

## **Sleep problems are one of the most common complaints among people with Myalgic Encephalomyelitis and/or Fibromyalgia.**

Higher levels of deep sleep and/or lower levels of light sleep have been reported in several all-night polysomnography studies in ME patients. This distribution of Non-Rapid Eye Movement Sleep (NREMS) contrasts with what would be expected if sleep was interrupted by micro-awakenings, such as in sleep apneas or periodic limb movements, where more light sleep and less deep sleep are commonly observed. This “paradoxical” distribution of NREMS could represent a characteristic feature of chronic fatigue and deserved to be investigated.

For a patient with both M.E. and Fibromyalgia, poor sleep is a major source of intensified symptoms. Sleep disturbances and insomnia are very common, with a pattern of restlessness and difficulty in falling and remaining sleep. Circadian rhythms are prominent in the regulation of many physiological processes that are crucial to health. This suggests that circadian rhythms in these patients needs to be explored, especially since the balance between the sympathetic and parasympathetic nervous systems, indicative of autonomic function, is mainly regulated by the circadian control of the suprachiasmatic nuclei.

Regardless of the number of hours slept, sleep is usually not restorative, meaning that people wake up tired rather than refreshed. This is likely due to an insufficient amount of the deepest and most restorative type of sleep, called delta sleep.

- Other sleep problems include
- Difficulty getting to sleep
- Frequent awakenings or waking early
- Phase shifting (hard to fall asleep until early morning hours)
- Oversleeping (8 to 10 hours is ideal)
- Vivid dreams
- Feeling "tired but wired" (feel exhausted but mind is racing)
- Restless legs
- Periodic leg movements

People with ME and FM experience intensified fatigue, achiness and mental fogginess that lasts one to two hours after rising. In addition to sleep problems due to ME and FM, a majority of people with the two conditions experience sleep disorders such as sleep apnea and restless legs syndrome.

Addressing sleep problems is a good initial focus for symptom management because treating sleep can both improve quality of life and reduce other symptoms. Sleep management plans usually include a combination of strategies from three categories:

- Sleep environment and habits
- Medications
- Sleep disorders

## 1. Sleep Environment and Habits:

Most people with ME and FM can improve their sleep by changing their sleep habits and their sleep environment, matching a solution to a problem. Common problems include:

- Irregular hours for going to bed or getting up / no schedule
- Noisy environment (including snoring by sleeping partner)
- Lack of control over light and temperature
- Uncomfortable bed
- Tension and worry
- Not allowing time to wind down
- Eating or drinking caffeinated products too close to bedtime

A starting point for better sleep is to address these and other aspects of your sleep hygiene.

**Have a Comfortable Environment.** Provide yourself with an environment conducive to good sleep by using a good mattress, and by exercising control over light, noise and temperature. Many feel most comfortable sleeping in a recliner, which can reduce back pain. Note: Noise includes snoring by your sleep partner. Some people with ME or FM sleep in a separate bedroom from their partner.

**Establish a Routine.** Go through the same routine each night and have a consistent bedtime. Prepare for sleep by gradually reducing your activity level in the several hours before bedtime and by having a regular routine you go through consistently at the same time each night. Your routine might include things like getting off the computer and turning off the TV at a certain hour, taking a bath, brushing your teeth and reading. These habits can help you wind down and get ready psychologically for sleep.

**Use Relaxation and Distraction.** If you find it difficult to fall asleep, consider listening to quiet music or distracting yourself in some other way. If you are still unable to sleep, get up and engage yourself with quiet activities such as reading or listening to soft music or relaxation tapes until you are sleepy. Watching TV, using the computer and playing electronic games all tend to make people more alert, rather than sleepy, so should be avoided if falling back asleep is your goal.

**Control Stress and Worry.** Stress often leads to muscle tension, which makes falling asleep more difficult. Practicing relaxation methods can help you ease tense muscles. Try relaxation procedures or soak in a hot tub or bath before going to bed. If you have difficulty falling asleep because you are preoccupied with problems, consider setting aside a "worry time" each night before going to bed. Write down all your worries and what you'll do about them. If worries come up as you are trying to go to sleep, tell yourself "I've dealt with that. I don't have to worry because I know what I'm going to do." Alternatively, you can make an appointment with yourself to deal with the issues the next day, then tell yourself "I've set aside time to deal with that tomorrow."

**Get Up at the Same Time.** If you are going to bed later and later, setting an alarm so that you get up at the same time each day may help you adjust gradually back to more normal hours. Usually, you may not need to compensate by changing your bedtime to an earlier hour; your body can adjust itself.

**Use Pacing.** Being too active during the day or early evening can create a sense of fatigue combined with restlessness called feeling "tired but wired." Keeping activity within limits and having a winding down period before going to bed are antidotes.

**Limit Daytime Napping.** Sometimes daytime napping interferes with nighttime sleep. If you nap during the day and find that you have trouble falling asleep at night, or your sleep is worse than usual when you nap, you might consider sleeping only at night. On the other hand, if napping does not disturb your nighttime sleep, you may need more sleep.

**Avoid Caffeine, Alcohol & Tobacco.** Consuming too much caffeine, drinking alcohol and smoking can make getting good rest more difficult. Avoid products with caffeine, such as coffee, tea, soft drinks and chocolate, for several hours before going to bed. Avoid alcohol before bedtime; it can create restless and uneven sleep. The nicotine in tobacco is a stimulant, thus smoking is a barrier to falling asleep.

**Check for Medication Side Effects:** Drugs taken for other issues may affect sleep or create sleep-related problems. For example, drugs can produce a feeling of grogginess in the morning. Also, medications taken for problems other than sleep may interfere with sleep if they contain substances like antihistamines or caffeine.

## **2. Medications**

Treating sleep with drugs is challenging because there is no single medication that has proven helpful in solving sleep problems for people with ME and Fibromyalgia. Also, many patients develop drug tolerance, so that a medication becomes less effective over time.

For both these reasons, sleep problems can benefit from a flexible, experimental approach that utilizes a variety of strategies. If you think medications might improve your sleep, first consider over-the-counter (non-prescription) products like melatonin, valerian, Tylenol PM and Advil PM.

If you prefer prescription medications, a reasonable approach is to find a physician willing to work with you to find what helps in your unique situation. Because no one drug is consistently helpful for treating sleep in people with ME and FM, you may have to experiment to find what helps you. Since people with ME and FM are extremely sensitive to medications, your doctor should start with low doses and increase slowly to find a dose that is both effective and tolerated.

Amitriptyline has been most widely and successfully used, but doxepin is available in a liquid form, so doses as low as one drop (equals 0.5mg) can be used.

While medications can improve sleep, they can also make it worse. Some drugs disrupt sleep by reducing slow wave sleep or causing restless legs and periodic legs movements.

Also, some drugs produce side effects, like a feeling of grogginess in the morning. Medications that contain caffeine and some antihistamines may interfere with sleep.

## **3) Sleep Disorders**

If your sleep doesn't improve despite better sleep hygiene and the use of medications, consider asking your doctor for a referral to a sleep specialist, who can examine you for sleep disorders. Sleep disorders are very common with ME/CFS and FM, affecting a majority of people with both conditions, perhaps as many as 80%. Treating them can have a dramatic effect on symptoms. Two of the most common sleep disorders are discussed below.

Sleep apnea, meaning absence of breathing during sleep, occurs when a person's airway becomes blocked during sleep and he or she stops breathing. An episode can last from a few seconds to a few minutes. The person then awakens, gasps for air and falls asleep again, usually without being aware of the problem. The cycle can occur many times a night, leaving the person exhausted in the morning.

Apnea is a treatable condition. A common remedy is the use of a CPAP (continuous positive airway pressure) machine. The patient wears a mask through which a compressor delivers a continuous stream of air, keeping the airway open and thus allowing uninterrupted sleep. Use of a CPAP machine can eliminate 90% to 100% of a person's sleep apnea. Other treatments are also used for this condition, including oral or nasal devices and surgery to enlarge the airway.

Restless legs syndrome (RLS) involves "twitchy limbs," strong unpleasant sensations in the leg muscles that create an urge to move. The problem is often at its worst at night.

Self-management techniques that may help include reducing consumption of caffeine and other stimulants, establishing a regular sleep pattern, doing exercise that involves the legs, distracting yourself by immersing yourself in activity, using hot or cold baths or showers, and taking supplements to counteract deficiencies in iron, folate and magnesium.

Several categories of medications may also help, including sedatives, drugs affecting dopamine, pain relievers and anticonvulsants. Three of the more commonly used drugs for RLS are the pills “Requip” and “Mirapex”, and the patch “Neupro”. On the other hand, antidepressant medications may trigger RLS. This possibility should be considered if your symptoms began after initiation of mood therapy.

## **Sleep Study**

### **What is a home sleep apnea test?**

A home sleep apnea test (HSAT) measures how well you sleep and the results from this test can determine if you have sleep apnea. These tests use a small home sleep recorder worn overnight while you sleep in the comfort of your own home. A board-certified sleep physician interprets the sleep test results to determine if you have sleep apnea. “A sleep test is meant to evaluate a patient for sleep apnea, and it monitors breathing parameters, not the sleep itself. The sleep test won’t analyze how long you’re in light or deep sleep, for instance. Instead, it will measure pauses in and absence of breathing, how much effort it takes to breathe and whether your breathing is shallow.

At-home sleep apnea testing is an easy, cost-effective way to figure out whether you’re having trouble breathing. A home sleep apnea test is a very simplified breathing monitor that tracks your breathing, oxygen levels, and breathing effort while worn. It does not fully capture what is monitored with an overnight sleep study.

Overnight sleep studies give a more thorough assessment of sleep issues. They are attended by a sleep technologist and capture many more signals, including brainwaves for sleep, muscle tone, and leg movements. For individuals with certain heart, breathing, or neuromuscular problems, an overnight sleep study at a sleep center may be better.

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