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## **Fibromyalgia remains the elephant in the clinic room**

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Dear Editor,

Optimising the use of DMARDs has transformed the lives of many with inflammatory arthritis. Despite this, rheumatology clinics still have patients with pain and disability. Fibromyalgia is a big contributor, affecting up to 5% of the UK population(1) and substantially more in our patient populations. Approximately one third of patients with RA fail DMARDs(2). How many of these patients are receiving/switching biologics because they also have fibromyalgia?

Sadly, patients with fibromyalgia in many rheumatology clinics receive little help, despite clinicians recognising that it is an important cause of pain/disability(3). Fibromyalgia remains “the elephant in the clinic room”.

The first steps in management of fibromyalgia is recognition and diagnosis. The 1990 ACR criteria were based on the number of tender points(4), but fibromyalgia is now thought of as a spectrum termed “fibromyalgiansess”(5). The widespread pain index (WPI) and the fibromyalgia impact score (FIS) are invaluable for screening, being both quick and easy to use in clinic(6).

To diagnose fibromyalgia requires a patient history of  $\geq 3$  months of constant widespread pain, with poor sleep and fatigue. Patients wake unrefreshed, usually after 2-4 hours of broken sleep. They are tender all over their body and often flinch when joints are touched. In RA, a high tender joint count with no swollen joints needs to trigger checking a WPI and FIS. By contrast, patients with CFS sleep for many hours (often  $>10$ ), without tender points or pain. Although it seems counterintuitive that patients could have both conditions, this is not uniformly accepted(7).

The tender points in the ACR 1990 criteria require firm pressure (4kg via thumbs). If this induces wincing when applied over the trapezius and shins it suggests fibromyalgia. If the WPI is positive ( $>11/19$ ), then a FIS is the next step(8). WPI/FIS takes 1-2 minutes for a patient to complete, and a minute for a clinician to calculate. The FIS is also invaluable to monitor patient’s progress once treatment for fibromyalgia has started.

The cornerstone of fibromyalgia management is explaining the condition to the patient. Patients score their pain higher than those with cancer or arthritis(3) and, despite looking well, invariably feel terrible. Furthermore routine clinic tests are usually normal, which is why acknowledging how bad patients feel and providing an explanation is so important.

Sleep assessment is crucial and needs a detailed history including: when they go to bed; how long before they sleep; when they first wake, how often and for how long. It takes 1-2 hours to get into deep restorative sleep, so most patients have little or none of this. A fitbit or similar gadget will generally indicate under an hour of restorative or deep sleep per night.

When poor sleep patterns persist, the brain begins to malfunction in different ways. Short-term memory loss is frequent, and elderly patients often believe they

have dementia. Patients, for example, forget why they have gone into rooms at home, or lose their train of thought. Many patients describe this as “brain fog”.

As the brain controls organ systems, these too can be affected: patients usually describe bloating, wind and pain(9). Bladder control is often affected with urgency/frequency. Chest tightness, TMJ pain and headaches are common. Autonomic system malfunction is frequent, with some patients displaying features of POTS.

Consequently many patients living with fibromyalgia may undergo multiple investigations including endoscopies and scans, with huge healthcare resource implications. These multiple investigations with normal results cause further frustration for patients, who cannot understand how they can feel so bad when “nothing shows up”.

Sensory inputs to the brain appear to become dysregulated. The “dampening” mechanism in the thalamus to “protect” the cortex from overload appears less effective. Light perception becomes too bright and uncomfortable, which may explain the “tinted spectacles sign”. Sound becomes accentuated, so the TV has to be turned down. Strongly flavoured food and smells can change. Sensory input from touch is amplified, so resulting in the characteristic widespread tenderness.

Patients with mild lumbar spondylosis can find their back pain unmanageable, leading to unremarkable scans or, worse still, abnormalities which may take patients down a surgical route. Understanding that these symptoms can be linked, why they experience these indicators, and why their tests are unhelpful is important.

Improving sleep patterns, and regaining restorative sleep, is crucial for improvement. Whether improving deep sleep (stage 4), or REM sleep (stage 2), or both, are important in recovery remains unknown. What is clear is that without improving sleep quality and reducing fatigue, patients cannot be expected to progress any exercise program.

First ensure patients have proper sleep hygiene, then consider over the counter sleep remedies (eg Nytol) and sleep apps. Cognitive behavioural therapy (if this is available) may be important.

If the above measures lead to no improvement in sleep quality, prescription medication is the next step. For those with concordant depression, using antidepressants which improve sleep makes sense. Mirtazepine or trazodone taken in the late evening is often helpful. For others, low-dose tricyclics in the evening, and titrating up to improve sleep may help. Morning doses of fluoxetine or duloxetine are further considerations in some patients, as there is some evidence of synergy(10).

Once patients have 6-8 hours unbroken sleep, and fatigue improves, they may start a progressive exercise program. Without adequate sleep, fatigue prevents progress. Fibromyalgia classes where patients meet and exercise together can

help, and also prevent them feeling isolated. Hydrotherapy appears beneficial, but exercise in any form needs to be every 48-72 hours if aerobic fitness is to improve.

Over 6-12 months as fitness steadily increases, patients sleep quality can improve, and evening medication may be reduced/withdrawn. With natural sleep rhythms returning, brain function can recover, with return of memory and other organ functions.

Rheumatologists can look back on the last 2 decades with satisfaction, having improved care of patient with autoimmune diseases. Managing patients with fibromyalgia whose FIS drops from over 80 to under 20 might garner even more satisfaction for clinicians, as this improved score may reflect treatment success.

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