and paper, try an internet search for a "symptom tracker template". You'll find many free templates that you can either use on your computer or print off and fill in by hand.

## Working with your healthcare team

Your healthcare team will be made up of different healthcare professionals, with you at the centre of the team.

You may see some of these healthcare professionals regularly, and you may see others only when you need help in managing a specific issue.

You'll be able to work best with your team and get the greatest benefit from their skills and your visits when you understand a bit more about the role they can play in your care.

## Doctors and specialists

**Your general practitioner (GP)**, also called a family doctor, is an important partner in managing your axSpA and is likely to be the healthcare professional you see most often. They can help you to:

- manage your condition day-to-day
- write repeat prescriptions
- manage any other health conditions you may have
- make sure you're up to date with health screens and vaccinations
- access other health professionals and services – including coordinating your care.

**Rheumatologists** are doctors who specialise in diagnosing and treating problems with joints, muscles, bones and the immune system.

Usually, you'll be referred to a rheumatologist to diagnose axSpA. Most people with axSpA will need the ongoing care that a rheumatologist can provide, while seeing a GP in between their specialist visits. You'll usually visit a rheumatologist every 3 months after your initial diagnosis and starting treatment. This may change depending on the type of treatment and symptom monitoring that's needed.

When your condition and symptoms are stable, you may progress to 6 monthly visits. This will also depend on the type of medicine you have been prescribed and how often you need a new prescription.

**Gastroenterologists** are doctors who diagnose and treat problems related to the digestive system and intestines such as inflammatory bowel disease.

**Ophthalmologists** diagnose and treat eye problems, like uveitis, which can be a symptom of axSpA. Your GP or optometrist will refer you to an ophthalmologist if your eyes are affected.

**Orthopaedic surgeons** specialise in the surgical treatment of bone, joint, ligament, tendon and muscle conditions. If your rheumatologist thinks you may need an operation for axSpA, they'll refer you to an orthopaedic surgeon.

**Pain specialists** are medical doctors who've undergone additional training to diagnose and treat pain. They come from a variety of different medical specialties such as psychiatry, anaesthetics and general practice. They often work with a team of other health professionals to treat all aspects of your pain, from the physical, to the mental and emotional aspects.

**Psychiatrists** are medical doctors who specialise in diagnosing and treating mental health conditions. A psychiatrist can prescribe medicine as well as use [talking therapies](#).

## Allied healthcare professionals

**Rheumatology nurses** have specialised knowledge about different types of arthritis and can provide you with education and counselling, as well as helping to monitor disease progression and coordinating other parts of your care. They'll also provide support when it comes to medicines that you may need to inject yourself (e.g. biologics and biosimilars).

**Physiotherapists**, often called physios for short, use physical therapies – like exercise, massage, heat and cold – as well as education and advice to help keep you moving and functioning as well as possible.

A physio can design an exercise program for you, show you pain relief techniques, and give you tips for better posture.

A physio is an essential part of your healthcare team when you have axSpA. Read more about how they can help in Section 2: Treatments for axSpA and in Section 3: axSpA needs exercise.

**Exercise physiologists**, also called EPs, can help to improve your health and fitness through exercise programs tailored to your specific needs. They can also support you in healthy lifestyle changes.

**Occupational therapists** or OTs can provide advice on pacing yourself and managing fatigue, as well as how to modify daily activities both at home and work to reduce strain and pain on your back and any other affected joints.

They can help you learn better ways to do everyday activities such as bathing, dressing, cooking, working, eating and driving.

OTs can also provide information on aids and equipment to make everyday tasks easier.

**Podiatrists** specialise in foot care and can assess, diagnose and treat foot and lower limb problems, including problems with your toes and ankles, and with walking.

They can also advise you about supportive footwear and shoe inserts, called orthotics.

**Hand therapists** are OTs or physios who have had extra training and can help to treat and manage arthritis symptoms in your hands, fingers, wrists and elbows.

**Dietitians** provide information and advice on food and nutrition. They can develop a healthy eating plan for you, helping you to get the different nutrients you need and provide you with specific advice if you have inflammatory bowel disease as part of axSpA.

If needed, a dietitian can also support you to lose weight or to gain weight in a healthy way.

**Psychologists** can help you to work through your feelings, especially if you're feeling anxious or depressed.

Many people with axSpA find it helpful to talk with a psychologist about how they're coping with pain and the emotions around living with an ongoing health condition.

A **psychologist** can provide different types of talking therapies, including cognitive behavioural therapy (CBT), and can help you to set goals.

They can also show you techniques to help manage your flares and any difficult physical limitations. Pharmacists can help you to understand more about your prescription and over-the-counter medicines – and how to use them correctly and safely.

## **How and where can I see these healthcare professionals?**

There are a number of different ways you can access different healthcare professionals.

To see a specialist doctor such as a rheumatologist, orthopaedic surgeon or psychiatrist, you'll need a referral from your GP or another specialist doctor.

To see allied healthcare professionals, such as a physio, dietitian or psychologist, you can:

- Ask your GP to book you in for consultation to prepare a [chronic disease management plan](#) with the healthcare professionals you need. The plan will include five sessions in a year with these healthcare professionals and Medicare will pay for part of the cost.
- See a healthcare professional through the public health system – in public hospitals and in community health centres and rehabilitation services – and at low or no cost. You'll usually need a referral from your GP to access these services and there'll most likely be a waiting list.
- Book an appointment directly with the healthcare professional of your choice at their private clinic. You don't need a referral to do this. Private healthcare professionals' fees vary, so always ask what the cost will be when you book your appointment. If you have 'extras' as part of private health insurance, it may pay for part of the cost.

You can ask your GP or call the Back Pain | Arthritis | Musculoskeletal Conditions (B.A.M) Helpline on 1800 263 265 (Mon–Thu) for more info.

## More to explore

We have a series of articles that cover the different groups of health professionals and therapists who'll help you to live well with a musculoskeletal condition such as axSpA:

- read more about the different [specialists](#) involved in your care
- learn more about different types of [physical therapists](#) and how they can help you
- find out about the different types of support available for [mental and emotional wellbeing](#).

Here are direct links to professional associations where you can search for a healthcare professional in your local area who has the expertise you need:

- [Find a rheumatologist](#)
- [Find an orthopaedic surgeon](#)
- [Find an ophthalmologist](#)
- [Find a psychiatrist](#)
- [Find a physio](#)
- [Find an EP](#)
- [Find an occupational therapist](#)
- [Find a podiatrist](#)
- [Find a hand therapist](#)
- [Find a dietitian](#)
- [Find a psychologist](#)

## Tips for getting the most out of your healthcare appointments

- Write down your questions – and leave space to write down your answers.
- Ask the most important questions first.
- If you have a lot of questions or several issues to address in one appointment, ask to make a double or long appointment.
- Remember to take your scans and test results with you.
- You might like to take another family member or a friend to your appointment – they may be able to help you ask questions and to chat with you afterwards about what your healthcare professional said.
- If you don't understand something your healthcare professional has said, ask them to explain it again.
- You generally don't need to make treatment decisions on the spot. If your healthcare professional has suggested a new treatment, it's fine to tell them you need some time to think and talk about it with your family.
- Ask as many questions as you need to about any new treatment your healthcare professional suggests – including the benefits, side effects, risks and costs. Some medicines may interact with other treatments or may need to be stopped if surgery is planned or if you're trying to conceive. So it's important to be fully informed.

## Questions to ask your healthcare team

Sometimes, it can be difficult to know where to start with questions for your healthcare team – especially if you've been recently diagnosed with axSpA or you're starting a new treatment.

Here are some questions that might help to get you started – many of these are most relevant for your rheumatologist and GP.

You might like to print this list and add extra questions of your own. Remember, there's no such thing as a silly question!

- How severe is my axSpA?
- What level of damage do I have to my joints?
- How often will I need to have blood tests and scans to check on the progress of my axSpA?
- How will my condition likely progress?
- What type of exercise program do you recommend for me?
- Can you recommend a physio or exercise physiologist with experience in axSpA to help develop my exercise program?
- What treatment/s – including medicine, exercise and lifestyle changes – do you recommend and why?
- Do I really need this test, treatment or procedure?
- What are the risks?
- Are there simpler, safer options?
- What happens if I don't do anything?
- What are the costs?
- What written information can you give me about these treatments?
- How will I know if the treatment is working?
- Why do we have to apply to the government for some of my medicines? And how long will it take to get approval?



- Will the dosage of my medicine be changed throughout treatment?
- Will I need to have extra blood tests on this medicine?
- Will this medicine affect my ability to have children?
- What should I do if I have new or worsening side effects or symptoms while on this treatment?
- What should I do if I'm already taking or need to start taking any other medicines?
- What local healthcare services do you recommend for additional support?
- Are there specific symptoms you want me to track for future appointments?
- Does your practice have a rheumatology nurse I can talk with?
- Will I be able to reduce my use of medications as my condition improves?

## Support from your family and friends

The support of your family and friends is really important when you have axSpA. Research has shown that people who have positive social support cope better with their pain.

To be able to support you, your family and friends will need to learn more about axSpA. They'll also rely on you being honest with them: so don't be afraid to let them know when you're struggling and need extra help. You might be experiencing pain and symptoms that other people can't see on the outside, so communicating how you're feeling is going to be very important as you establish a support network.

## Tips for talking to your family and friends about axSpA – and asking for help

- Your family and friends are on a big learning curve with you and, just like you, will need to understand what axSpA is, how it's treated, the ways it will affect you, and what the future may have in store. You might like to email or print parts of this self-care plan to help them understand more. And there are many websites ([including our own](#)) that have reliable information you can share with others. See the More to Explore sections for details.
- You may like to take a close family member or friend to your doctor's appointments.
- It's important that everyone can be honest about their feelings. Let your family and friends know how you're feeling – and ask them to share how they're feeling too.
- Let your family and friends know what type of support you would like from them. It can be difficult to ask for help and it can be difficult for others to know how to offer help – so be as specific as you can. Here are some examples to get you thinking about the type of support you might need and how you could approach these conversations with family and friends:
  - "I need your help making sure I move every day, and keep up my strength, mobility and flexibility exercises. Can we talk about some things you might be able to take off my to-do list to help me free up some time? And maybe there are some exercises we can do together?"
  - "Gardening isn't easy for me anymore as I find bending over painful. Is that something you can give me some extra help with? Or we could find a local gardener to come regularly."
  - "axSpA makes me very tired and I need to get to bed earlier, but I'm not so good at sticking to my own plans. Can you please help me to make sure I'm in bed by 10.30pm every night? Sometimes, that means certain things just won't get done."

- “My pain and stiffness are much worse in the morning, and I really need extra help getting started for the day. Can you take charge of getting the kids ready for school and making lunches, so I can focus on my mobility exercises to get me moving for the day?”
  - “Having someone else do the housework would be the best possible thing for me right now.”
  - “When I’m having a flare, the pain makes me feel really cranky. Please don’t take that personally and try to be extra-patient with me.”
- You may also need to tell family and friends what you don’t want help with! If you have set up honest two-way communication from the start, this will be much easier.

## More to explore

- Creaky Joints Australia’s booklet [A patient’s guide to living with axial spondyloarthritis in Australia](#) is a downloadable PDF booklet with a large amount of useful information about axSpA. Chapter 10 (page 51) has good information about how to talk to your family, friends and employer about axSpA.
- The UK [National Axial Spondyloarthritis Society \(NASS\)](#) provides lots of helpful information about living with axSpA, including online exercises.

## Support from other people with axSpA

There’s nothing like talking with someone who knows what living with axSpA is like. Sometimes you might want to talk with a friend who also lives with arthritis or pain. Or you might want to look into joining a peer support group. They’re available all over the country. Some meet face-to-face, while others connect through social media and websites.

If you’re interested in online support, you’re not just limited to Australian groups. There are some very interesting forums, social media pages and blogs all around the world.

If you find some you like, remember to bookmark their page or join them so that you can get back in touch when you need to.

## More to explore

- Find out more about our network of support groups [here](#).
- Call the Back Pain | Arthritis | Musculoskeletal Conditions (B.A.M) Helpline on 1800 263 265 (Mon-Thu) to find out more about support groups in your area and that fit with your needs.
- Spondylitis Association of America has an [active online forum and virtual support groups](#) where you can ask questions and connect with other people living with axSpA around the world.
- [Creaky Joints Australia](#) has good information about how peer support groups work.
- The [Spondylitis Association of America](#) has a lot of forums and online community groups you might like to explore, or search for a specific topic you’re wondering about such as ‘sleep’ or ‘surgery’.

## 2. Treatments for axSpA

### Things to remember

- There are many different treatments that can help you to manage axSpA and to live a healthy and active life.
- Treatment for axSpA includes starting a supervised exercise program designed by a physio or exercise physiologist (EP) as soon as possible.
- Your doctor will prescribe medicine to help manage your symptoms and slow the progression of your condition. These medicines are always used in combination with exercise, physical therapies and other lifestyle changes.
- The main two medicines prescribed for axSpA are non-steroidal anti-inflammatory drugs (NSAIDs) and targeted therapies. Your doctor will explain the benefits and risks of each.
- Targeted therapies can dramatically improve the quality of life for people with axSpA who need more than NSAIDs to manage their condition.
- Physical or manual therapies are an important part of your treatment plan. They include hands-on therapies to help relieve your pain and stiffness and to improve your mobility, movement and joint function.
- Many people with axSpA are interested in trying complementary therapies. There is not as much evidence for these as for conventional therapies, but the evidence is increasing. Always talk to your doctor before trying any complementary therapy.
- Occasionally, people with axSpA may need surgery if all other treatments haven't provided enough relief from symptoms. A surgeon will discuss the risks and benefits so you can decide if surgery is right for you.

### There are many effective treatments to help manage axSpA

While there's no cure for axSpA, there are many different types of treatments to help you manage the condition and its symptoms and reduce joint and any organ damage, so you can continue to lead a healthy and active life. The earlier you start treatment for axSpA, the better it will usually work. That's why it's so important to see your GP and get a referral to a rheumatologist as soon as possible if you're concerned about any of your symptoms.

For most people, treatment will include both prescribed exercise and medicines, as well as physical therapies and lifestyle changes. For some people, treatment may also include surgery.

As well as using medicines, treatment for axSpA includes starting an exercise program that is tailored and supervised by a physio or exercise physiologist as soon as possible. This 'exercise prescription' will help to improve your physical function, mobility and flexibility, and to reduce your pain and level of disease activity. Section 3 of your self-care plan focuses on exercise as a treatment for axSpA.

## Medicines

Your rheumatologist will recommend and prescribe medicines for your axSpA. You may need to take one or more medicines – because different medicines work in different ways.

The two main types of medicines used to treat axSpA and help manage its symptoms are NSAIDs and biologics:

**Non-steroidal anti-inflammatory drugs** (NSAIDs) are nearly always used as the first medicine to treat the pain, inflammation and stiffness of axSpA, unless there's a reason that you can't take them. Research shows that NSAIDs are very effective in managing these symptoms of axSpA. Some people may need to take them regularly, while others will only take them as needed. This will depend on your symptoms and how you respond to the NSAID. Your rheumatologist will talk with you about how often you should take NSAIDs, and the benefits and risks of using NSAIDs long-term.

There are many different types and brands of NSAIDs – some are available over-the-counter, while others are only available on prescription. Your rheumatologist will talk with you about the best type for your needs.

**Targeted therapies** are medicines that target specific proteins in the immune system that produce inflammation. They include biological disease-modifying anti-rheumatic drugs, biosimilars and targeted synthetic disease-modifying anti-rheumatic drugs.

Your medicines may also change over time. Your rheumatologist might need to try different medicines to find out which will work best for you, or you may need another or a different medicine if your condition or symptoms get worse.

Usually, you need to have tried a certain number of medicines before another is recommended for you. For example, bDMARDs are only prescribed if your axSpA is active and if you haven't had success with standard treatments.

- Biological disease-modifying anti-rheumatic drugs (bDMARDs), which are also called biologics, have dramatically improved the quality of life for people with axSpA who need more than NSAIDs to manage their condition. These medicines work to control your immune system in a targeted way, slowing down the attack on your spine and joints. Most people simply call these treatments biologics, so that is the name we'll use from now on.

Your rheumatologist will talk to you about using biologics if you need more than NSAIDs to manage your axSpA symptoms, progression and its impact on your life – or if you're not able to take NSAIDs. Biologics are given by injection or through a drip into a vein (called an IV infusion).

There are two main types of biologics used to treat axSpA. Some of these are available through the Pharmaceutical Benefits Scheme (PBS) for both non-radiographic axial spondyloarthritis (nr-axSpA) and ankylosing spondylitis (AS), but some are only available through the PBS for AS:

- **Tumour necrosis factor inhibitors**, shortened to TNF inhibitors or TNFis. TNF is a protein that is overactive in people with axSpA, and leads to inflammation that causes swelling, pain and stiffness. TNFis block TNF, which can reduce inflammation, improve symptoms, and may slow the progression of axSpA.

- **Interleukin 17A inhibitors**, shortened to IL-17A inhibitors. People with axSpA have high levels of IL-17A, a protein that is associated with inflammation. These medicines work by blocking the activity of IL-17A, which can reduce inflammation, improve symptoms, and may slow progression of axSpA.
- **Biosimilars** are medicines that are copies of biologics. They're very similar, but not identical to, the original medicines. Your rheumatologist can explain more and will let you know if you're taking a biologic that can be substituted with a biosimilar. It's important to continue with the same medication that your rheumatologist has prescribed. On your script the 'no substitution' box should be ticked to ensure you receive the medicine that you have been prescribed.
- **Targeted synthetic disease-modifying anti-rheumatic drugs** (tsDMARDs) are a newer medicine for treating inflammatory forms of arthritis, including ankylosing spondylitis. One type of tsDMARD that is used for AS is called a Janus Kinase (JAK) inhibitor. JAK enzymes create signals in the body's immune system that cause inflammation. JAKi reduces or inhibits these signals to prevent inflammation.

### What is the PBS?

The PBS is short for Pharmaceutical Benefits Scheme, a scheme where the government subsidises the cost of a prescription medicine so you only pay the price of a standard prescription.

New medicines are continually being added to the PBS after approval by the Therapeutic Goods Administration (TGA).

Prescription medicines that are subsidised for AS are often subsidised for nr-axSpA at a later date, increasing the range of treatments available to people living with different stages of axSpA.

Ask your rheumatologist what treatments are available through the PBS for your type of axSpA.

Depending on your specific symptoms (including symptoms outside your pelvis and spine) and overall health, your doctor may also recommend using other medicines in addition to NSAIDs or biologics at different times. These may include:

- **pain relievers** (also called analgesics) for temporary pain relief
- **corticosteroids** that act quickly to control or reduce inflammation
- **disease-modifying anti-rheumatic drugs (DMARDs)**, which control your overactive immune system
- **nerve pain medicine**, to reduce pain caused by damage or pressure on your nerves.

Your rheumatologist might need to try different medicines to find out which will work best for you, or you may need another or a different medicine if your condition or symptoms get worse.

Taking your medicines as prescribed and talking honestly with your doctor about your symptoms and the changes you're noticing is a really important part of working out the best treatments for you.

## Side effects of medicines

All medicines have possible side effects. These can vary a lot from person to person and may be mild or more serious.

Knowing about the possible side effects and talking openly about these with your doctor can help you to plan together and quickly get on top of any that you experience.

Ask your doctor about the more common side effects with your medicine and what you should do if you experience any of these.

Biologics and DMARDs can increase your risk of infections. Your rheumatologist will tell you more about this, and ways you can reduce this risk.

If you're prescribed certain medicines, you'll need to have regular blood tests that check for side effects and monitor your disease activity.

## How we can help

You can call the Back Pain | Arthritis | Musculoskeletal Conditions (B.A.M) Helpline and speak to one of our friendly team to learn more about treatments for axSpA and ask questions about your treatment.

Call 1800 263 265 (Mon-Thu) or email [helpline@muscha.org](mailto:helpline@muscha.org).

## More to explore

- Creaky Joints Australia's booklet [A patient's guide to living with axial spondyloarthritis in Australia](#) is a downloadable PDF booklet with a large amount of useful information about axSpA. Chapter 8 (page 29) includes detailed information about medicines.
- [The Australian Rheumatology Association](#) produces medicine information sheets on each of the main prescription medicines used to manage axSpA. The medicines are listed from A-Z by ingredient name.
- [NPS MedicineWise](#) provides information to help you make the best decisions about your medicines. You can search the 'Medicine Finder' for information on prescription and over-the-counter medicines – or call 1300 MEDICINE (1300 644 424) for more information on your medicines.

## Treatments for eye symptoms of axSpA

Some people living with axSpA develop an eye problem called uveitis, which causes a painful red eye with blurred vision and sensitivity to light.

If you develop eye symptoms, it's always treated as a medical emergency and you'll need to quickly get your eye checked and treated by an ophthalmologist. Treatment is usually with prescription eye drops, which reduce the chance of permanent eye damage.

While this sounds very scary, and it is a significant problem, it's important to know that by understanding this risk, and knowing what signs to be alert for, you can reduce the risk of damage to your eyes.

Ask your GP or rheumatologist what you should do if you develop any eye symptoms.

## More to explore

- National Axial Spondyloarthritis Society (UK) has a booklet you can download about [uveitis and its treatment](#).

## Our community's tips for taking your medicines

- Talk with your pharmacist about any medicines that you haven't used before. Ask about potential side effects, when and how you should take them, and how to store them correctly.
- Create a [medicines list](#) that you can keep handy in your purse or wallet, or on your phone. Or use an app like the free [MedicineWise app](#) from the National Prescribing Service. Having a list of all of your medicines can be very handy, especially if you need to go to hospital (planned or suddenly) or need to give a list of all your medicines to another healthcare professional.
- Many pharmacies also have their own apps to track and store information about your medicines. Ask your pharmacist if they have one.
- If you have trouble remembering to take your medicines, or you take several medicines, a pill organiser is extremely helpful. It allows you or your pharmacist to store your weekly medicines in compartments for the day of the week and time that your dose is due. This is also really helpful when you are fatigued or have brain fog, as you can quickly see if you've missed a dose.
- Talk with your doctor or pharmacist about what you should do if you miss taking a dose of your medicine. It happens to all of us, so be prepared.
- For Aboriginal and Torres Strait Islander people living with chronic conditions, you may be eligible for the [Closing the Gap Pharmaceutical Benefits Co-payment Program](#). Ask your GP or prescriber to register you.
- When taking a new medicine, keep an open mind. Try not to prejudge what to expect from it. Advice from your doctor, or information from other people who've used it can be a useful guide about what to expect, but it's only a guide. Your own body and mind are the real judge about how a medicine is working for you.
- If you're experiencing physical or mental side effects that you haven't expected or been forewarned about, don't ignore them. Make an appointment to discuss them with your doctor.

## Physical therapies

Physical or manual therapies are an important part of your treatment plan for axSpA.

These therapies use a hands-on approach to help relieve your pain and stiffness and to improve your mobility, movement and joint function.

The most common of these include physiotherapy, occupational therapy, massage, myotherapy and osteopathy.

## Physiotherapy for axSpA

Physiotherapists, or physios, are an essential part of your healthcare team when you have axSpA.

When you're first diagnosed, you'll be referred to a physio who has experience in managing axSpA, and you'll probably need regular appointments, especially in the early days.

A physio can help you to improve your mobility, flexibility and strength while also reducing your pain.

They can help to do this in many ways, which may include:

- developing a personalised daily exercise program for you that includes stretching, mobility and strengthening exercises
- using hands-on therapies like ultrasound, mobilisation, massage and acupuncture
- giving you advice on posture at work and during different activities and teaching you how to regularly check your posture
- providing practical tips to make driving more comfortable
- helping you continue with sports and exercises you already enjoy so they don't aggravate your condition.

Your physio may recommend attending group exercise classes with other people who have axSpA or similar conditions.

It's important that your physio knows you have axSpA and understands the disease, as some manipulation can cause additional pain or flares.

## Spinal manipulation

This treatment should be avoided if your spine has fused or if you've developed osteoporosis as a result of your axSpA.

If you would like to try this treatment, but aren't sure if it's safe for you to do so, talk with your rheumatologist.

### How a GP chronic disease management plan can help

You may have heard people talking about having a management plan from their GP to help manage a chronic (ongoing) health condition like axSpA.

These plans include five visits a year to other healthcare professionals – like a physio, exercise physiologist or podiatrist – and Medicare will pay for part of the cost. These five visits may be to one healthcare professional or be spread between several professionals.

If you're interested in this service, book an appointment with your GP and let the receptionist know you want to create a chronic care plan. You'll usually need a long or double appointment to do this.



## More to explore

- You can read more about how to access a physio and about other types of physical therapies in Section 1 of the axSpA self-care plan.
- Our article [Physical or manual therapies](#) tells you more about different physical therapies used to manage musculoskeletal conditions.

## Complementary therapies

Complementary therapies include a wide range of medicines, products or practices that are not currently considered to be a conventional or mainstream medical treatment.

These therapies include acupuncture, supplements, herbal medicines, meditation, massage, aromatherapy and naturopathy.

Complementary therapies are widely used by people with arthritis, including people with axSpA to help:

- manage symptoms such as inflammation, pain and fatigue
- deal with anxiety and stress
- with sleep
- feel in control of their own health.

While many people feel that using complementary therapies benefits their health and wellbeing, there isn't as much evidence to support their use for axSpA as there is for conventional treatments.

For many complementary therapies, there aren't enough well-designed randomised controlled trials to show whether or not they're effective.

More and more research is now focusing on these therapies, but because the evidence is still lacking, it's wise to be cautious.

If you're interested in using any complementary therapy, it's important to remember that they may have side effects and they can interact with your other treatments. That's why it's so important to talk with your doctor about any complementary therapies you're interested in trying.

Acupuncture and massage are two complementary therapies that people with axSpA often find helpful in providing temporary relief from stiffness and pain. If you're interested in using these therapies, it's ideal for them to be part of your treatment plan from a qualified physio who's experienced in treating axSpA.

## More to explore

- Our article [Do your research](#) includes detailed tips to consider before starting a new complementary therapy, including helpful suggestions for doing your research and questions to ask.
- Our resource [Complementary and alternative treatments](#) includes brief information about many of the popular types of complementary therapies and links to professional associations for their therapists.

## Surgery

Most people with axSpA will be able to manage their condition using a combination of exercise and physical therapies, medicines prescribed by their GP or rheumatologist, and self-management like healthy eating and caring for their mental and physical wellbeing.

In severe cases, surgery may be considered if all other treatments haven't provided enough relief from symptoms, or if you have a spinal fracture or dislocation. Surgery is never used as a first line treatment for axSpA.

Surgery that may be considered includes:

- hip arthroplasty (replacement) surgery if you have severe and persistent hip pain
- cervical fusion, where bones in the cervical (upper) spine are fused together to treat a fracture or dislocation
- wedge osteotomy to remove a wedge-shaped piece of bone from a vertebra to allow the spine to be realigned.

If your doctor thinks that surgery might be a good option for you, they'll refer you to an orthopaedic surgeon. Together, you can discuss the benefits and risks of surgery and decide if it's right for you. If you're not sure about surgery or don't feel comfortable about the information from the surgeon, ask your doctor to refer you to another surgeon for a second opinion.

## Understanding your surgery

You should discuss the risks of your specific surgery with your surgeon and anaesthetist before you decide whether to go ahead with it. And if you don't understand something, ask them to explain it some more.

As well as understanding the procedure and what to expect, don't forget to ask your doctor about any rehabilitation required, the costs involved with surgery and for an idea of how long you may be waiting for your surgery. Also ask how long it will take you to recover and get back to doing your usual activities.

It can be helpful to take someone with you to these consultations. There can be a lot to take in, so an extra set of eyes and ears can help you make sense of it all. They can also provide you with support if you feel anxious or stressed (which is completely understandable!).

## More to explore

- Our article [Surgery and musculoskeletal conditions](#) includes information about some of the more common types of surgery used for arthritis. It also covers what to discuss with your surgeon, getting ready for surgery, recovering from surgery, and the possible costs.
- Arthritis Foundation (USA) has a [helpful checklist](#) to help you prepare for going home after surgery.



## 3. axSpA needs exercise

### Things to remember

- Being physically active is the single most important thing you can do to manage your axSpA.
- The right types of exercise can help to improve stiffness, pain, fatigue, breathing capacity, posture, flexibility and range of movement – as well as boosting your mood and overall wellbeing.
- A physio or exercise physiologist (EP) with experience in axSpA will help you to develop an exercise program with the right moves for your needs.
- Your program will include exercises for flexibility, strength, overall fitness, posture and breathing.
- Making an exercise plan can help you to keep track, stay motivated and see how exercise helps you manage symptoms.
- It's also important to find the right balance between exercise and rest – and to know when you need more or less of each.
- It can be more fun to exercise with friends, in a group or as part of a team. We can help you to find a class, group or centre that suits you.

### Why exercise is so important for axSpA

You probably already know that your pain and stiffness are at their worst when you haven't been moving much – like when you've been sitting at your desk, driving or first thing in the morning after lying in bed all night. On the flip side, you're sure to have noticed that most of your symptoms ease when you're moving around and exercising.

Exercise is the single most important thing you can do to help manage your axSpA. Exercise can improve symptoms including stiffness, pain, fatigue, breathing capacity and posture. It helps increase your flexibility and range of movement so it's easier to do many everyday tasks.

As soon as possible after receiving your diagnosis, you should ideally begin a personalised exercise program developed by a physio or exercise physiologist (EP), and aim to do some exercise every day.

Remember that you can take pain relievers if you need to before exercising. Just make sure you follow your doctor's instructions.

Being active is also important for your overall health and wellbeing. It helps keep your muscles, bones and joints strong so that you can keep moving. It reduces your risk of developing other conditions such as heart disease, osteoporosis, diabetes and some forms of cancer. It boosts your mood, benefits your mental health, helps with weight control and improves sleep.

### Different types of exercise for axSpA

The types of exercise that will be best for you will depend on what you enjoy and suits your lifestyle, the severity of your symptoms, and whether or not you have other musculoskeletal conditions or health issues.

Because of the nature of axSpA and how it affects your spine, it's a very good idea to begin your exercise program with the support and supervision of a physio or EP who has experience with axSpA.

You may work with a physio or EP in a clinic or gym, where you'll learn the activities and exercises that will help strengthen your spine and improve your range of motion and mobility. You can then integrate these exercises into your daily routine at home.

It's ideal if you can do some form of exercise every day.

Your physio or EP will work with you to develop a plan that includes several different types of exercises including:

### **Flexibility exercises**

Stretching and range of movement exercises help improve the flexibility of your joints, reduce stiffness and pain, and minimise the risk of the joints in your spine fusing together. Stretching exercises after a hot shower or bath can be especially helpful in easing morning stiffness.

### **Strength exercises**

Strength exercises build muscle strength, provide stability to your joints, improve your bone health, and improve your ability to perform daily tasks.

Exercises that strengthen the muscles around your spine, including the abdominal and back muscles, are important for people with axSpA.

### **Overall fitness exercises**

Exercise that gets you moving and increases your heart rate – like brisk walking, swimming or cycling – will help improve your heart and lung health and can also help with endurance, weight loss, and preventing other health problems like diabetes. This type of exercise is also called aerobic exercise, cardiovascular exercise or 'cardio'.

When you have axSpA, cardio exercise is particularly important, because joint stiffness can limit your chest expansion. Regular cardio exercise such as swimming, helps expand your chest and maintain your joint mobility.

Many people with axSpA find exercising in water to be a helpful way to work on mobility and overall fitness. The buoyancy of the water removes pressure on the joints, and the warm water can help ease stiffness and pain.

### **Posture training**

Exercises that help maintain your posture are important for everyone, but are especially important for people with back conditions.

axSpA can make your spine feel 'frozen' or fixed in a position. Your physio or EP can teach you posture training exercises to help prevent excess curving of the spine that can make your symptoms worse.

## **Breathing exercises**

Usually, our ribs move up as we inhale and move down when we exhale. But when you have axSpA, the rib joints that attach to the spine can stiffen and even fuse, preventing them from being able to rise and fall. This reduces chest expansion and can make you feel short of breath and tight around your chest.

Deep breathing exercises help to maintain mobility in your ribs and chest, and your capacity for chest expansion. Your physio or EP will explain how and when to do these.

Remember to always see your doctor if you're concerned about your breathing, or if you're getting out of breath with very little movement.

## **What exercise is best for me?**

In addition to specific stretching and other exercises that your physio or EP will prescribe, it's handy that there are lots of activities that can help with your flexibility, strength and overall fitness all at the same time. Many of these are suitable for people with axSpA and might be included in your exercise program:

- swimming or water exercise classes
- cycling, including using an exercise bike
- Pilates
- yoga
- tai chi
- brisk walking
- chair exercises
- low-impact aerobics
- strength training.

Work with your physio or EP to make sure your plan includes activities that you enjoy, are committed to doing, and that fit with your lifestyle and experience of axSpA.

### **The feel-good chemicals released by exercise**

When you exercise, your body releases chemicals such as endorphins, serotonin and dopamine into your bloodstream.

They're sometimes called 'feel-good' chemicals because they boost your mood and make you feel good.

These chemicals also interact with receptors in your brain and 'turn down the volume' on your pain system.

More good reasons to keep active!

## Make an exercise plan and keep track

You'll find it's easier to exercise regularly if you plan it. It's very easy for life to get in the way – work, family, social activities, household chores – and exercise is often the casualty.

You can create a simple chart with the days of the week, the types of exercise you'll do and how long you'll exercise for. There are many different ways you can record this information: you might like to keep the chart on your computer desktop, write it down in a notebook, or use a health and exercise tracking app.

Day	Time	Exercise	How long
Every day	7.50am	Stretching exercises at home after morning shower	10 mins
Every day at work	Every 30 mins	Quick posture check, stand up, move and stretch	1 min
Sunday	9am	Walking the dog with the kids	45 minutes
Monday	6pm	Aqua aerobics class after work	1 hour
Tuesday	8am	Strength exercises before work	30 minutes
Wednesday	12.30pm	Lunchtime tai chi class in the park	45 minutes
Thursday	6.30pm	Strength exercises after work	30 minutes
Friday		Rest day (but remember to keep up stretches and posture checks!)	
Saturday	9am	Walk to and from the farmers' market	1 hour

You might also find it useful to jot down some notes about how you felt after being active: Did your pain improve? Did you feel your mood lift? Or did you overdo it?

These notes can help you to better manage your axSpA and see how it responds to exercise and how you might want to adapt your plans. It can also help motivate you on days when you don't feel like exercising, if you can see how exercise has helped manage your pain and stiffness.

This information can also provide useful feedback to help your physio or EP fine-tune your exercise plan.

## Our community's tips for balancing exercise and rest

Sometimes it can be difficult to exercise due to pain, stiffness or chest tightness. But remember that even light and low impact movement can help your pain.

It's important to find the right balance of rest and exercise. If you're not sure what the right balance is for you, talk with your doctor, physio or EP for advice.

These tips from our community may help you too:

- Be mindful of the things you need to do in your day, including exercise, so you can pace yourself and have enough energy to get you through.
- Be aware of not pushing yourself too hard. Trust your own judgment about how much you can do and listen to your body.
- You might need to shift your expectations and perceptions of 'what the new normal might look like', especially after surgery. For example, just because you could do something a year ago, you may not be able to do the same thing now.
- You may need to manage your pain levels before exercising. For example, have a warm shower or use a heat pack to loosen tight muscles, or take some pain medicine.
- Rest can involve meditation or other practices with a low level of physical exertion but a higher level of mind-body interaction.

## How to find an exercise class, group or centre that suits you

It's often helpful to exercise with friends, in a group, or as part of a team – especially if you find it difficult to get motivated.

As a bonus, some organised exercise classes are run by physios, EPs or others who are aware of any special considerations needed for people who have musculoskeletal conditions like axSpA.

Try these sources to find an exercise class, group or centre that suits you:

- **Neighbourhood houses and community centres** are ideal starting points to find exercise options close to you. Visit the Australian Neighbourhood Houses and Centres Association [Members page](#) to find your state or territory's website, where you can then search for local houses or centres and find exercise programs they offer.



- **Local councils** are also a good source of information about exercise programs. Go to your local council's website and search 'exercise classes' to see what they offer.
- **Some larger gyms and physio centres have heated indoor swimming pools** where you can swim laps or join a warm water exercise class. You can also search online for classes held at community swimming centres.
- **Walking groups** are a fun way to get active, meet new people and socialise. The Heart Foundation has over 1200 walking groups around Australia, you can search for one close to you [here](#).
- **parkruns** are free, weekly community events are held all around the world with 5km walks and runs in parks and open spaces on Saturday mornings. Everyone is welcome, there are no time limits, and no one finishes last!
- **The Back Pain | Arthritis | Musculoskeletal Conditions (B.A.M) Helpline** 1800 263 265 can tell you more about exercise classes or groups in your area.
- **There are lots of free exercise apps, YouTube channels and websites with free online exercise programs.** These can be especially helpful when you need or prefer to exercise from home. Enjoy searching these to find something that fits with your needs.

[Our article on online exercise](#) includes tips to help you assess online offerings and see if they're right for you, as well as links to some great free exercise videos suitable for people with musculoskeletal conditions.

## Tips for getting started with exercise

If you've just been diagnosed with axSpA, haven't been active for a while, or if you're in the midst of a flare, you might not know where to start with an exercise program.

Don't worry: once you find the right activities and support, you'll find it easier and reap the benefits. Here are some tips for getting started:

- Check with your doctor or rheumatologist before starting an exercise program.
- When you have axSpA, it's especially important to see a physio or EP for advice about specific exercises. They can suggest safe exercises tailored for you and make sure you're doing them correctly, so you don't cause an injury.
- Always build up slowly. When you first start, do less than you think you'll be able to manage. If you cope well, do a little bit more next time, and keep building up gradually.
- You may feel a bit sore the first few times you try a new activity. As you get used to it, this will usually get better.
- If one type of exercise always causes a flare-up, you might need to find a different type of exercise.

## More to explore

- Our resource [Exercise for musculoskeletal conditions](#) includes more information about exercising in water and tai chi, as well as some helpful exercise cautions and suggestions.
- We also have a detailed article on [water exercise](#) and all its benefits.
- National Axial Spondylarthritis Society (UK) has [some great videos](#) and resources on exercising with axSpA, including specific videos on posture, balance, stretching and strength building. They also have a video on breathing exercises and a [downloadable PDF](#) of exercises to help manage your axSpA.
- Spondylitis Association of America (SAA) has a series of free videos 'Back in action', again for axSpA. There are separate videos for cardio, strength, morning and evening stretching, and yoga. SAA also has a handy [stretch and mobility guide](#) you can print and put somewhere you will see regularly, as well as a [downloadable exercise brochure](#).



## 4. Healthy eating when you have axSpA

### Things to remember

- Even though there isn't a miracle diet for axSpA, eating a wide range of healthy, unprocessed foods can help you to feel as well as possible.
- An ideal eating plan for axSpA includes plenty of vegetables, fruits, wholegrains, legumes and beans, lean meat/tofu, along with nuts, seeds, fish and oil.
- People with axSpA are at increased risk of osteoporosis (brittle bones), so it's important to make sure you get enough calcium and vitamin D.
- About 1 in 10 people with axSpA have inflammatory bowel disease. A gastroenterologist can diagnose this and can help you to manage it with the help of a dietitian.
- Omega-3 fats found in oily fish, flaxseeds, chia seeds, walnuts and fortified foods have been shown to help reduce inflammation that's part of axSpA.
- Sometimes the pain and fatigue of axSpA can make it difficult to prepare food and eat well. We have lots of tips that can help.
- If you're overweight, losing weight can help to take pressure off your joints and improve your overall health and wellbeing. There's no need to try and lose weight on your own - find the right healthcare professionals to support you.

### What is the best eating plan for RA?

Your body works best when you eat a wide range of healthy foods.

While there's no special diet or miracle food that can cure arthritis, most people find that they feel better if they enjoy a balanced eating plan filled with fresh, unprocessed foods, while limiting processed, fatty, salty and sugary foods.

### What does this type of eating plan look like?

A healthy eating plan for axSpA looks a lot like a typical Mediterranean diet and includes:

- foods that are as unprocessed as possible
- a rainbow of fresh whole vegetables and fruits (not juices),
- wholegrains like brown, black or red rice, quinoa, buckwheat, oats, as well as whole grain breads and pastas
- legumes like chickpeas, lentils, cannellini, red kidney and other beans
- raw, unsalted nuts and seeds
- fish, seafood, poultry and tofu
- healthy oils such as olive and flaxseed.

This type of eating generally includes eating less:

- red meat
- foods high in sugar, salt and fat
- highly processed foods.

Eating in this balanced way and drinking enough water can help you to:

- keep up your energy levels
  - maintain your weight
  - sleep better
  - improve your mood
  - have a greater overall sense of wellbeing
  - prevent other health problems, like heart disease and diabetes.
- And all of these effects may help to improve your symptoms – like pain, stiffness, inflammation and fatigue.

### More to explore

- The type of eating plan we've described is sometimes called an anti-inflammatory diet. We've written an [article](#) about anti-inflammatory diets, the evidence for them and tips to move your eating plan in this direction.
- Our [Handy tips for eating well with arthritis](#) includes helpful tips for keeping your eating plan in balance.
- For healthy meal ideas, have a look at our [Healthy meals on a budget](#) and [recipes](#).
- Arthritis Foundation's [The ultimate arthritis diet](#) looks at the different parts of the Mediterranean diet and how they may benefit joint health.
- If you need help in making changes to your daily eating, it's a good idea to chat with an [accredited practising dietitian](#).

### Eating for healthy bones

People with axSpA are at higher risk of developing [osteoporosis](#), so it's important to make sure you're getting enough calcium and vitamin D in your eating plan.

Find out how much [calcium and vitamin D](#) you need and learn more [bone health tips](#) in our resources.

### Inflammatory bowel disease in axSpA

About 1 in 10 people with axSpA have inflammatory bowel disease (IBD).

There are two main types of IBD: Crohn's disease and ulcerative colitis.

Symptoms of these conditions include:

- diarrhoea
- stomach pain and cramping
- loss of appetite
- weight loss
- fatigue
- blood or mucus in your bowel motions.

If you have axSpA and develop gut symptoms, ask your GP or rheumatologist to refer you to a gastroenterologist for further tests, diagnosis and ongoing management.

If you do have inflammatory bowel disease, your gastroenterologist may recommend seeing a dietitian who has experience with these conditions and can provide you with specific recommendations for your eating plan.

Always chat to your doctor or dietitian if you're thinking of making any major changes to your eating plan.

Big changes to your eating, where you eat a lot more or a lot less of one type of food or restrict your kilojoules too much, can lead to imbalanced eating where you're getting too much or not enough of certain nutrients.

Some supplements may interact with your prescribed medicines. Speak with your doctor or pharmacist before taking any new supplements.

Your doctor or dietitian can provide guidance to help make sure you're getting all the nutrients you need.

### **What about omega-3 fats?**

You've probably heard people talking about omega-3 fats (often called omega-3 fatty acids, or simply omega-3s) for joint, heart and brain health.

Foods and some supplements that are rich in omega-3 fats have been shown to help reduce inflammation that's part of axSpA.

Omega-3s don't reduce inflammation as much as medicines, but when you eat them through food sources, they don't have side effects and may have other health benefits.

So, it makes good sense to add a few servings of omega-3-rich foods to your weekly eating plan.

Foods rich in omega-3s include:

- oily fish and seafood including salmon, tuna, mackerel, sardines, anchovies and oysters
- flaxseeds and flaxseed oil (also called linseeds and linseed oil)
- chia seeds
- walnuts
- foods that fortified with omega-3s, including some dairy products, eggs and margarines.

### **Fish oil supplements**

Fish oil supplements are also a rich source of omega-3 fats.

Remember that you'll need to talk to your doctor or pharmacist before taking any supplements to make sure you're taking the correct dose for your needs and to make sure it won't interfere with any other medicines you're taking.

## Our community's tips for healthy eating

- Have a regular schedule for your meals and snacks – eating moderate amounts of food at set times during the day will give you steady energy levels throughout the day.
- Go grocery shopping when you're feeling well and energised. And be sure to shop when you're not hungry, to help you make healthier food choices.
- Ask your doctor or a dietitian if there are any foods that may interact with your medicines.
- If you need help with healthy eating, include a dietitian as part of the allied health visits within your chronic disease management plan (if you have one). If you don't have a plan, chat to your doctor about your options for seeing a dietitian.
- Some medicines, such as prednisolone, can increase your hunger and cause weight gain. Be aware of this and chat to your doctor or dietitian about ways to manage your hunger. It can help to have a range of healthy snacks, such as cut up raw vegetables, ready for when hunger strikes.

## What to do when you don't feel like cooking or eating

Sometimes, the pain and fatigue of axSpA can make it difficult to eat enough and to eat well. Research shows that during periods of intense pain, most people report eating less. Some people also lose their appetite or feel nauseous as a side effect of their medicine.

Pain and fatigue may also make it difficult for you to shop for healthy food and prepare well-balanced meals.

If your appetite is low for some time, it can affect your health. You may be missing out on nutrients you need, become underweight and affect your immune function, making it harder for your body to fight infections.

Knowing that you might lose your appetite from time-to-time can help you to plan ahead:

- **Ask for advice.** If you need help planning meals, or finding simple ways to prepare nutritious meals, chat with a dietitian for information and advice.
- **Prepare meals in advance.** When your pain and fatigue are under control, take some time to make extra meals that you can freeze for the times you need them. This way you'll be eating meals that you know are healthy and that you enjoy.
- **Look up options for healthy food delivery services** and consider using one of these for a short time during flares.
- **Talk with your doctor about supplements.** You may need a supplement if you can't get enough of some nutrients through your eating plan or if you have a deficiency. Your doctor is the best person to advise you on this.

## Tips for low-effort meals

There are lots of healthy ingredients you can stock up on and store in your pantry or freezer to make low-effort meals easier when pain and fatigue make it difficult to cook. Here are some simple ingredients and ideas to try:

- **Canned sardines** (a great source of omega-3 fatty acids, protein and calcium) on wholegrain toast with a simple side salad.

- **Low-salt baked beans** served on a baked potato or baked sweet potato.
- **Frozen veggie burgers** cooked and served in a wholemeal pita bread pocket with any of your favourite burger toppings (try beetroot, sliced tomato and crunchy lettuce).
- **Canned chickpeas or other beans** and canned chopped tomatoes, simmered with veggie stock and any veggies you have on hand to make a quick minestrone.
- **Free-range eggs** (which usually keep well in the fridge for weeks) scrambled, boiled or poached and served on top of wholegrain toast and baby spinach with some sliced avocado on the side.

### More to explore

- Our article [Now we're cooking!](#) includes lots of tips for preparing meals with less stress when you have a chronic illness.
- Try any of these [17 healthy no-prep recipes](#) for the days when you just can't.
- Versus Arthritis' [Five easy ways to eat well with arthritis](#) includes some great tips and quick recipes for a super-simple breakfast, lunch and dinner.

### Keeping to a healthy weight

Being overweight is linked to increased stress on your joints as well as increased pain, so keeping to a healthy weight and losing weight if you need to makes good sense when you have axSpA. Carrying extra weight can lead to a bit of a vicious cycle when you have axSpA: extra weight on painful joints will increase the pain you experience. Being in pain may then affect your ability to be as active as you'd like. This can make your pain worse and may lead to more weight gain. It can also be difficult to be more active when you're overweight, which can also lead to increased pain and weight gain.

As well as directly affecting your axSpA, there are many other long-term health problems, like heart disease and diabetes that are linked to being overweight.

To lose weight, you'll need to:

- set a realistic goal
- create a healthy eating plan that supports your weight loss goal, your health needs and fits with your lifestyle (big hint: 'diets' are not the way to do this!)
- learn new ways of being active and build this into your everyday life
- finding the right healthcare professionals to support you.

Losing and maintaining healthy weight does take work, but the results in improved wellbeing and reduced pain are well worth it.

It's important to note that some medicines can contribute to weight and/or fluid gain. If you notice any changes to your weight, but your diet and exercise levels haven't changed, it's a good idea to discuss these changes with your doctor.

## More to explore

- We've written lots of helpful articles on losing weight when you have a musculoskeletal condition, here are a few to explore:
  - [Handy hints for eating well](#)
  - [Setting goals](#) - Using SMART goals and weight loss as a practical example
- Better Health Channel's [Weight loss - a healthy approach](#) is designed to help you make small, achievable changes to your lifestyle that can help you to lose weight the healthy way.





## 5. Managing your pain

### Things to remember

- Experimenting with and finding new ways to manage ongoing pain is an essential part of your axSpA self-care plan.
- Your treatment plan, staying active and eating well will all contribute to managing your pain – and there are lots of additional strategies and tools you can use as well: from soothing heat and cold to getting absorbed in activities you really enjoy that distract you from pain.
- Learning to balance activity and rest using a strategy called pacing can help to reduce your risk of pain, flares and fatigue.
- Poor sleep, fatigue and pain are closely tied together, with each one making the other worse. Learning to break this cycle will give you significant relief.
- Flares are part of the unpredictable nature of axSpA. Having a plan to manage them, including creating your own care package, can help put you back in control.
- Setting clear goals gives you something to aim for – and the steps you take towards your goals can help you to better manage pain. Our step-by-step guide will show you how.

### Living well with ongoing pain

Experiencing and managing pain is a major part of living with axSpA and an important part of your self-care plan.

When you live with the ongoing (often called chronic) pain of axSpA, it can affect your daily activities and work, exercise choices, sleep, energy levels, mood and relationships. In turn, these effects can then increase your experience of pain.

For example, ongoing pain can make it difficult for you to sleep, which can make you feel more fatigued during the day. The inflammation of axSpA that causes pain can also make you feel fatigued. When you are more fatigued, your pain may feel worse and limit your activities more than usual.

Over time, living with ongoing pain can have longer-lasting effects on your mood, self-confidence and sense of wellbeing.

The good news is that there are many simple, practical ways to manage your pain and the impact it can have on your life.

For example, most people with axSpA experience the most pain during the second half of the night, when they first wake up, or when they haven't been moving much during the day. Finding ways to move more and incorporate exercise into your day are important ways to help manage your pain.

Having plenty of different strategies and tools that you can turn to when you need them can help give you more control over your pain and make life with axSpA easier to manage. These tools will take some time and effort from you: but you'll soon realise that the rewards are well worth it.

## More to explore

- Our booklet [Managing Your Pain](#) provides an A-Z kit of pain management tools that you can dip into whenever you need them. It includes lots of practical suggestions that you can easily try out to see if they work for you. Some of the tools in the booklet are covered in this section, and there are many more in the booklet.
- You'll also find that a lot of the info in Section 6 of the axSpA self-care plan: [Your mental and physical wellbeing](#), like mindfulness and using relaxation techniques, can help to manage your pain.

## How axSpA causes pain

The pain you experience from axSpA is likely to vary over time, and can be caused by a number of different things going on in your body including:

- inflammation around your joints, tendons and muscles
- the shortening and tightening of tendons and muscles
- protective muscle spasms.

You'll most likely feel this pain as a combination of dull aches and intense, sharp pain.

Most of the pain will be in your back and neck, but you may also feel it in your pelvis, feet and hands.

The pain of axSpA is often referred to as persistent, chronic, long-term or ongoing pain. This distinction from acute or short-term pain is important to understand, because our brains and bodies respond to ongoing pain in different ways.

## More to explore

When you understand what's really going on behind the scenes with pain signals and the way your body reacts to them, it can help you to see your pain differently and perhaps be a little more open to trying new things that can help you to manage pain and get out of the vicious cycle it tends to create.

You might like to have a look at:

- [Pain, the brain and your amazing protectometer](#) – Our Koadlow Public Lecture presented by Professor Lorimer Moseley.
- [Treating pain using the brain](#) – Our Koadlow Public Lecture presented by Adjunct Associate Professor David Butler.
- Our resource [Persistent pain](#).
- [National Axial Spondylarthritis Society \(UK\)](#) page on managing axSpA pain. Scroll through this page to find resources on the type of pain you're experiencing and want to learn more about, including night-time, neck and shoulder, jaw, knee, lower back and foot pain.
- Versus Arthritis' [Managing your pain](#).

## Medicines

The medicines you're using for axSpA all play a role in helping to manage your pain. At different times, you and your doctor may use different types of medicines to help manage your pain in different ways.

It's always important to balance the benefits of medicines with the side effects they may have.

Also remember that medicines are just one part of your pain management tool kit, and they'll have the most benefits when you're able to combine them with other strategies like exercise, distraction, relaxation, healthy eating and getting a good night's sleep.

## More to explore

- Section 2 of the axSpA self-care plan: [Treatments for axSpA](#) includes an overview of the medicines used to manage axSpA.
- [Medications for pain](#) in our Managing Your Pain booklet explains more about the different types of medicines used for pain and tips for using these.

## Physical therapies

Physical therapies like physio, massage and occupational therapy use a hands-on approach to help relieve your pain and stiffness and to improve mobility, movement and joint function.

You can read more about many of these different types of therapies in Section 1 of the axSpA self-care plan under [Working with your healthcare team](#) or in our blog [Physical or manual therapies](#).

## Complementary therapies

Complementary therapies are widely used by people with axSpA to help manage their symptoms, including pain.

Read more about complementary therapies and explore other resources in Section 2 of the axSpA self-care plan: [Treatments for axSpA](#).

## The importance of exercise

Being physically active is such an important part of managing axSpA, we have dedicated a whole section of your self-care plan to it!

[Read axSpA needs exercise](#) to learn all the different ways that being active can help to improve pain, stiffness and fatigue of axSpA - as well as boosting your mood and overall wellbeing.

## **Soothing heat and cold**

Applying heat or cold to painful or stiff joints and muscles can help to relieve your pain.

Some people prefer heat, others prefer cold – and some types of pain prefer either heat or cold.

As a general rule, heat can relieve joint stiffness, and muscle spasms and tension. Cold can reduce swelling and may be especially helpful for a hot, tender joint.

Depending on where you are – home, work, out and about – there are many different ways you can use heat and cold, from hot showers, heat packs or an electric blanket through to ice packs and cooling gels.

When you have axSpA, using heat to relieve stiffness in your spine can be especially helpful. You might like to try:

- a warm shower or bath before bed
- an electric blanket to help with night-time pain (make sure you turn the blanket off before you go to sleep, and follow any safety instructions)
- a warm shower when you wake up to help you start moving and relieve morning stiffness.

## **More to explore**

- Our resource [Heat and cold therapy](#) includes more examples of heat and cold as well as important safety tips you need to keep in mind when using them.

## Balancing activity and rest: The art of pacing

'Pacing' is often a new concept for people with axSpA, and it's one that is definitely worth learning more about.

You probably already know about the trap that's so easy to fall into when you live with persistent pain: when you feel good, you do as much as possible and often over-do things. Then, because you're now in pain you avoid doing much because it hurts. Both of these things – overdoing and avoidance – aren't helpful for managing persistent pain and they can actually make your pain worse.

Pacing can be an effective strategy to help you do the things you want to do by finding the right balance between rest and activity (both physical and mental). This can help to reduce your risk of pain, flares and fatigue.

Balancing activity and rest in this way means you'll need to listen to your body and understand what you can do on a good day (when your pain is under control) and on a bad day (when your pain is more intense).

### How to work out your limits

Pacing is all about the amount of time you can do things before your pain or fatigue worsens.

For example, if you know that you can walk the dog for 20 minutes before your pain becomes worse, then that's your current limit. Then you need to take a rest break. A rest break means switching from the active thing you're doing (walking the dog) to doing something more passive (like reading a book, paying your bills online, or creating a meal plan for the coming week).

Working out your current limits can take some trial and error. Recording your activities and pain levels in a [health tracker](#) or pain journal will help you keep track. It will also help you clearly see the activities, or the time spent on activities, that may be causing you problems.

If you find that your limit changes quite a bit from day-to-day, you can work out your average limit with some simple maths:

- Over a week or two, record the amount of time you can do an activity (walking the dog, for example) before your pain becomes worse.
- Add these amounts of time up and then divide by the number of times you've measured how long you can walk the dog.
- This will give you an average limit.
- For example, if you've recorded the times of five walks, add all the times up and then divide them by five:
  - walk times:  $20 + 22 + 15 + 22 + 21$
  - added together equals 100
  - divide by five equals 20 minutes.
- Now work out 80 per cent of this limit. So, if your average was 20 minutes, 80 per cent will be 16 minutes. By reducing your average limit by 80 per cent, you're giving yourself a limit that's achievable to do most days – good or bad.
- This will be your new current limit for walking the dog.

- Over time you'll be able to gradually increase this limit.
- If you're not sure how to work out percentages, [try this online percentage calculator](#).

## How you'll benefit from pacing

By understanding your limits, and what you can do at this point in time, you can plan and take control of your day and the things you do. You can plan activities and rest breaks so that by the end of the day, you've done most of the things you wanted or needed to do, and you haven't made your pain or fatigue worse.

Pacing will also help you gradually increase the amount of time you spend being active and performing certain activities.

For example, if your current limit for walking the dog is 20 minutes, do this regularly for a week. In the second week, try increasing the amount of time by 10 per cent – so instead of 20 minutes, walk for 22 minutes.

Record how you're going in your pain journal. If you're able to tolerate this increase, try adding another 10 per cent in week 3. And so on.

Keep recording your progress and set milestones – like being able to walk for 30 minutes – and reward yourself when reach them. Don't be hard on yourself if this takes time. Slow progress is still progress.

Remember that you can apply these formulas for pacing to mental activities in the same way you do to physical activities: because concentrating on hard mental work for long periods of time can also wear you out when you're living with a condition like axSpA.

## Tips for pacing yourself

- Plan your day.
- Prioritise the things you want and need to do – what really needs to be done?
- Can you do some things tomorrow?
- Break jobs into smaller tasks and rest in-between. The job will still get done, and you should have more energy for other things. For example, if you know your current limit for gardening is 30 minutes, then choose what you can do in 30 minutes and nothing more. Then take a rest break – even if you feel okay.
- Switch between physical jobs and less active ones. For example, vacuum the lounge, then sit and pay your bills. You're still getting chores done, but you're not overdoing it.
- You can apply the same principles at work. For example, if using your computer keyboard and mouse is hard work on your joints, work out your limit for computer-based work and then switch to a task that doesn't involve using your computer – like returning phone calls or having a staff meeting. Try to take a stretch break after sitting at your desk for any length of time – and set a timer to remind you to take that break!
- Do a little less than you think you can on a good day and a little more than you think you can on a bad day.
- Ask for help when you need it.

## More to explore

- The Department of Health Western Australia's [painHEALTH](#) website has a section on pacing and goal setting, and includes a helpful pacing work sheet.
- National Axial Spondylarthritis Society's (UK) [booklet on living with axSpA fatigue](#) has helpful information on pacing from pages 18 – 21, including understanding the pattern of boom and bust.

## Close cousins: Sleep, fatigue and pain

You'll find that lots of the information we've included about managing pain overlaps with understanding and managing sleep and the fatigue of axSpA.

That's because the three are so intertwined, it can often be difficult to tease them apart. It therefore makes sense that you can often help manage your pain better by managing your sleep and fatigue – and by managing your sleep and fatigue, you help your pain.

If getting a good night's sleep is difficult for you, and fatigue is one of your major symptoms along with pain, you'll find the information on pacing earlier in this section especially helpful.

## Managing sleep and fatigue

### Sleep problems, pain and axSpA

Many people with axSpA report problems with pain during the night, as joints and muscles stiffen up while you're in bed. This pain can make it hard to sleep, especially during the second half of the night, or wake you earlier than you wanted to get up.

Unfortunately, not getting enough quality sleep lowers your pain threshold. This in turn affects the quality of your sleep. Pain can affect your ability to be active – which affects your quality of sleep and your pain levels. This can make you anxious or stressed – which again will impact on your quality of sleep and the amount

The diagram on the right helps to visualise how this happens.

### How to break the pain-sleep cycle

The good news is there are many things you can do to break this cycle – and improve both your sleep and your pain.

**Talk with your doctor** about your sleep and pain. Is your axSpA being managed well enough? Is there something more you can be doing to ease the pain you're experiencing? Managing your condition and your pain levels will help you get a better night's sleep.



The pain-sleep-cycle



**Try not to put too much pressure on yourself to go to sleep.** This can lead to anxiety if you don't fall asleep quickly. Feeling anxious will impact on your ability to sleep – and on the pain you experience.

**Develop a sleep routine.** Try to go to bed and get up at the same time each day. This will help your body clock regulate production of the hormones needed to go to sleep (melatonin) and to stay awake (serotonin). Limit your time in bed to the amount of sleep you think you need each night. This will help to reduce wakefulness during the night.

**Get out of bed if you're unable to sleep.** Don't stay in bed tossing and turning. Have a warm caffeine-free drink (like chamomile tea or milk), do some gentle stretches or slow breathing exercises and go back to bed when you feel more comfortable. You may need to do this a few times throughout the night if you have a difficult night sleep-or pain-wise.

**Try some relaxation techniques.** These might include mindfulness or visualisation (like counting sheep), deep breathing or a warm bath before bed. Experiment with these techniques to see what works best to help you feel more relaxed, which may help you manage your pain better so that you can get to sleep – and sleep well.

**Be active during the day.** As well its many other benefits, regular exercise, even gentle exercises like stretching, can help you fall asleep and stay asleep longer.

**Eat well.** Your body works best when you eat a wide range of healthy foods. A balanced diet and drinking enough fluid can help provide you with better energy levels and give you a greater sense of wellbeing, which may improve your symptoms and, therefore, your sleep.

**Keep a sleep diary.** This will help you and your doctor work out what may be causing your sleep problems because it tracks the things that may impact on your sleep.

- Track these details every day for 2 weeks:
- what time you go to bed
- how long you're in bed before falling asleep (a guesstimate is fine here – don't check the clock!)
- what time you get up
- how often you wake during the night
- the things you eat and drink during the day
- your daily activities
- how you felt that day – noting both your pain and fatigue levels on a scale of 1-10, with 1 being no pain/fatigue and 10 being severe pain/fatigue.

You can keep track in a notebook, or there are many apps you can download and use.

**Allow 2-3 hours after your last main meal** before going to bed. This way, your body isn't trying to digest food when it needs to be resting and repairing.

**Avoid alcohol for at least 4 hours before going to bed** as it can affect your ability to fall asleep and the quality of your sleep.

**Avoid caffeine for a minimum of 6 hours before going to bed.** Caffeine can affect some people's sleep for longer than 6 hours, so you may need to make your caffeine cut-off time earlier. Keeping track of caffeine consumption in your sleep diary is a good way of working this out for yourself.

**Consider your bedding.** Your bedding can have a big impact on your comfort and the quality of your sleep. Is your mattress or pillow affecting your sleep? Are they too hard, too soft, or not providing enough support? Are they worn out? Is your linen comfortable, clean and keeping you warm or cool enough (depending on the season)?

**Try an electric blanket.** Some people with axSpA find that the heat from an electric blanket can help with pain during the night. Make sure you turn the blanket off before you go to sleep, and follow any safety instructions.

**Don't look at the clock (or your phone!).** Often, when you can't fall asleep, or you wake in the middle of the night, you look at the clock or your phone and start thinking about how many hours to go until you need to get up. This creates anxiety and anxiety makes it hard to sleep. Try removing your clock or phone from the bedside, or cover it up at night.

**Write it down.** Thoughts, worries and anxiety can prevent good sleep. Don't take them to bed with you. Keep a 'worry journal' instead. Choose a time during the day – away from your bedtime – to write down your key worries and consider options for dealing with them. When you're in bed at night, firmly tell yourself that bedtime is not worry-time and you'll re-visit your worries tomorrow with your journal.

**Light.** Is your room dark enough to allow you to sleep well? Or do you have a streetlight, light from an alarm clock or phone, or light from other rooms making your bedroom too bright for sleep? If this is a problem, look at solutions – such as new window coverings, a dim switch on your alarm clock, putting your phone onto night mode at bedtime, or closing your door. You might also want to try using an eye mask.

**Noise.** Just as light can interfere with your sleep, so can noise. If you have no control over the noise in your environment (like a barking dog, loud party, or your partner's snoring), ear plugs may be an option. You can pick these up from your chemist. Some people also find that playing soothing, gentle music softly in the background can be helpful for cancelling out other more annoying noises.

**Don't use technology in bed.** It's easy to get caught up and lose track of time reading emails and checking social media on smartphones and tablets. Another problem is that the blue light from these devices suppresses the hormone melatonin that makes us sleepy at night. So be sure to stop using screens at least 1 hour before bed.

**Room temperature.** To fall asleep, your body's core temperature needs to drop a few degrees. This means it's best for your bedroom temperature to be a little cooler (but not cold), rather than warm. A helpful tip from the American Academy of Sleep Medicine is to think of your bedroom as a cave: it should be cool, quiet, and dark.

This is another reason why a warm bath before bed can be especially helpful: as well as relaxing you and easing pain and stiffness, when your body temperature drops after the bath, it prepares you perfectly for sleep.

**Use sleeping tablets** sparingly and **ONLY** in times of acute stress to help temporarily reset your sleep pattern. Always talk to your doctor before using any sleep aids that you are thinking about buying over-the-counter.

### **More to explore**

- Arthritis Foundation (USA) has a helpful [joint-by-joint guide](#) to positioning yourself for a good night's sleep.

### **Fatigue and axSpA**

Many people with axSpA also say that fatigue is one of the most challenging symptoms they live with. Research has shown that 75 per cent of people with axSpA experience fatigue, so you're not alone if you're living with fatigue.

You already know that the fatigue of axSpA is very different from everyday tiredness that people without an autoimmune disease might experience. The fatigue of axSpA can be described as an extreme, and sometimes overwhelming feeling of physical and mental tiredness – even exhaustion. And even though sleep and fatigue are linked, this type of fatigue often doesn't improve a lot with rest or sleep.

There are several different factors that can contribute to axSpA fatigue, including:

- autoimmune disease activity that causes inflammation throughout your body – the inflammatory process releases chemicals in your body that make you tired
- living with ongoing pain
- sleeping problems – which may be due to pain or other things
- feeling [depressed or emotionally low](#) – which may be a result of the pain you're experiencing – or other parts of living with axSpA
- anaemia (low red blood cell count), which can be associated with axSpA
- muscle weakness, which makes completing everyday activities fatiguing
- side effects of some medicines.

## Tips for staying on top of fatigue

Like everything else when it comes to managing axSpA, it's often the combination of self-care tools that you use that can help you better manage fatigue.

Many of the strategies that you use to manage your pain can be used to manage fatigue – and therefore to manage the complex relationship between the two. These include:

- making exercise part of your daily life
- learning relaxation techniques
- eating a healthy diet
- pacing your activities
- learning to say 'no' when you need to – it's a skill that gets better with practice!
- getting a good night's sleep
- going to bed early
- having short daytime naps to recharge when you need to – limit these to no more than 20 mins so they don't affect your night-time sleep though
- avoiding going out at busy times of the day to avoid too much traffic and crowds
- telling family and friends how axSpA affects you and how they can help share the load
- connecting with other people who have axSpA so you can learn from their experiences
- seeing a healthcare professional if you're feeling low or think you may be depressed
- talking with your doctor about your medicines – different treatments that better manage your disease activity and pain may also help your fatigue, and some medicines may cause fatigue as a side effect. You and your doctor can discuss this and decide if a change to your treatment plan may help.

## More to explore

- Versus Arthritis (UK) has a comprehensive guide to Managing fatigue on their website, including a helpful fatigue chart that you'll find under 'Lists and charts'.
- National Axial Spondylarthritis Society's (UK) booklet Living with axial SpA fatigue has lots of helpful information and explains how you can use a fatigue diary to see how different activities might be contributing to your fatigue (see page 23 onwards).
- Spondylitis Association of America's Fatigue in spondylitis includes a webinar on mind-body approaches to fatigue and brain fog.

## Flares and how to manage them

Most people with axSpA will go through periods where their pain and other symptoms are worse. This is called a 'flare' or 'flare-up'.

We don't always know what causes a flare – they can sometimes appear for no reason.

Other times, a flare may happen because you've been more active than usual, or you've pushed yourself way past your usual activity levels. For example, you went for a 5km walk when you normally only do 2kms, you spring-cleaned your entire house from top to bottom, or you spent extra hours working at night to meet a deadline.

A flare may also occur when you change some medicines. This may be as a result of stopping one and starting another, or changing the dose.

And flares can also occur when you're stressed or upset.

Flares are temporary, but can be frustrating and painful while they last. So, it's important that you have a plan for how you manage a flare when it happens:

- **Write down** what you were doing before the flare. This can help you identify if there was something you did that triggered the flare. If there was a trigger, hopefully you can avoid repeating it.
- **Pace yourself.** If the flare is the result of overdoing things, think about getting people to help you, or spread the activity over a longer period of time.
- **Prioritise** your tasks and activities. This can also reduce the risk of overdoing things.
- **Manage your stress** – as stress can increase your pain levels. See the ideas for relaxation techniques in Section 6 of your self-care plan.
- **Talk with your doctor or pharmacist** before making any changes to your medicines.
- **Pull out all of your pain management strategies.** Use heat or cold packs, get a massage, go for a walk, distract yourself ... use all the tools that you know can help you to manage pain.
- **Rest when your body needs it** – but not for too long. Going to bed and not being active during a flare can make your pain and fatigue worse. Continue to exercise, but at a lesser intensity than usual. Listen to your body.
- **Move gently.** Movement will help with the stiffness you're feeling in your joints and muscles. Try doing some very simple and gentle exercises while you breathe deeply, or go for a short walk. You can also do some gentle exercises in a warm water pool to relax your muscles and get your body moving
- **Use aids and other gadgets** when your joints are painful and swollen. This will help protect your joints, and reduce some of the pain you feel when doing everyday tasks.

## Remember your posture checks and exercises during a flare

Due to pain and inflammation associated with a flare, you might find yourself curving your spine to protect yourself and to find relief. There is a risk that this will lead to posture changes, such as 'stooping', where your shoulders round forward and a hunch may form in your spine.

In people with severe axSpA, new bone can grow because of the inflammation, causing the spine to fuse and become immobile. This is one of the main reasons why people with axSpA require surgery.

It's very important that, even during a flare, you continue to do your posture exercises and try not to hunch or curl up for extended periods of time.

You might like to chat with your physio about posture exercises you can do when you're experiencing a flare.

## Create a care package

When a flare strikes, imagine how it would feel to open up a care package that you've created ahead of time.

When you're feeling quite well, gather the things you know can help to distract you from pain and boost your mood. Put all these items together in a box or basket, so that when you have a flare, you can access it easily.

What you put in your care package is entirely up to you. It may include a favourite magazine that you enjoy every now and again, some really good quality chocolate, your pain playlist, photos from a wonderful holiday (or a brochure for a holiday you're planning), a favourite aromatherapy oil, or some luxurious hand cream. Whatever you put in there is purely for you – so get creative!

## Our community's tip for creating your own care package

- My feet get cold and my brain gets fuzzy, so in my care package I have warm, fluffy socks, strawberry Freddo frogs, and a beautiful photographic travel book (I can look at the images and don't have to focus on a plotline). As soon as I feel better, I replenish the chocolate and swap the socks and book for others. That way it's ready for the next time.

## More to explore

- National Axial Spondylarthritis Society's (UK) has a comprehensive and helpful booklet that you can download, [Managing my axial SpA flares](#).
- [This webpage](#) from National Axial Spondylarthritis Society's (UK) includes videos explaining what a flare feels like, and how to prepare for and manage them.

## Create a 'pain playlist'

There's plenty of evidence to support the use of music for managing pain.

Listening to music has been shown to reduce anxiety, fear, depression, pain-related distress and blood pressure. And when we listen to our preferred style of music, it has an even greater positive effect.

It's not exactly clear how or why music can have such an effect on pain, but it may be that enjoyable music triggers the release of opioids in your brain (which is your body's own morphine).

Or it may be that music distracts your mind from focusing on your pain.

Whatever the reason, it's an easy, cost-effective and enjoyable way to get some relief from your pain.

So why not create a special 'pain playlist', and load up your phone or music player of choice with your favourite tunes?

Read more about the power of music [here](#).

## Staying connected: Focus on the people and activities that make you happy

An important tool for managing pain is to stay connected and involved with the people and world around you.

It can be very easy to stop doing the things you enjoy when you're living with pain. You may worry that some activities will make your pain worse, or that you won't be able to participate as well as you have in the past. On days when your pain is intense, or you're feeling tired or frustrated, these negative thoughts and worries have the potential to keep you from the things you love. Pain becomes your focus.

That's why it's important to work at staying connected to those around you. Focus on doing activities that make you happy, such as catching up with friends, participating in sporting and social clubs, working, discovering new hobbies, volunteering, exploring the world, or simply getting out and about with your family.

These connections can help you manage your pain better. They engage your mind and energy and distract you from the pain so it's no longer your main focus. If you find that it's difficult to do some of the things that you used to do, focus more on a few activities that you really enjoy.

When you keep doing things you enjoy, you stay connected and involved. This is what makes our lives rich, colourful and exciting.

## More to explore

- Our article on [relationships with family and friends](#) includes lots of easy and lovely ways to nurture your relationships – and is a good reminder that keeping friendships alive doesn't need to take heaps of time, just a little thought.
- Arthritis Foundation's article, [Keeping friendships strong when you have arthritis](#) covers some of the common challenges with friendships when you have arthritis and provides practical suggestions to respond to those challenges.
- Section 6 of your axSpA self-care plan is all about looking after your mental and physical wellbeing, where you'll find more info on intimate relationships.

If you're struggling with negative emotions and finding it difficult to stay connected, talk with someone you trust. It might be a close friend or family member, your doctor or a mental health professional like a psychologist or psychiatrist. Talking about the problem, and getting support and advice can help you to take some positive steps forward.

You can read more about mental health professionals [here](#).

**If you're thinking about suicide or experiencing a personal crisis, call Lifeline on 13 11 14.**

## Driving with axSpA

axSpA is likely to impact many areas of your life, so it helps to be aware of small adjustments that can make a big difference for you.

Driving is a regular activity that may be more challenging because of your stiffness and pain.

If you're finding driving difficult, these tips might help:

- Break up long drives by stopping every 45 – 60 minutes to stretch and walk around.
- Ensure your headrest is correctly positioned to support your neck – your physio or OT can help with this.
- Try placing a small cushion behind your lower back to help with back stiffness.
- If you're buying a car, consider one that is as easy as possible to get in and out of, is automatic and has power steering. All of these features can help to reduce strain on your shoulders and hips. Oh, and if it's an option, a heated seat would be the ultimate bonus!

If you're finding driving challenging or painful, or have any concerns about the safety of your driving, speak to your doctor.



## More to explore

- National Axial Spondylarthritis Society (UK) has a [detailed article](#) about adjustments that can help make driving as comfortable as possible.
- Check out our articles: [Driving with a musculoskeletal condition](#), and [Driving with more comfort and less pain](#) for more practical information and tips.

## Goal setting

Having goals is important in life, giving you something to aim for. And that's even truer when you're living with ongoing pain. Having clear goals for an end point that you want to achieve can help you to put the steps into place to get there.

The 'side effect' of setting these goals and taking those steps is often better management of your pain. You can think of goal setting as one way of bringing together many of the ideas in your axSpA self-care plan for managing pain.

Here's an example of how goal setting could work in managing the pain of your axSpA.

*Let's say your pain is affecting your ability to play golf because swinging the club hurts and you tend to stoop, which then makes your pain worse. But because you're no longer playing golf with your friends, you feel out of the loop and you're exercising less, even though you know exercise helps your pain overall.*

*Your goal could be to find a way to get back to your regular golf game without increasing your pain. To do that, you'll need to break down your goal into smaller steps, working with your healthcare team to achieve each of these.*

*To put this goal into action, write down your goal and the steps you need to take to achieve it. Put this somewhere that you'll see it often – like the fridge or bathroom mirror. This will help to motivate you. Make sure you include a date when you'll review how you're going. This way you can modify the steps if you're not getting closer to achieving your goal.*

*Using the golf example, here's what your goal and steps might look like:*

### My getting back to golf

Today's date: 29 October 2023

My goal is: To rejoin my regular golf game by 1 February 2024

To reach my goal, I need to do these things:

1. Find a physio with experience in axSpA to help me with a more structured exercise program to increase my muscle strength and flexibility
2. Make an appointment and see the physio
3. Work on strengthening my core and back muscles
4. Remember to do my flexibility exercises (stretching) every day
5. Modify my golf swing based on my physio's suggestions
6. Start slowly and play a short game of golf
7. Slowly increase the number of holes I play

Review date: 15 December 2023

Comments: I'm getting there, but I need to remember to keep pacing myself ... don't try to do too much too soon! Ask my physio about more stretches I can do to reduce my back stiffness before each game.

You can use this approach for all types of goals you'd like to work towards.

### More to explore

- Our [Setting goals](#) page takes you through setting SMART goals: goals that are Specific, Measurable, Achievable, Realistic and Timed. It uses a weight loss goal as an example, and you can use this same approach for any goal you are working towards.
- Arthritis Foundation (US) has an app called [Vim](#) that's free to download for iPhone or android. Vim aims to give back what chronic pain takes away, by helping you to set achievable goals, manage your pain and lead a more fulfilling life.



## 6. Your mental and physical wellbeing

### Things to remember

- Understanding the link between your mind and body and the symptoms you experience can help you make small changes to your thinking and actions that can have a big impact on how you feel.
- Mindfulness meditation and different types of relaxation are helpful ways to relieve stress and improve your mood.
- Living with axSpA can affect your intimate relationships and your sex life. Talking openly with your partner and using some of our tips for easing pain and enjoying yourself in the bedroom can help – and you'll have fun trying them out!
- Sometimes, feelings of anxiety and a low mood can be more intense and long-lasting. These may be signs of an anxiety disorder or depression, which are real and treatable illnesses.
- There are many effective treatments for anxiety and depression, including talking therapies, prescription medicine and self-help.

### The link between mind and body

Your mind and body are so closely linked. Living with axSpA has probably made this more obvious to you than ever before.

The physical symptoms you experience – like pain, stiffness and fatigue often have a direct impact on how you feel emotionally. And then, how you are feeling can impact your physical symptoms.

Recognising and acknowledging how your mind and body interact with each other – and that emotional challenges are part of living with an ongoing health condition – can help you to find new ways to care for your mental health as part of your overall plan of self-care.

This section will help you to explore the relationship between your mind and body, so you can better understand how one influences the other. We'll introduce tools that have helped other people with axSpA to support both their mental and physical wellbeing – often helping both at the same time.

You'll also find that many of the ideas in the [Managing your pain section](#) of your self-care plan – like pacing yourself and getting better quality sleep – can help your overall sense of wellbeing.

### Exploring the link between mind and body a bit more

Take a moment to picture this scenario and how your mind and body interact with each other ...

*You're in the middle of a flare and your pain is making it difficult to sleep. You wake up fatigued and your pain feels even worse. A friend who wants to help suggests catching up for a walk and a chat, but all you want to do is crawl under your doona. So, you say no, and as the day goes on, you feel more stiff and sore – and now you feel disconnected from your friend as well.*

*You have a work project that you've been putting off, but you feel too tired and sore to even begin. By the end of the day, you feel angry with yourself for not putting in at least a bit of an effort, because now you're even further behind with the project's deadline.*

*When the rest of your family comes home, you're irritable and snappy with them. By now, you feel overwhelmingly fatigued and decide that an early night is the best answer. But now you can't sleep.*

### **Turning this scenario around**

*When you begin to understand how close the link is between your mind and body, you can begin to see ways that you might turn this scenario around ...*

*You're in the middle of a flare and your pain is making it difficult to sleep. You wake up fatigued and your pain feels even worse. A friend who wants to help suggests catching up for a walk and a chat, but all you want to do is crawl under your doona.*

*BUT you know that once you get moving, you often feel better – and it's been a while since you've had a catch-up with this friend. You explain to her that you're feeling especially tired and sore, but you do need to get out of the house. You decide on a short walk, and your stiffness begins to ease. You chat to your friend about how your pain has been getting you down and so you decide to make a date to walk together twice a week.*

*You get home and feel ready to tackle a work project you've been putting off. You get absorbed in the job for an hour and realise that you haven't thought about your pain while you were working. But you also know that you can't push yourself too hard: pacing yourself is what allows you to manage your pain better. You take a well-deserved break, dipping into one of the magazines you've squirreled away in your care package and feel satisfied with what you've been able to achieve today.*

*That night, the combination of some gentle physical activity, your morale boost from tackling some tricky work and then having some down-time, means that you're able to wind down more easily and you actually get a better night's sleep.*

We know that you can't turn around all difficult days in this way. But these scenarios do highlight how some simple, positive decisions on your part can help to change the way you feel, which can have some very real changes on your physical symptoms.

The rest of this section will explore more of the tools that can help tip the balance in favour of more days like the second scenario and fewer days like the first.

## Acceptance

“Acceptance doesn’t mean resignation; it means understanding that something is what it is and that there’s got to be a way through it.” – Michael J Fox

Accepting that you have axSpA and the ongoing symptoms and challenges it creates is a key step in managing it more effectively.

Acknowledging your condition and how it affects you from day to day means you can find practical ways to deal with it.

Acceptance doesn’t mean ‘thinking positive’. It means understanding that you have axSpA, but that axSpA doesn’t define who you are. By accepting your condition (and its baggage!), you use your energy to take control the best way you can.

Part of this acceptance also means recognising and acknowledging that you’re like to have many emotional ups and downs along the way. It’s natural for you to feel a range of emotions, including fear, sadness, stress, anger and frustration – and it’s important to allow yourself to experience these feelings, talk about them and find ways to manage them.

Speaking with someone – a friend or family member, the NBack Pain | Arthritis | Musculoskeletal Conditions (B.A.M) Helpline on 1800 263 265 (Mon–Thu), your GP, a mental healthcare professional (like a psychiatrist or psychologist) – can help you work through your feelings and get back on track.

Writing it all down in a journal or pain diary is another option. The important thing is to keep working on it.

It’s also important for you to recognise when you’re experiencing these feelings more intensely and for longer periods of time – signs that you may have anxiety or depression and need some extra support from a mental healthcare professional. We’ve covered these treatable health conditions at the end of this section.

## Mindfulness meditation

Mindfulness meditation is a way of focusing your mind on the present moment. It trains your mind to be alert and pay attention to the thoughts and the sensations you feel, and accept them without judgement.

Research has shown that regularly practising mindfulness meditation can help to improve mood, relieve stress, improve sleep, improve mental health and reduce pain.

### So, what exactly is mindfulness meditation and how do you do it?

It's a type of practice that can be formal or informal:

- **Formal mindfulness meditation** is when you put time aside to practice meditation where you focus on one thing for a certain amount of time. You might focus on your breath or the sensations in your body for 10 or more minutes at a time.
- **Informal mindfulness or everyday mindfulness** is where you consciously bring your attention to everyday situations or activities. For example, when you're going for a walk, you notice how your body feels as it moves. How your feet feel against the ground, how your arms feel as they swing by your side, how the air feels against your skin, and the sun feels on the top of your head. You notice all of these sensations and focus on how they feel.

Both types of mindfulness practices can have many benefits for your mental and physical wellbeing. That's partly because mindfulness meditation involves becoming more self-aware and accepting our experiences and feelings without judgement. This can lead to a greater ability to self-regulate your thoughts, emotions and behaviours. In turn, this can help you to manage stressors, chronic pain and health conditions.

Research also shows that regular mindfulness meditation can lead to positive changes in our brain and our genes.

### More to explore

- Our [mindfulness meditation resource](#) explains more, and includes great tips on getting started and how to do a simple body scan.
- To learn about the changes and other effects mindfulness has on our body, [watch this short Smiling Mind video](#) featuring Associate Professor Dr Craig Hassed from Monash University.
- The Department of Health Western Australia's painHEALTH website has a page on [Mindfulness and pain](#), which includes a body scan and breathing meditation that you can play online.

## Relaxation

Living with the persistent pain of axSpA can be stressful. And stress can make your pain worse by causing the muscles throughout your body to become tense or to spasm.

By easing your stress and muscle tension, you can help to reduce your pain levels, and create a better sense of overall wellbeing. There are so many things you can try to help you relax.

You might like to try:

- focused and controlled breathing
- gardening
- visualisation
- progressive muscle relaxation
- listening to music
- catching up with friends
- getting a massage
- laughing (try watching a funny movie or silly video clips on YouTube)
- visiting a museum, gallery, exhibition or library (in person or virtually)
- distraction
- reading
- playing with your pet (or someone else's if you don't have one)
- guided imagery
- taking a warm bath or shower
- playing a musical instrument or singing
- doing some art and craft
- getting back to nature – a stroll by the sea or a walk in a park.

See which of these you enjoy and help you – and then find ways to make them part of your everyday life and ongoing self-care plan to live better with axSpA.

## Working is good for your wellbeing

Working – whether it is paid or voluntary – is good for your mental and physical wellbeing. For many people with axSpA, it's an important part of living well by connecting with others, having a sense of purpose, and having a focus outside of your pain.

- But axSpA can sometimes interfere with your work:
- Your morning pain and stiffness can make it difficult to get moving first thing and might make it harder to get to work on time.
- Sitting in one position for too long, for example at a computer or in a car, can cause pain and stiffness.
- Feeling fatigued, getting tired easily, and not having the same amount of energy as your co-workers will mean you need to plan and pace your work more carefully.
- Pain, stiffness and inflammation may make it difficult for you to move around and do some physical tasks.
- The unpredictability of flares can throw an extra complication into the mix.

Fortunately, there are many things you can do to help you continue working – including using the pain management techniques in [Section 5](#) of your self-care plan, [modifying your workspace](#), using helpful [aids and equipment](#), and having some flexibility with the hours you work.

### More to explore

- Our workplace resource [WorkWise](#) provides information to help you manage your symptoms, and give you tips, strategies, and resources to help you continue to work, change jobs, understand your rights and more.
- Our articles [Musculoskeletal conditions and work – part 1](#) and [part 2](#) include many more helpful tips and links to support your working life.

### Adam's experience



*During my time as a maintenance cleaner of regional BBQ areas and toilet blocks I had to sit in my car and drive long distances between jobs everyday. This often aggravated my back and hips. So with my employer we developed a few routine to help this: changed the route to minimise the driving; ensured I always had a co-worker to help with either the driving or cleaning when needed; changed the size of the cleaning materials so I didn't have to lift heavy drums and equipment; ensuring my shifts were spread out so not doing the same work every day.*

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## Sleep and why you need it

Sleep helps you to recharge – both mentally and physically.

While you sleep, your body is busy doing important jobs to help you wake up refreshed and healthy. Your brain is cleaning itself of waste products and consolidating memories. Your muscles, bones, and organs are repairing themselves. Sleep also helps keep your immune system healthy. That's why it's important to get a good night's sleep – both in quality and quantity.

The amount of sleep you need varies depending on your age. Most adults need about 7-9 hours of sleep each night. However, some people need more sleep and some need less.

The aim is to make sure you have enough quality sleep so that you wake up feeling rested and able to do the things you need to do (so don't feel anxious if you think you're not getting a certain 'magic' number – just focus on getting the right amount of sleep for you).

You're probably very aware of how you feel when you don't get enough sleep: it can make your threshold for pain, stress and everyday living lower than the days after you've slept well.

Not sleeping well can both contribute to mental health conditions like anxiety and depression, and also be a symptom of these conditions.

Many people with axSpA have problems going to sleep, staying asleep and waking too early.

**Managing sleep and fatigue** in [Section 5](#) of your axSpA self-care plan explains more about the connection between pain, sleep and fatigue and includes a comprehensive guide for getting on top of your sleep that can help you manage pain and your overall sense of wellbeing.

## Personal relationships and intimacy

Living with axSpA can affect your intimate relationships and your sex life.

Pain, fatigue, body image issues and side effects from medicines can really interfere with these important parts of your life.

Added to the physical and emotional effects of axSpA, the everyday pressures of work, study, family, finances and more can affect your close relationships and your desire to be intimate.

Even though your relationships may change because of axSpA, it doesn't need to be in a negative way. Many couples find that they can actually become closer as a result of axSpA because it makes it necessary to talk more openly, which can strengthen your relationship.

There are also many things you can do to increase your desire for, and enjoyment of, sex.

A lot of this begins with being open and honest with your partner, because trust builds closeness and romance. This gives you the basis to start planning, exploring, getting adventurous and generally having some fun. The links below will give you more details on the 'how' of all this.

## More to explore

- Our article on [Nurturing relationships with your partner or spouse](#) includes many tips for communicating with your partner and strengthening your relationship.
- Our article [Getting your groove back](#) covers lots of clever tips for happy, sexy times when you have a musculoskeletal condition.
- Versus Arthritis (UK) has a helpful page on [Sex, relationships and arthritis](#).
- Staying connected beyond your intimate relationships by enjoying the company of other people and losing yourself in activities you enjoy, is another important tool in your self-care that supports both your mental and physical wellbeing. Read more in Section 5: Managing your pain.

## Living with flares

Flares – periods where your pain and symptoms are worse – are part of the unpredictability of axSpA, and can have a big impact on your mental and physical wellbeing.

That's why it's really important to plan in advance and have a system and care package ready for when flares strike.

Learn more about flares and how to manage them in [Section 5](#) of your self-care plan, which is all about managing the pain of axSpA.

## Anxiety and depression: When you need extra support for your mental health

### Anxiety

Most of us will have times when we feel fearful, stressed and anxious. These are normal responses to stressful situations and are sometimes part of living with axSpA.

But these anxious feelings can become a problem when they begin to interfere with your everyday life, making it difficult for you to relax, concentrate or make decisions – or making you feel constantly irritable or panicky.

There's also a link between ongoing pain and anxiety. You might find it hard to look forward to social activities or to plan ahead because you're concerned that you might be in a flare or in too much pain to enjoy yourself.

These may be signs of an anxiety disorder, which is a real and treatable illness, and is more than just feeling stressed.

### Depression

Most of us feel sad, lonely, unhappy and miserable at times. These are also common, normal feelings when something causes you emotional pain or stress, which can include certain times when you're living with axSpA.

However, some people experience these emotions frequently and very intensely for longer periods of time. They lose interest and motivation in their lives and the world around them – and in the activities and people that normally make them feel good. These may be signs of depression, which is a real and treatable illness that is more than feeling low.

## Getting help for anxiety and depression

Many people living with axSpA experience anxiety and depression, and it's very normal for your mental health to be impacted by your diagnosis and condition.

Because axSpA is more common in younger people, you may feel a sense of loss and grief about how your life will change and the potential impact of your condition on your career, relationships, parenting, playing sport and your social life.

All of these feelings are normal and valid with a chronic and unpredictable health condition like axSpA. It's important to be aware of when you have signs of depression or anxiety, so that you can get the help you need. There are effective treatments that can help you to feel much better:

- If you think you may have signs of anxiety or depression, it's really important to talk to a healthcare professional as soon as you can.
- Chatting to your GP is often a good place to start. Your GP can then recommend and link you to the type of mental health professional who can best help you. If needed, they can work with you to create a [mental health treatment plan](#), which means that Medicare will pay for part of the cost for you to see certain mental health professionals.
- Our article [Support for mental and emotional wellbeing](#) explains more about the different types of mental health professionals, tips for choosing which type of professional might be good for you, and the types of support available.
- [Support from other people](#) with axSpA through a support group or from other people living with [depression or anxiety](#) can also be a great help. Talking with someone who really understands what you're going through and has lived experience and practical info is priceless.

## Treatments for anxiety and depression

There are many different types of treatment options available for anxiety and depression. The important thing is to find the right treatment and health professional that works for you.

### *Psychological or talking therapies*

Psychological therapies (which are sometimes called talking therapies) can help to change your thinking patterns and to cope better with life's challenges.

These therapies are often the most effective types of long-term treatment and prevention for anxiety and depression. As well as helping you to recover, they build your coping skills and reduce the risk of anxiety and depression coming back.

There are many different talking therapies, two types that are often used are:

- **Cognitive behaviour therapy (CBT)**, which helps you work out how the way you think and act affects the way you feel. The aim is to help you think about, assess and change your thought patterns and how you react to different circumstances.
- **Interpersonal therapy (IPT)** focuses on you and your relationships with other people to help improve your relationships, increase social support and resolve symptoms.

## Medicines

If your anxiety or depression is severe, your doctor may suggest including treatment with prescription medicine.

If they think prescription medicine may help you, they'll do a full health check and talk to you about how the medicine can be used as part of your treatment plan together with talking therapies and self-help.

Your doctor will talk to you about the medicine's possible side effects and what to expect from treatment.

## Self-help

There are many things you can do to help yourself when you have anxiety or depression. It's good to know that many of tools we've covered in this self-care plan – like [staying active](#), [eating well](#), using [mindfulness meditation](#) and [relaxation techniques](#), and enlisting the [support of your family and friends](#) – can help your mood as well as many of the physical symptoms of axSpA.

These tools aren't just for people with diagnosed anxiety or depression either – they can help anyone to build skills to support their mental health and wellbeing.

## More to explore

- Our resource [Understanding anxiety and depression](#) includes some of the common symptoms of anxiety and depression as well as helpful tips to support your mental wellbeing.
- National Axial Spondyloarthritis Society's (UK) webpage [Emotional wellbeing](#) includes lots of short videos and written information with tools to support your wellbeing, covering relaxation, pain management, managing anxiety, mindfulness, mindful movement, self-care and more
- Arthritis Ireland's [Coping with emotions eBook](#) discusses the range of emotions that you may feel at the time of RA diagnosis and as time goes on, and then provides practical suggestions for coping.
- Versus Arthritis (UK) has an [Emotional wellbeing](#) section of their website that includes lots of helpful information and tips.

### Don't delay in asking for help

If you're struggling with anxiety or depression, remember that you don't need to manage by yourself - there is always someone available to help:

- Beyond Blue Support Service provides one-on-one calls and chats with a trained mental health professional and are completely confidential. They can provide you with brief support and point you in the direction of the help you need.
  - You can call them 24 hours a day/7 days a week on **1300 22 4436** or chat online between 1pm and 12am 7 days a week.
- If you need urgent help at any time of the day or night, call the **Lifeline 24-hour telephone counselling service on 13 11 14.**



## 7. Looking after yourself

### Things to remember

- Avoiding or reducing certain risky behaviours and paying extra attention to your hygiene are essential parts of your self-care too.
- Smoking is linked to developing axSpA and can make symptoms worse. Quitting smoking is one of the best things you can ever do for your health.
- Drinking too much alcohol can be risky when you have axSpA: interfering with your meds, sleep and mental health and increasing your chance of an injury. Reducing how much you drink can have lots of health benefits.
- Protecting yourself from the sun is especially important when you are taking certain medicines. Check our list and take extra steps to protect yourself.
- Having axSpA and the medicines used to manage it can affect your immunity. Protecting yourself from germs is vital to prevent developing or catching infections and other illnesses.
- There are many aids gadgets that can make your daily care easier when you have stiff, sore joints.

### Extra steps you can take to protect your health

As well as all the positive steps you can take to help manage axSpA and your overall health – like being more active, enjoying healthy eating and managing your pain – there are also some high-risk behaviours that you can avoid as part of your self-care.

Some of these, like quitting smoking and reducing how much alcohol you drink, can take some careful planning. Others, like protecting yourself from the sun and regularly washing your hands, are very simple everyday steps you can take to protect yourself.

This section includes lots of practical strategies and tips to help you include these key parts of self-care into your plan for living well with axSpA.

### Quitting smoking

Did you know that smoking is linked to the development of axSpA? Research has also shown that people with axSpA who smoke have worse bone damage. Because of the impact of axSpA on your ribcage, smoking can make this pain worse as smoking affects your lungs and breathing.

Smoking can make it more difficult to manage your pain. It causes fatigue and slower healing, which can make your pain worse. And it can make some biologic medicines less effective.

If you're a smoker, you may be less likely to be as active, and less physical activity can increase your pain too.

The good news is that research shows that people with axSpA who stop smoking can expect significant improvements in their disease activity, mobility and quality of life.

These benefits are on top of all the other benefits of quitting for your overall health – like a reduced risk of developing many cancers, and heart and lung diseases.

Within weeks of quitting, you'll breathe better and have more energy, making it easier to exercise and do day-to-day activities. Over time, your risk of many serious health problems associated with smoking will reduce.

Quitting isn't easy, but the rewards are incredible and there's so much support available. There's no reason to do this alone!

## Tips for quitting

- Get help. Talk to your doctor and call the Quitline on 13 78 48.
- Decide on a strategy. Are you going to use nicotine replacement, medicine, coaching or a combination of these?
- Talk to your family and friends. Let them know what you're doing and ask for their support.
- Write down the reasons you want to quit and put this list in prominent places to encourage and motivate you.
- Think of all the situations where you usually smoke and have a plan for what you'll do instead.
- What will you do if you're around other smokers? What will you do instead of smoking when you have your first cup of coffee or tea in the morning?
- Be kind to yourself. You may have a slip-up to two. It's not the end of the world, or the end of quitting. Get back on track.
- Use some of the money you save and treat yourself to something special, like a massage or gold class movie tickets.
- The [Quitline's website](#) includes heaps of information to help you plan to quit, quit in your own way and support you along the way.

## Reducing alcohol

Australia is a country that loves to drink! Wine with dinner, beer at the footy, cocktails at the local bar with friends.

As a result, many of us drink more than the [Australian Alcohol Guidelines](#), which provide recommendations for healthy women and men. When you have axSpA, the risks involved with drinking alcohol can be even greater.

Here are some ways that alcohol may impact your health when you have axSpA:

**Alcohol can interact with your meds** – including commonly used medicines such as non-steroidal anti-inflammatories like ibuprofen – where the combination can cause problems like ulcers, bleeding in the stomach and liver damage.

Be aware of the risks, and always read the labels and consumer medicine information (the leaflet that comes with your prescription medicines) about side effects and interactions.

Talk with your doctor or pharmacist about how alcohol can interact with any of the medicines you are taking.

**Alcohol affects your sleep.** Getting enough quality sleep is vital for our overall health and wellbeing. People with axSpA often struggle with sleep – getting to sleep, staying asleep and feeling fatigued when they wake up.

While the idea of a nightcap to help you wind down in the evening may sound like a good idea, alcohol will actually affect the quality of your sleep. Even if you sleep through the night, you're more likely to wake up feeling unrefreshed and foggy.

**Alcohol increases your risk of getting injured.** If you've been drinking, especially if you've become tipsy or drunk, you're more likely to injure yourself. When you become drunk, you lose your balance and coordination, increasing the risk of falling. Because you have axSpA, you already have an increased risk of osteoporosis (brittle bones), which makes the chance of a fracture even greater if you have a fall. A tipsy fall, a broken bone and axSpA are not a good combination.

If you do drink too much, you're also more likely to engage in risky behaviours, such as driving, which puts yourself and others at risk.

**Alcohol can affect your mental health.** Many people turn to alcohol to relax after a stressful day or if they're feeling a bit down. While it may provide a very temporary mood boost; it doesn't last. In the long run, drinking can actually make it harder to deal with stress – and can add to feelings of anxiety and depression.

## **The many benefits of taking a break from booze**

On the upside of all this, if you reduce the amount of alcohol you drink, you're likely to experience lots of benefits – including losing weight, saving money, having more meaningful times with family and friends, sleeping better, having a clearer head and performing better at work.

## **More to explore**

- If you're thinking about slowing down on your drinking, our article [Should I take a break from booze?](#) includes lots of smart tips to help you reduce the hooch (almost painlessly!).
- Sleep Foundation's article [Alcohol and Sleep](#) explains how alcohol affects sleep and answers FAQs on the topic.



## Protecting yourself from the sun

Some medicines used to treat axSpA, as well as other more general medicines, can cause your skin to become sensitive to sunlight, where you can become sunburnt and develop skin rashes, even after a very small amount of exposure to the sun. This is called photosensitivity.

Medicines that can make you more sun sensitive include:

- non-steroidal anti-inflammatory drugs (NSAIDs) – like diclofenac and ibuprofen
- disease modifying anti-rheumatic drugs (DMARDs) including azathioprine, cyclosporin, leflunomide, hydroxychloroquine and methotrexate
- antidepressants
- oral contraceptives
- tetracycline-based antibiotics.

Your doctor or pharmacist can tell you more about medicines that are likely to make you sun sensitive.

If you're taking any of these medicines, it's especially important to protect yourself from the sun, by seeking out shade, covering up with clothing, wearing a hat, and using a minimum SPF30+ sunscreen on any areas of skin that you can't cover up.

### More to explore

- Our article [Enjoying the sun safely](#) includes more practical tips to protect yourself in the sun.
- We all need to balance the need for sun protection with our need for vitamin D. This info will help you to find that balance:
  - Our article on [Calcium and vitamin D](#)
  - Osteoporosis Australia's [Vitamin D & Bone Health](#) page, which includes a map to work out how much daily or weekly sun you need for your vitamin D in each area of Australia.

### Daily care

Both axSpA and many of the medicines used to manage it can affect the way your immune system works, which means that you have an increased risk of picking up infections. That's why it's important to keep your skin clean with careful wiping after using the toilet, a daily shower or bath, and regular handwashing.

Washing your hands thoroughly helps to prevent the spread of diseases, especially after you've been in contact with other people and when you've been out and about at shops, restaurants, movie theatres, sporting venues – anywhere that you're likely to be exposed to germs.

Sometimes, these seemingly simple everyday tasks of using the toilet, showering and washing your hands (if your finger joints are affected) can be a bit more challenging.

To make this daily care easier, you could try:

- a toilet seat riser to help you sit down and get up from the toilet
- a bidet to help with cleaning difficult to reach areas
- toilet wipes instead of toilet paper (but remember that they're not flushable)
- toilet paper tongs or aids to help with gripping
- pump action bottles for shampoo, conditioner and shower gel
- a long-handled sponge for washing hard to reach areas when you're showering
- a shower cap in the shower – or use a dry shampoo – on days when you don't have the energy or movement to wash your hair
- giving yourself time to have a longer warm shower or bath to soothe stiff joints
- mixing up your routine and having a longer bath in the evenings to really relax and benefit rather than having a quick shower in the morning
- a soap dispenser instead of a bar of soap
- lever taps or tap turners instead of taps that you need to twist to turn on or off.

## **Aids and equipment to make life easier**

When you have axSpA, many previously simple daily tasks at home and at work can become difficult and painful.

Fortunately, there are plenty of aids, gadgets and other equipment that can help reduce stress on your muscles and joints, prevent and relieve pain, save energy, prevent fatigue, and basically make your life easier.

Aids and equipment can help you with everything from cooking, cleaning, bathing, writing, mobility, technology and driving.

You can buy some of this equipment from pharmacies, medical suppliers, and hardware stores.

Some items can be made by a home handyperson.

If your equipment needs to be installed, you'll need to make sure it's done properly – as equipment like grab rails and bath seats can be dangerous if they're not properly installed. A competent home handyperson and some tradies can do the job – or chat to your local council to see if they can arrange installation.

## How an occupational therapist (OT) can help

The range of aids, equipment and other gadgets available is enormous, so you might want to chat with an occupational therapist (OT) to get specific information and advice about the right aids for your needs.

An OT can help you in many other ways when you have axSpA, so it's worth enlisting their help as part of your [healthcare team](#).

## Common aids and equipment

Some helpful aids and equipment for people with axSpA include:

- bathroom grips or rails to help you with getting in and out of a shower or bath
- raised toilet seats to make sitting down and standing up easier
- cutlery with thick handles for an easy grip
- buttonhooks to fasten buttons
- long-handled combs and brushes
- long-handled shoehorns to help put on shoes
- large-handled items such as can openers, gardening shears and scissors
- walking aids - cane, walking stick or frame
- swivel seat cushion to help you get in and out of the car
- modified computer keyboard and mouse.

This is a very small list to help you understand some of the options available to help you. There are many more aids and equipment available to suit specific tasks and needs.

## More to explore

- Find an occupational therapist [here](#).
- [Freedom Solutions](#) is a not-for-profit organisation that makes and modifies equipment needs for people with a disability.
- You may be eligible for assistance with the cost of aids through the [Victorian State-wide Equipment Program \(SWEP\)](#). This can sometimes help with the cost of aids such as wheelchairs or alterations to bathrooms. Have a chat to your GP or OT about this program and your eligibility. It's important to note that there may be a long wait for items available through this scheme.



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