



## SLEEP . . . ELUSIVE SLEEP

*By Yvette Taylor*

*O sleep! O gentle sleep!  
Nature's soft nurse, how have I frighted  
thee,  
That thou no more wilt weigh my eyelids  
down,*

*And steep my senses in forgetfulness?*

William Shakespeare, *King Henry, in Henry IV, Part 2, act 3, sc. 1, l. 5-8.*

You finally get your diagnosis, finally learn why you hurt all over, why—no matter how hard you try—there are times that you absolutely have to lie down, too exhausted to do *anything*. You have fibromyalgia. “What is fibromyalgia?” I asked, while being scraped off the ceiling after what seemed to me a sadistic assault on various parts of my body. I was handed a brochure to read and told that the doctor would come back to answer my questions to the best of his ability. There is still much to be learned about fibro, so my doctor couldn't give me all the answers I wanted. I did learn about trigger points and what treatments and medications were currently available to help with the symptoms of fibro. There is currently no cure, though I am happy to report that there are now 2500 studies published in peer-reviewed journals by physicians and researchers investigating fibromyalgia. This wonderful news, which I picked up while attending the professional portion of the National Fibromyalgia Association meeting, is very noteworthy. Getting published in a peer-reviewed journal means that two or three experts in the area of study make sure that the research is properly conducted, analyzed, and discussed.

At least my problems had a name, even though it was one I had never heard of! I realized that all my symptoms were described in that one brochure. I was lucky—I did not have *all* of the symptoms. I especially focused on the paragraph about sleep, or lack thereof. The pain was bad, but the fatigue was even worse—and so began my journey as a fibro patient and my search for pain relief and restorative sleep.

I began with all types of medicines in various combinations to help me sleep. I spent many nights without ever drifting off to dream land, learning what worked and what didn't, having doses changed and new meds combined. I discovered early that it is a very difficult task to knock me out! Finally, after years and years, there were no

combinations left, and my doctor sent me to a sleep disorder clinic, and I am very glad he did.

I went to the clinic and described my sleep problems to a neurologist, who recommended a sleep study. I was shown a lovely, small bedroom where I would spend the night. But where was the TV? Where was the bedside light? Panic set in. I usually read until my eyes get tired, and then I turn the TV on as background as I try to fall asleep. But no--that is *not* good sleep hygiene, I was informed. Your bed is for sleep, and I suppose fooling around, but I was not invited to bring anyone along for entertainment.

I read the instructions carefully before I went to my sleepover a few days later, noting that PJs were advised rather than a nightgown. I complied and packed my bag with my favorite pajamas: tiny embroidered flowers and lace on my prettiest, but kind of flimsy, night attire. I thought I would be hooked up in my room, but it was a group activity, and I was the only female and the only one under 200+ pounds. I was not happy. I did not want this group of rather large men to discover that my body had succumbed to the gravity of age, but as tube after tube of glue was squeezed on my head for the electrodes, and wires were attached all over me, snaking down the pajama top and bottom, I quickly lost any concern I had about my appearance.

I was the last one finished, possibly because I have a lot more hair than did the guys. It took a *lot* of glue. There were TVs recording every room that the technicians watched throughout the night. I was very jealous when one of the men fell asleep as soon as his head hit the pillow. The snoring began within 2 seconds. I knew I would lie awake for a long time, but I didn't think I would snore. I was right on the first supposition, and wrong on the second.

Although I slept 7 hours, I did not get *any* restorative sleep. I was also told that I had sleep apnea. I stopped breathing an average of 11 times an hour, the longest being 47 seconds! I was told, among many other things, that a "snort" was a gasping for air and that sleep apnea can be serious.

The doctor wanted me to use a Continuous Positive Airway Pressure (CPAP) machine. He hoped that would help me get restorative sleep. The CPAP is a small machine that attaches to you via a long, flexible tube that connects to plastic tubing that ends up in your nose. A chin strap holding your mouth closed completes the fashion statement. It's *not* pretty and *not* easy to get used to. You can hear every breath you take. I sound like Darth Vader. In fact, my son asked whether he could borrow the equipment for Halloween. After a month, however, I am, in the words of my doctor, "a compliant patient." Of course, he doesn't know about the time I ripped the tubes out of my nose or when I woke up to discover all the CPAP parts flung across the room. I think the dog did it. Certainly, I wouldn't do anything like that!

I took my CPAP machine to Washington, DC, in August, where I became a National Fibromyalgia Association International Leader Against Pain. While at the professional portion of the meeting, I learned that the majority of people with fibromyalgia have sleep apnea! I was very lucky that my roommate was a physician. Dr. Lina really helped me out when my tube sprung a leak! I wonder how many years of medical school went into her nifty solution. She put a Band-Aid on the tube.

I did some research when I got home and was surprised to find out that the majority of the general population has sleep apnea too! You don't have to be an overweight man.

If you aren't too sleepy to remember, consider talking to your doctor about getting a sleep study. No, it wasn't fun, but fibro isn't fun. There is hope, though, that should give you a big smile. Because I was still awake much of the night for my first month with a tube up my nose, my doctor prescribed a medication that is FDA-approved for narcolepsy and may soon be FDA-approved for us! It promotes restorative sleep. I have had none of the side effects that many people have, and I actually get out of bed when I wake up. I have had success with Xyrem. It isn't for everybody, but it's giving me that heretofore elusive sleep.

(Don't call and ask me for my doctor's name, though. He isn't taking new patients. Anyway, I probably will be asleep, tubes and all!)

PS: To my wonderful neurologist: "Dr. \_\_\_\_\_ (who will be reading this article), "Do you think I'm practicing good 'sleep hygiene' now?" You'll never know!!

**PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE  
DISORDERS ORGANIZATION FOR RESEARCH AND  
ADVOCACY - 501 c 3 - ID # 550795076  
C/O VIÑA + COMPANY, 255 Alhambra Circle, Suite 715, Coral  
Gables, Florida 33134  
Main Office: 305-441-1591 • Volunteer Help line: 954-783-6771  
Fax: 954-783-1098 • [www.pandoranet.info](http://www.pandoranet.info)  
E-mail: [contact@pandoranet.info](mailto:contact@pandoranet.info)**

**Built on Hope • Strong on Advocacy • Finding a Cure through Research**