

Axial Spondyloarthritis (axial SpA)

Ankylosing Spondylitis (AS)

Fatigue

What is fatigue?

Fatigue is common among people with AS. Many people with AS will experience fatigue at some point.

Everyone gets tired or even exhausted at times, but after a few good nights rest or a break away they usually feel refreshed. Chronic or long term fatigue in AS is not like tiredness. It can last for days or weeks at a time and no amount of sleep or rest will relieve it. Some people describe it as overwhelming. You may feel that:

- It is a different type of tiredness from what you have experienced before
- After sleeping you do not feel refreshed
- It is not due to exhaustion
- It is not simply a loss of motivation, which people with depression often experience.

Here's what some people with AS have to say about how fatigue from AS affects them:

"I was tired all the time when I had my first symptoms and now I am still tired a lot of the time. It used to be overwhelming, exhausting tiredness that no amount of sleep helped with but it isn't quite so bad now."

"Most days I seem to hit a wall in the early afternoon. If I am at work I plod on slightly less productively than at other times but if I am at home I generally shut down and sleep for a few hours."

"It feels as if lead weights are tied to my eyelashes."

A whole range of different factors can contribute to fatigue:

- The underlying inflammatory process in AS can lead to fatigue. Researchers have found that chemicals called cytokines are found in inflamed tissue. These are similar to the type of chemicals released during viral illnesses such as colds and flu, and can cause extreme fatigue
- Anaemia is often found alongside inflammation
- Pain, especially long term pain, wears you down and can wake you up at night, adding to tiredness
- Sleep disturbance due to pain and stiffness in the night
- Certain drugs used to treat arthritis can cause drowsiness and interfere with concentration, which may make fatigue worse. Medications containing codeine or other opioids and medications such as amitriptyline are most likely to cause these side effects
- Weakness of the muscles can occur. This can contribute to fatigue since more effort will be required to perform certain activities
- Any long term condition can cause distress and uncertainty about the future. This can lead to depression, which is associated not only with a low mood but also with various physical symptoms, one of which is fatigue.

What treatments are available to help my fatigue?

Medications which help to control inflammation in AS, resulting in reduced pain and stiffness, should also help to reduce the fatigue you are feeling. If you are on pain medications which cause drowsiness and loss of concentration then do speak to your GP or rheumatology team about possible alternatives to these.

Ask your GP to check if you are anaemic. If you are anaemic your GP can prescribe an iron supplement to restore the iron that is missing from your body. Your GP can also advise you on how to include more iron in your diet. The GP may wish to run tests to see why you are anaemic and short of iron.

If you do feel that living with AS is leaving you feeling anxious and depressed do go and talk to your GP about how you are feeling. You may feel better and more energetic on anti depressant medication. Do try to share any worries you have with someone else. It often helps to acknowledge negative feelings and thoughts.

How can I help myself?

The right exercise regime can improve strength, flexibility, wellbeing, energy levels and sleep. Ideally you should get advice from a specialist rheumatology physiotherapist. Don't forget NASS branches meet weekly for hydrotherapy and/or gym based physiotherapy.

It's important to remember that taking enough rest periods is just as important as taking exercise. How much rest you need and how often you need to take a rest will vary from one person to another but resting for 10 minutes every hour is often recommended. Rest times could include reading a book or magazine, watching a favourite TV programme or having a warm bath. Relaxation techniques can help the body recharge itself and may also improve sleep.

Pace yourself. People with AS can find that pacing activities can help them regain some control over their feelings of fatigue. Try to prioritise so that you are doing the most important things first and leave more difficult jobs for when you are feeling at your best. Ideally try to plan ahead so you develop a weekly schedule which sets a pace you can live with, allows you to address your top priorities and leaves you time for rest.

Try to get a good nights sleep by getting into a good bedtime routine. This is known as sleep hygiene.

Eat a healthy, balanced diet to make sure you get all the vitamins you need. No special diets or particular products from health food shops have been proven to help with the fatigue caused by AS. Do discuss with your GP or rheumatology team before deciding to take any supplements.

No complementary therapies have been scientifically proven to improve energy levels in people with AS. However, people have told us they find some complementary therapies beneficial.

Do:

Go to bed and get up at the same time each day.

Get regular exercise each day, preferably in the morning.

Get regular exposure to outdoor or bright lights, especially in the late afternoon.

Keep the temperature in your bedroom comfortable and keep your feet and hands warm.

Keep the bedroom dark and quiet - try thicker curtains, sleeping at the back of your house or even ear plugs to avoid being woken by noise.

Use your bed only for sleep and sex.

Use a relaxation exercise or tape just before going to sleep or try muscle relaxation to help distress and unwind, e.g. a warm bath or a massage.

If you lie in bed awake for more than 20-30 minutes, get up, go to a different room (or different part of the bedroom), participate in a quiet activity (e.g. non-excitabile reading or television), then return to bed when you feel sleepy. Do this as many times during the night as needed.

Don't:

Exercise just before going to bed.

Engage in stimulating activity just before bed, such as playing computer games, watching an exciting program on television or movie, or having an important discussion with a loved one.

Have caffeine in the evening (coffee, tea, chocolate, etc.).

Drink alcohol in the evening or use alcohol to sleep (it may make you drowsy but it doesn't improve sleep and you will wake to go to the toilet).

Smoke before going to bed - nicotine is a stimulant and will keep you awake.

Read or watch television in bed.

Go to bed too hungry or too full.

Take another person's sleeping pills.

Take daytime naps or doze off in front of the TV in the evening - keep yourself awake with something stimulating or your risk resetting your body clock.

Mentally command yourself to go to sleep. This only makes your mind and body more alert.



The NASS HELPLINE
is open 09:00 to 12:00 Monday to Friday

CALL 020 8741 1515

E: asknass@nass.co.uk