

Sleep and AS: do we consider the implications of the quality of sleep on our patients?

By Jane Martindale

For several years now as part of my routine assessment of all our AS and Axial SpA patients, I have been asking how well people felt that they had slept over the past week. I use a simple verbal VAS scale from zero to 10 with 10 being 'I have slept wonderfully' and zero being 'I haven't slept at all'. There is no science behind the question but it is meant to open a conversation and it does.

I hear a varied range of explanations as to why sleep has been interrupted and poor which have included a full spectrum ranging from menopausal flushes, stress at work, trips too frequently to the toilet, babies and children in general of all ages and early waking pets etc. etc.



However what I listen for is the waking in the middle of the night with pain and stiffness as this gives us an opening to ask what (if any) coping strategies people employ. From listening to our patients over the years I now advise not fighting the pain and or stiffness and stubbornly lying there but to get up and stretch.

I say 'go down stairs (if you have them), put the kettle on (you don't need to make a drink and if you do steer away from caffeine) and stretch whilst it boils. If you are sore,

heat your wheat pack in the microwave and stretch as it warms then take it back to bed with you.'

Alas we have no science to ensure that people sleep better. The best I have is to advise on 'sleep hygiene' which is a term that I confess I squirm when saying. Poor sleep is blamed for increasing fatigue and generally lowering our mood and resilience in coping with life in general. A very recently published study on sleep in AS authored by Alison Wadeley (Clinical Rheumatology (2018) 37:1045-1052) is the first of it's kind in the UK and is well worth a read.

It is a large cross sectional, observational, single centre study using the data of 659 patients with both AS and Axial SpA . Key messages are that not unsurprisingly poor sleepers have higher disease activity and fatigue scores and more night-time back pain than good sleepers. Poor sleepers also had poorer quality of life, general health, mood and work-related measures. Poor sleep was also associated with poor mood, female gender, greater fatigue, greater disease activity (specifically, spinal pain and stiffness) and better mobility although the direction of causality between poor sleep and markers of active disease was undetermined. A further thought is that we need to standardise the measurement of sleep disturbance.

Having now begun to absorb the messages from this study, as a clinician this all makes perfect sense. Wouldn't it be wonderful if we could use a short questionnaire that would help us to understand the implications that sleep quality has had on our patient's lives and then be able to have the intervention to help to improve this. Frustratingly I fear that several years may need to pass and a lot of hard and dedicated work to reach this stage.

For the time being, I will continue to ask about sleep and do my best to suggest how this may be improved without 'proper science'. My thanks go to Alison and her co-authors for highlighting sleep as an important and integral aspect of a person's life as they live with their AS. I would encourage our Rheumatology community to at the very least to have a conversation with their patients about the quality of their patient's sleep. At the very least this would acknowledge that we are aware of the impact that this could be having on the way that they are currently coping with their condition.



Jane