



THE NETWORK

A Publication of Narcolepsy Network, Inc.

First Quarter 2011

A Perfect Week to Raise National Awareness about Sleep *By Vanessa Oliveira*

For hard-working and sleep-deprived Americans, National Sleep Awareness Week (NSAW) offers a time to highlight the critically important relationship between sleep and health. This year NSAW took place between March 7th and 13th. The National Sleep Foundation (NSF) created NSAW as an annual event to provide education and awareness about developing healthy sleep habits. In addition, the week created the opportunity to improve awareness about sleep disorders such as sleep apnea, fibromyalgia, restless leg syndrome, narcolepsy, and idiopathic hypersomnia.

Narcolepsy Network mailed two orange bracelets to each member with the motto *Sleep Well Live Better* to celebrate NSAW. Each mailing included instructions to wear



one bracelet and share the other with a friend, family member, or coworker in order to spread narcolepsy awareness. We hope that all members used the bracelets to spur discussion about narcolepsy, other sleeping disorders, and the importance of healthy sleep habits in general.

NN members around the country celebrated NSAW in their own ways. Julie Flygare celebrated NSAW by organizing a "Sleep Walk" in Washington, DC on the national mall to celebrate sleep and raise awareness about sleep disorders. A video of the event is available on You Tube.

The week's celebration began when NSF released the annual Sleep in America poll results. Over 1,500 people were

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New and continuing memberships to NN can be purchased on the NN Website by clicking on "*Become a Member*" in the top right-hand corner of the homepage. Annual memberships run by the calendar year.

If you haven't renewed your NN membership for 2011, please remember to do so in order to continue receiving these informative newsletters.

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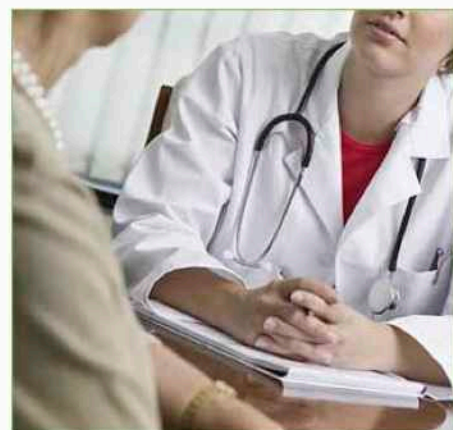
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Tips for Talking With Your Sleep Doctor

By Julie Flygare

I'll never forget my first meeting with my sleep doctor. We discussed my sleepiness at length. He nodded understandingly as I described my cataplexy and crazy nightmares. The symptoms that were so mysterious to the rest of the world were commonplace inside his office. I cherished his expertise and acceptance, but all too soon, our time was up. I left the office unsatisfied, wishing we could've talked much longer.

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Tips for Talking with your Sleep Doctor *continued from page 1*

Sleep doctors are often on very tight schedules. Yet, our meetings with them are vital to our health and happiness. Below are a few ideas for maximizing our time with our sleep doctors. (Drawn from personal experience and interviews with neurologists and other PWNs.)

1 Picking priorities: In preparation for visit, pick out 3-5 top issues to discuss. Having difficulty choosing priorities? Make a list of all possible issues and share with someone you trust. They can help you sort through your thoughts and identify priority points.

2 Following Plan: When trying a new treatment, try to stick to plan for a specified amount of time before abandoning doctor's recommendations. Accessing whether a new treatment "works" should be done after at least 10-14 days and some treatments take months before the full benefits will be felt. (Of course, severe side-effects and symptoms should be reported to the MD right away).

3 Tracking Habits: Keeping a sleep log can be helpful for various reasons. Consider using a simple visual one (See example from Stanford's Center for Narcolepsy on page 10). Marking your sleep and medication times can help both the physician (to assess what is working and not) and the patient (to be more regimented about their habits). Logging this information may increase self-awareness and lead to better choices or habits in the future.

4 Help them help you: Doctors are there to help us — but they can't read our minds so it's important to be honest and assertive. Be truthful about what you are and aren't doing with your health/medical care (trying to impress your doctor by being a "good" patient often backfires). Similarly, try to assertively express your priority needs. If you'd like to try a different medication or request a letter written on your behalf, be sure to let them know and work together to make progress.

5 Staying Open to Different Ideas: In the age of the Internet, it is easy to gather information — some credible, some not — from home. It may be tempting to diagnose oneself and pick treatments before meeting with a sleep doctor. Thus, it is important to stay open to a sleep doctor's perspective, even if it conflicts with our expectations. Finding the best possible diagnosis and treatment options can be a frustrating long process — but we must trust that doctors have our best interests in mind, even if this conflicts with what we think we "need." I strongly resisted my sleep doctor suggestion that Xyrem might be an effective treatment in my circumstances. I had never heard of Xyrem nor liked the rules around taking it. Ultimately, I followed his suggestion and I'm very glad I did.

However, if you are very unhappy with your current sleep doctor, seek a second opinion. Not all doctor/patient relationships are a good fit.

6 Success with Tweaking: When things aren't going well, it's tempting to conclude that increasing dosages or switching medications altogether is the best solution. Sometimes success comes in the tweaking. Changing the timing of doses, practicing consistency, or adding a behavioral change can make a huge difference. Short planned proactive naps are often the best treatment for alertness and a clear head.

7 Additional Support: Finding a network of support is an invaluable compliment to medical treatment. Although originally I was compelled to tell my sleep doctor "everything" — I've found other people (with more free time) to talk with in order to cope with my daily experience of narcolepsy. I've enjoyed weekly meetings with a therapist and slowly built a larger support system of friends, family members, mentors, and other PWNs (that I met at conferences, in support groups and online via my blog).

A Banner Day for NN: Helping One Sleepy Child at a Time *continued from page 3*

behavioral components of the problem. To the best of our knowledge, there was no consideration of creating an Individualized Education Plan (IEP) nor did he have a 504 plan in place.

Once this boy's mother reached out to NN about the behavioral problems her son was having at school and the negative psychosocial effects he was experiencing as a result of the excessive sleepiness, our experts took action. Joyce Scannell, our office manager, sent out an urgent email and fax while Eveline Honig put a team of experts together. Mothers Michele Profeta and Kim Yourick wrote letters, sent out their educational plans and calmed down the boy's mother; Charlie Severson, NN Trustee also counseled the mother; and Eveline Honig spoke with several school officials in an effort to help the situation. In this great team effort NN representatives, including staff and volunteers, were carrying out the mission of our organization by providing information and resources to those who needed it most — those uninformed about how to deal with a sleeping disorder like narcolepsy when it strikes at such a young age.

An example of an existing IEP for another student with narcolepsy was sent immediately to the boy's school and family. We also wrote a letter including facts about narcolepsy to inform and educate the school administrators about narcolepsy itself, as well as offer suggestions about potentially successful ways to manage the student's condition in a socially appropriate way. The added outreach is critical to our mission because without understanding why certain actions are recommended, the administrators won't understand enough to potentially help future students with narcolepsy (or potentially other sleeping disorders) who may need these same types of accommodations. People from

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