



**Living well  
with axSpA**



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# Living well with axSpA

Living well with axSpA means taking a positive approach to managing your disease. We know that people do better who:

- take their prescribed medication
- find out more about their disease
- are active
- eat well
- don't smoke
- join a patient organisation or support group.

In this brochure we look at issues that are common to axSpA patients and provide some tips on how to cope. You'll find that there is a very close relationship between these topics. This brochure will also be useful for family and caregivers in understanding how axSpA affects you.

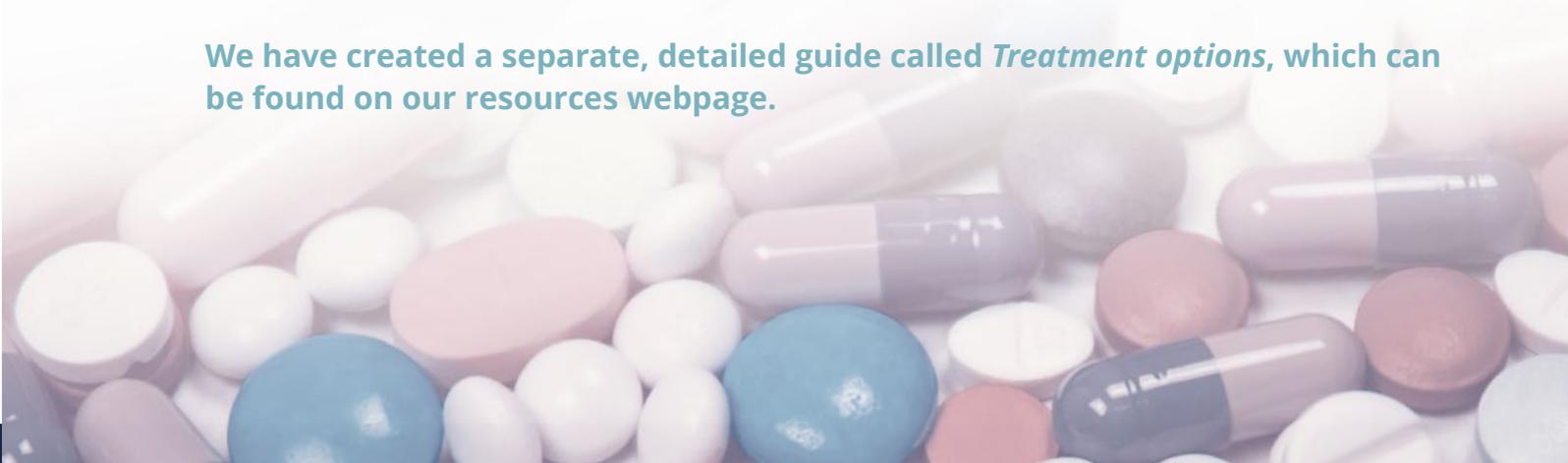
## Pain

Pain is probably the most severe symptom of axSpA.

It is caused by inflammation, which in turn is caused by the body mistakenly perceiving its own cells and tissues as harmful and launching an attack on them. This results in stiff and painful joints. Chronic inflammation is inflammation that lasts for months or years.

If not treated, it can lead to years of long-term pain and damage to joints and tissues. Inflammation is treated firstly with non-steroid anti-inflammatories (NSAIDs). Most, but not all, patients respond well and gain pain relief from NSAIDs. There are other medications that can treat pain and inflammation, including biologics and analgesics.

**We have created a separate, detailed guide called *Treatment options*, which can be found on our resources webpage.**



For some people, pain persists despite aggressive treatment. In this case, another mechanism may be at work. Centralised pain describes any pain that happens when the central nervous system doesn't process pain signals properly. Pain messages are continually being sent to the brain. Because the central nervous system is changeable, nerves that deliver pain messages get better at it over time. Then, the body may begin to respond to small messages of pain as if they are big ones. Also, if you keep experiencing pain, your brain may develop a 'pain memory'. It may have faster and stronger responses to pain signals. With centralised pain, you may feel pain more strongly, and your ability to tolerate pain is decreased.

**More doctors now understand the importance of treating centralised pain as its own disease. Help your doctor find the right treatment for you. Take steps to stop pain before it becomes chronic or centralised.**

**Make discussing your pain a priority.** Consider keeping a pain diary or use an app to track how you feel daily and discuss it with your doctor. Be specific about what you're experiencing.

Self-care is important; for example, restful sleep and exercise should be priorities. Exercise can be as simple as stretching or walking. **Activity is important**, because it reduces inflammation as well as having other benefits.

**We have created a separate, detailed guide called *Exercise and Movement*, which can be found on our resources webpage.**

People with chronic pain often experience insomnia, depression, anxiety, and irritability, which in turn can make pain worse. Living with chronic pain can become all-consuming and affect your quality of life. Learning more about pain and the disease can be helpful, but if medication is not relieving your pain, it is important to talk to your doctor.



## Stiffness

Lower back pain and stiffness is the most common symptom of axSpA. Back stiffness is usually worse during the night, in the morning and after periods of inactivity. Pain and stiffness may start on one side of the body, but as inflammation persists, over time they are likely to be felt on both sides. On waking in the morning, it can be helpful to **stretch or do at least 30 minutes of activity. Having a hot bath or shower, or taking an NSAID can also relieve the stiffness.**

## Fatigue

Fatigue is a feeling of lack of energy or motivation, which can be physical, mental or both. It is not the same as drowsiness, but the desire to sleep may also be present. Doctors sometimes don't understand how much fatigue can impact someone's life. For some people, fatigue and its accompanying 'brain fog' can be more debilitating than pain.

Fatigue negatively affects relationships, social life, work and daily functions. If you are feeling fatigued discuss the matter with your healthcare provider.

**Inflammation and associated fatigue can be reduced by medications, increasing activity, exercise, and good sleep hygiene.**

## Sleep

Pain and fatigue are two reasons that you may have poor sleep quality. Good sleep hygiene means having a soothing bedtime routine, such as a warm bath or a period of mindfulness, at the same time every night and getting up at the same time each morning. Find a bed and pillows that are comfortable for you. Avoid distractions in bed such as TV and electronic devices.

Other things you can do are to avoid caffeine and alcohol in the evening and to eat healthily. You can also increase your activity during the day so you are physically tired at night. **Deep restorative sleep improves pain, memory and fatigue.** In some circumstances medications for sleep may be necessary or, particularly if you have severe kyphosis (bending of the back), being checked for obstructive sleep apnea may be a good idea.

## Flares

Many people experience periods when their axSpA becomes more active and their inflammation and pain flare up. Some relaxation techniques you can use to manage flares are deep breathing exercises, guided imagery and mindfulness meditation.

Relaxation exercises may help to reduce your symptoms, such as pain or stress, raise your energy level, sleep better, and manage your emotional responses such as anger or anxiety. Additionally, pacing yourself in your daily life can help you to avoid flares.

**When you feel well, don't overdo things; you may risk bringing on a flare.**

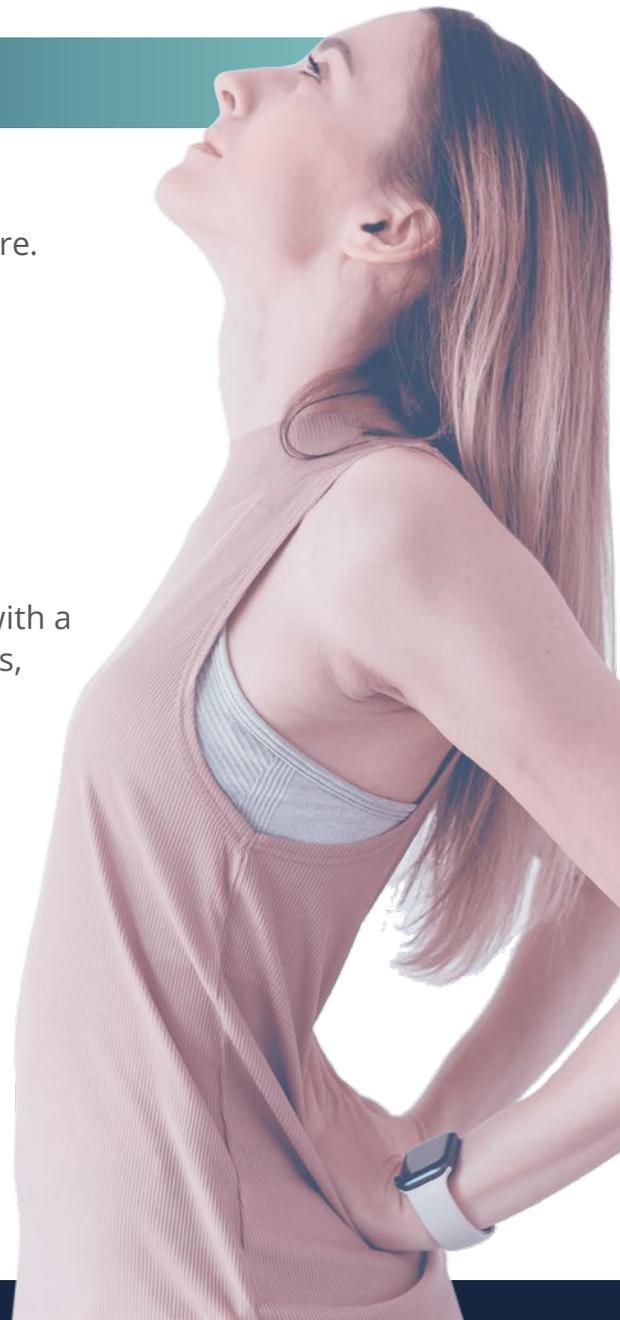
## Posture

Pain and stiffness can affect how you hold yourself. It's important to relieve the stiffness to maintain your posture. There are exercises that can help your posture, such as:

- Posture stretch
- Trunk side stretch
- Neck rotation
- Trunk rotation

Try not to lean forward, sit up straight, use a firm chair with a back that allows your knees and hips to be at right angles, and remember to stand tall!

**We have created a separate, detailed guide called *Exercise and Movement*, which can be found on our [resources webpage](#).**



## Emotional and psychological well-being

Sometimes you may feel overwhelmed by how axSpA affects you and impacts the things you want to do. This can lead to shame, stress, anxiety and depression. Some people might worry about their body image. People might be fearful about how badly their disease might progress and what their bodies will be capable of in the future. It can be incredibly difficult to accept your diagnosis and the changes it means for you. You may experience a wide range of emotions, from relief at having a name for what is causing your pain, to anger and denial. Whatever you feel, your feelings are valid. Many people find counselling or therapy can help them process their feelings.

Exercising can help to manage your emotional wellbeing. **Try to connect with people and activities that give you pleasure.** Spend time with friends and family who support and encourage you. Eat a healthy balanced diet and practice good sleep habits.

## Everyday challenges

Dressing, cooking, doing housework and other normal daily tasks can be challenging. Look for resources or life hacks for dealing with many aspects of daily life. Search out adaptive clothing and devices that may help you dress and reach things. Other products may be helpful if you have limited or painful movement, such as long shoe horns, electric toothbrushes and thick-grip utensils. **Pace yourself throughout the day.** Don't overdo it on the days you feel well and be kind to yourself on the days you don't feel good.

## Driving

You may have increased pain and stiffness during long drives, so be sure to stop every hour to walk and stretch. Driving can be uncomfortable. A small cushion behind your back can help. Make sure you properly adjust your seat, headrest and steering wheel.

An extra wide rear-view mirror is useful if you are unable to fully turn your neck. To reduce the need to twist your torso or bend over too much when getting in and out of a car, first sit down, with your legs still outside the vehicle. Once you're seated, pivot your body and bring your legs into the vehicle with minimal effort. To get out of your car, go through the same process in reverse.

## Travel

If you enjoy travelling, there is no need to stop it because of your axSpA. But it does need some planning to ensure that you and your loved ones enjoy the experience. Before you go, make sure that you have a sufficient supply of your medications for your trip. If you are on a biologic drug, check with your provider about how to keep the drug cool. Travel kits with cooling packs may be available from the manufacturer. Always fly with your medications in carry-on luggage. You may also need a letter from your doctor to smooth the way through airport security checks and border control. If you need to avoid a lot of walking at airports, take advantage of mobility services like electric carts and access to wheelchairs.

When flying, take a neck pillow with you. An inflatable camping pillow is also useful to put behind your back. A tennis ball can be used to massage your legs and help get the knots out of your glutes from sitting too long. Wear supportive footwear, and if going on long flights, choose shoes that are easy to take off and on. Keep hydrated and eat healthy foods at regular times whilst on holiday. Most of all, **don't over-schedule events** and sight-seeing. Pace yourself and **listen to your body**.

## Work

Approximately two-thirds of people living with axSpA report work related issues, like having to take sick leave or reduce working hours. It is a personal decision whether to disclose your condition to your employer. If you choose to tell your employer, determine exactly what you want to achieve. Studies show that if employers make accommodations, it improves employment outcomes and reduces job disruptions. Accommodations may mean changes in working hours, making the workplace accessible, and providing ergonomic designs such as adjustable chairs and sit-stand desks. Find opportunities in your day to move your body and stretch.



## Diet

It is important to eat a healthy balanced diet. Unfortunately, there is no specific diet that has been found to be beneficial for axSpA. Some people say that a particular diet, such as the Low or No Starch diet, has worked for them to reduce pain and increase energy. Certainly, if you have found a diet that works for you, go with it. Similarly, there are no supplements that are necessary to take for your axSpA unless advised by your healthcare provider. If you do take supplements, be sure to let your doctor know as some can interfere with your medications.

## Support network

You may find that your friends and family don't fully understand what you're going through, or you may not feel comfortable talking openly with them. It can be tempting to shut yourself off and stay inside, and some days you may not even want to get out of bed. Studies show support groups can improve mood, provide better coping skills, decrease pain and provide relief from negative emotions, such as fear, resentment and hopelessness.

**Finding a group of people who understand what you're experiencing, who understand what it's like to live with chronic illness and chronic pain, can be a great way to find the inner strength to face the challenge of your condition and live a fuller life.**

Check the [ASIF website](#) to see if there is an axSpA or arthritis patient organisation in your country. They usually provide an informative website as well as local support group meetings and social media channels. Online support groups such as Facebook can be very helpful for learning coping strategies and sharing experiences.

## Relationships

Feeling supported by family and friends is directly linked to experiencing less intense pain, less depression and anxiety, and overall a better quality of life. **Relationships can be important in helping you manage the disease through support and social interactions.** The key to relationships is communication. You may feel a burden to those around you, particularly if you have limited mobility. However, talking about how you feel, especially with those that love you, can help to alleviate some of those negative feelings.

Living with axSpA may affect your intimacy and sexual relations. There is a general lack of informed discussion or resources regarding the effects of inflammatory arthritis on reproductive and sexual health, meaning that many people are uncomfortable bringing up the topic with their partner or healthcare provider. However, **a healthy sex life lies in clearly communicating and discussing with your partner any limitations you have,** and in being imaginative in how you approach intimacy.

## Communicating how you feel

Talking with your doctor openly and confidently is important. If you can communicate how you feel and how you have been doing since your previous appointment, it can help you and your doctor manage your disease better. Our **Talk to be Heard Discussion Guide** can help to facilitate productive communication with your family, friends and rheumatologist.

It might also be useful to track your disease to better understand how you are doing. Our discussion guide or keeping a health journal can help with this; or you can use a health tracker app.





## Disclaimer

This material is for information and education purposes only. It is not medical advice and does not replace consulting with a doctor or healthcare professional.

ASIF is not liable for risks or issues associated with the information in this guide.



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