

# The case for taking the sleep problem in fibromyalgia very seriously

Insomnia is a serious and often ignored problem, especially for people with chronic conditions like fibromyalgia.

I would like to suggest that we need to take this more seriously.

## Key facts

- Insomnia is a key problem for people with fibromyalgia and many other chronic illnesses
- Insomnia is debilitating and makes other already incapacitating symptoms worse
- Insomnia is a recipe for a shorter, less fulfilled life
- Insomnia causes pain – even for those without chronic pain conditions
- Insomnia costs money – in health care costs from those who suffer the side effects, in absenteeism from inability to work, in lost income, if you could place a value on a fully functioning human being able to participate fully in life then multiply that by the 10 million people estimated in the US alone (and 3-6% of the world's population) it would be a massive number.
- Sleep helps pretty much every symptom of fibromyalgia
- Sleep improves our quality of life and our emotional state
- We can improve sleep! It might be multifactorial and a doctor needs to help in many cases, but we can improve sleep.

Shall we take a look into the literature that supports my (bold?) statements?

## Does insomnia lead to death?

Laboratory animals subjected to extreme sleep deprivation can die relatively swiftly of unknown causes — exactly what goes wrong is not clear, but their body temperatures start to drop and then they suffer rapid and widespread physiological failure.<sup>1</sup>

## Does insomnia cause pain?

“According to the majority of the studies, sleep deprivation produces hyperalgesic changes.”<sup>2</sup> (That means yes!)

**What side effects does insomnia cause?** A summary based upon all of the research I have ever done and experienced after more than a decade living with it.

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<sup>1</sup> Insomnia Until it Hurts, The role of sleep deprivation in chronic pain, especially muscle pain, Paul Ingraham, updated Mar 5, 2019  
<https://www.painscience.com/articles/insomnia-until-it-hurts.php>

<sup>2</sup> Kundermann B, Krieg JC, Schreiber W, Lautenbacher S. The effect of sleep deprivation on pain. *Pain Res Manag.* 2004;9(1):25–32

- Fatigue
- Pain
- Headaches
- Attention problems
- Anxiety and/or depression

### **Sleep as a treatment for pain**

"More broadly, our findings highlight sleep as a novel therapeutic target for pain management within and outside the clinic, including circumstances where sleep is frequently short yet pain is abundant (e.g. the hospital setting)."<sup>3</sup>

Why is sleep a novel (or innovative) treatment for pain??

So we have found that research supports insomnia as life threatening, costing money, leading to pain (and sleep is a treatment for pain) what is the insomnia problem specifically relating to fibromyalgia?

### **What is insomnia, exactly?**

- Trouble falling asleep
- Difficulty staying asleep
- Waking too early
- Not achieving good quality sleep
- Waking unrefreshed

### **What's happening for people with fibromyalgia and sleep?**

Dr Ginevra Liptan, MD, writes about sleep in her book *The Fibro Manual* (2016):

*"Sleep studies show that Fibromyalgia subjects show abnormal 'awake-type' brain waves all night long, with reduced and interrupted deep sleep and frequent 'mini-awakenings' (Brandi 1994; Kooh 2003). This deep-sleep deprivation leads to pain, fatigue, and poor brain function (Lerma 2011; Moldofsky 2008; Harding 1998). Treatment focused on increasing deep sleep is the key to improving all these symptoms."*

In plain terms, people with Fibromyalgia don't tend to reach stage four of the sleep cycle (the deep, restorative stage), and therefore, they suffer from chronic, deep sleep deprivation, which causes all sorts of issues with the body: pain, fatigue, fog, anxiety, etc.

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<sup>3</sup> Krause AJ, Prather AA, Wager TD, Lindquist MA, Walker MP. [The pain of sleep loss: A brain characterization in humans](#). *J Neurosci*. 2019 Jan. [PubMed #30692228](#). □

Insomnia—along with poor sleep in general—is believed to make fibromyalgia symptoms more severe, which means treating your sleep problems may have the secondary effect of improving pain, fibro fog, and more.<sup>4</sup>

Let's just repeat that – treating sleep should help with pain, fatigue and fibro fog.

### **How have I experienced insomnia?**

Every single night for more than a decade (including my entire twenties), despite researching and using a lot of sleep hygiene tips and natural sleep aids, having trouble falling asleep, not staying asleep for more than one hour at a time, spending time awake in the night too exhausted to get up but too sore to remain lying still and waking feeling more tired than I went to bed.

This was while on the only option the doctor every offered me – amitriptyline.

Finally in 2017 I began taking low dose naltrexone and it helped me to start sleeping in blocks of up to a few hours. This made such a difference on my quality of life. But I still struggle with insomnia every single day.

I can't imagine how much more I could achieve if I could sleep well. Or what it might have been like if my doctors had been willing to work with me to help me achieve more sleep. Even utilizing low doses of medicines for a short amount of time to achieve some rest, like two prominent physicians who have fibromyalgia and treat patients with it suggest (Dr Teitelbaum *From Fatigued to Fantastic* and Dr Liptan *The Fibro Manual*).

I was miserable and missed out on the usual things one does in their twenties. I couldn't do my OE, I could hardly make it through the day let alone travel long distances.

Now, with the amount of sleep I've been able to reclaim I am managing day to day, but I still experience severe costs. I cannot stay up late, it is difficult to manage my children myself, I cannot work and when I do work I can only manage part-time work (so a cost of 30,000-80,000 per year lost there). Add the costs of things I need to manage such as the low dose naltrexone prescription, doctors' visits, supplements, physiotherapy, and the many, many things I have tried to help myself. Add in the impact on my quality of life of dealing with chronic pain all day every day. I don't know what a pain free day might look like!

And there are people who are worse off than me.

### **What do other people with fibromyalgia and insomnia say?**

"Fibromyalgia insomnia is a very real issue for me. I am currently breastfeeding a six month old. She wakes for one feed a night and resettles quickly back to sleep. It then

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4 Coping With Insomnia and Fibromyalgia **Common** Bedfellows By Adrienne Dellwo | Medically reviewed by a board-certified physician  
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takes me two to three hours to get myself back to sleep. I am exhausted. I have not had a good night sleep in years." – Amanda

"Where do I start? It's a vicious cycle in so many ways. If it's not the pain keeping me up, it's restless leg syndrome or another of the plethora of symptoms and comorbid disorders that come with fibro. Otherwise, it's pure anxiety from having night terrors brought on by my medication and the trauma that landed me with fibro in the first instance. The more I get into a terrible sleeping pattern, the worse my pain and other symptoms get, the worse my mental health gets, the worse my relationships get because I just cannot function or am not physically able or awake to conduct a "normal" life. And of course all of these things contribute to not being able to sleep or sleep well. Which perpetuates the issue.

While I was at uni my insomnia was seriously affecting my studies but I got flat out told by several doctors that they refused all students sleeping meds because they were so highly abused. I cried in Drs appointments, I cried as I lay awake at night in pain, I cried when I was forced to ask for extensions on my coursework, I cried when I got sub-standard grades because I knew it wasn't a reflection on my ability but my circumstance. It's such an underestimated burden that so many are forced to "put up with" because "everyone's stressed" or "everyone's tired" for one reason or another. I wish it was taken as seriously as my pain, which has had all manner of meds thrown at it. I'm sure it hurts me just as much." - Rebekah

**So for them, and for me, I want to beg doctors to take the sleep problem much more seriously. I want to beg researchers to look into how we can fix this (ideally without long term drug use).**

**If you are suffering from insomnia and fibromyalgia what can you do?**

- Learn (I have a [Sleep and Fibromyalgia 101 micro course](#), and offer [coaching](#) to help you work through your sleep plan and the other key areas of fibromyalgia)
- Experiment
- Beg for help – show your doctor you have tried all the things and hope for help!

Now that you have read this information what can you do?

SHARE it – let's get the word out there.

TALK about it – let people hear about this issue.

If you have a blog please write your own post about it. If you have social media share this post and create your own posts.

## Resources

[Getting a Great Night's Sleep](#) – webinar from Dr Teitelbaum (50 minutes long)

["A Prescription For Sleep": Sleep Drugs For CFS and FM](#)

[Sleep, Sleep Research, Sleep Hygiene, Sleep Tips](#) – Melissa vs Fibromyalgia

[13 Tips for Getting a Better Night's Sleep with Fibromyalgia](#) – Fed up with Fatigue

[13 Tips for Quality Sleep](#) – Being Fibro Mom

[Natural and Alternative Sleep Tips](#) – The Disabled Diva

[Insomnia posts](#) – Spoonie Living

[How much time are you wasting on sleep?](#)– A Chronic Voice

[Why Sleep Testing is Important if you Have Fibromyalgia](#) – Counting My Spoons

[Guide to Restful Sleep](#) – Ashley's Anatomy

[Coping with Insomnia](#) – A Journey through the Fog (a good, comprehensive post)