

ORGANIZATION NEWS

Information/Education Page

Practical Sleep Information for People With Multiple Sclerosis



Purpose

To provide information to people with multiple sclerosis (MS) and their support network about:

- Common sleep problems in people with MS.
- General recommendations for sleep promotion techniques.

Prevalence of sleep problems in people with MS

- 40%-70% of individuals with MS report sleep disturbances or poor sleep quality.¹⁻⁴
- The prevalence is likely higher due to under-reporting and lack of objective evaluation.¹

Common sleep disorders in people with MS^{1,5}

- Insomnia: difficulty falling asleep, staying asleep, or waking up too early.
- Sleep apnea: occasional pause or reduction in breathing while sleeping.
- Periodic limb movement disorder: frequent movement of the legs (typically) or arms while sleeping.
- Rapid eye movement sleep behavior disorder: excessive movement and acting out dreams while sleeping.
- Narcolepsy: unintentionally sudden falling asleep during the day.

Possible causes and contributors of sleep problems¹⁻⁵

- MS lesions in the areas of the brain that regulate the sleep/wake cycle.

- Disruption in the chemicals in the brain that regulate the sleep/wake cycle.
- Side effect of medications including dimethyl-tryptamine, corticosteroids, and stimulants to treat fatigue or daytime sleepiness.
- Fatigue.
- Stress, anxiety, and depression.
- Other MS-related symptoms, including pain, spasticity, and urinary or bowel issues.
- Napping and reduced activity during the day.
- Caffeine, nicotine, and alcohol.

Common sleep problems in people with MS¹⁻⁵

- Difficulty falling asleep.
- Waking up periodically during the night.
- Difficulty returning to sleep after waking up in the middle of the night or early in the morning.
- Excessive daytime sleepiness.
- Waking up feeling like unrested despite getting 7 to 8 hours of sleep.
- Excessive movements while sleeping.

Talk to your doctor and health care providers

The first step to address your sleep concerns is to prepare and have an informed conversation with your doctor. To prepare for this conversation, answer the following questions using your previous month of sleep⁶:

- (1) How long, on average, has it taken you to fall asleep?
- (2) How many hours of sleep, on average, did you get per night?

- (3) How many times, on average, did you wake up per night?
- (4) How many minutes per night, on average, did you spend in bed awake, unable to fall back asleep?
- (5) How rested, on average, did you feel upon waking in the morning?
- (6) How often, on average, did you take naps during the day?
- (7) How often did pain interfere with your sleep?
- (8) How often did spasticity or restless legs/limbs/body interfere with your sleep?
- (9) How often did urinary or bowel symptoms interfere with your sleep?
- (10) How often did you take medication (prescription or over-the-counter) to help with sleep?
- (11) How often did you snore or experience shortness of breath upon waking?
- (12) How difficult was it to maintain alertness and energy during the day?

Your doctor may ask you additional questions about your sleep issues, review your medications, and conduct a thorough medical evaluation. Your doctor may recommend that you undergo an overnight sleep study in your home or in a laboratory, if warranted.

Depending on the type of sleep problems you are having, you may benefit from working with different health care professionals, including primary care physicians, neurologists, sleep medicine specialists, physical therapists, occupational therapists, psychologists, and psychiatrists.

Treatment considerations^{5,7}

Treatment should:

- Be individualized for the person with MS.
- Consider the individual's physical and mental symptoms.
- Address concomitant issues such as anxiety and depression.
- Consider caregiver support and/or bed partner if indicated.
- Consider sleep health promotion techniques (table 1).

Possible treatment options for common sleep disorders⁵

- Insomnia:
 - Treatment of the underlying cause.
 - Cognitive-behavioral therapy for insomnia.⁷
 - Sleep promotion techniques (see table 1).
 - Medication if other therapies are not effective.
- Sleep apnea:
 - Positive airway pressure therapy.
 - Oral appliance.
- Periodic limb movement disorder:
 - Treatment of the underlying cause.
 - Iron supplementation if indicated.
 - Medication.
 - Physical activity.
- Rapid eye movement sleep behavior disorder:
 - Make sleeping environment safer to avoid injury to self or bed partner.
 - Medication.
- Narcolepsy:
 - Napping during the day.
 - Medication to increase alertness.
 - Medication to treat the cause of narcolepsy.

Resources

National Multiple Sclerosis Society

- Sleep webpage: <https://www.nationalmssociety.org/Living-Well-With-MS/Diet-Exercise-Healthy-Behaviors/Sleep>
- Sleep Disturbances and Multiple Sclerosis: http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Documents/Sleep_Hughes_2016.pdf
- Sleep Disorders and MS: The Basic Facts: https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Sleep-Disorders-MS-BasicFacts_FINAL.pdf
- Importance of Sleep webinar: <https://www.nationalmssociety.org/Programs-and-Services/Programs/Importance-of-Sleep,-December-13>
- Managing Pain and Sleep Issues in MS: <https://www.nationalmssociety.org/Programs-and-Services/Resources/Managing-Pain-and-Sleep-Issues-in-MS-Part-2-Sleep?page=1&orderby=3&order=asc>

Table 1 Sleep promotion recommendations

Enhance circadian rhythm

- Wake up at the same time every day. Ideally, also go to bed at the same time every day, but only go to bed when you are adequately tired to fall asleep.
- Expose yourself to bright light (natural is best if possible) when you first wake up (at ideal regular wake up time).

Increase sleep drive

- Use your bed for only sleep and sexual activity to help train your brain that if you are in your bed, you should be sleeping.
- If you are not able to fall asleep within *what feels* like 15-20 minutes (do not watch the clock) or if you start to feel worried/anxious about not sleeping, get out of bed, go to another room (if possible), and do relaxing activity (i.e. listen to audiobook or music). Return to bed when sleepy.
 - o If unable to leave the bed due to limited mobility or safety concerns, do relaxing activity in bed until sleepy.
- Avoid/limit daytime napping so that you are sleepy at night and can fall asleep easily.
 - o If you need to take a nap, limit to 20-30 minutes, and nap earlier in the day. Set an alarm if needed.
 - o Avoid napping in the evening, if possible.
 - o If you nap, you may need to delay your bedtime at night until you are adequately sleepy to fall asleep easily.
- Be physically active during the day. Talk to your physical therapist about how to safely increase your physical activity if needed. Being very active close to bedtime may interfere with your sleep.

Reduce arousal before bedtime

- Develop a relaxing bedtime routine. This may include taking a bath, reading a book, journaling, and/or meditation.
- Avoid stimulating activities before bedtime (such as watching TV, being on electronic devices, or discussing a stressful topic).
- Stop using light-emitting electronics held close to your eyes (i.e. smartphone, tablet) at least 1 hour before bedtime as the blue light that is emitted can disrupt sleep by suppressing melatonin production. Also, the content being viewed on the electronics can be stimulating or engage you longer than you intended.
- Avoid caffeinated foods and drinks at least 4 hours before bedtime (includes most tea, coffee, chocolate, soft drinks). Check the presence of caffeine in your drink, food, and medicines by reading the label. De-caffeinated items still contain some caffeine.
- Refrain from drinking alcohol or smoking at least 3 to 4 hours before bedtime. Although alcohol may relax you before bedtime, it can increase the number of times you wake up during the night and can cause you to wake up early. Also, nicotine is a stimulant that can cause difficulty falling asleep.
- Avoid eating a large meal or spicy food 2-3 hours before going to bed. Your digestive system slows down while you are sleeping, which can stimulate acid secretions that cause heartburn. A light snack may be helpful if you are hungry. Avoid excessive liquid 2-3 hours before bedtime but stay adequately hydrated.

Make environment conducive to sleep

- Make your sleeping environment as dark as possible. Darkness tells your brain it is time to sleep; light tells your brain it is time to wake up. Consider light-blocking curtains or an eye mask if needed.
- Turn your clock around or remove the clock from your bedroom so you are not tempted to stare at the clock. This may also reduce the light in your bedroom.

(continued on next page)

Table 1 (continued)

- Reduce/eliminate noise. Use ear plugs or a white-noise machine if needed.
 - Keep the temperature comfortable. Being too warm or cold may disturb your sleep.
 - Use a comfortable and supportive pillow and mattress.
- Other recommendations
- Do not take unprescribed or over-the-counter sleeping medication unless recommended by your physician for your sleep disturbance.
 - Talk to your doctor if you are having trouble sleeping. Underlying factors that may be causing or contributing to your sleep disturbance may need to be addressed, and an individualized treatment plan may be needed.

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Centers for Disease Control and Prevention

- Sleep and Sleep Disorders: <https://www.cdc.gov/sleep/index.html>

Authorship

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References

1. Brass SD, Li CS, Auerbach S. The underdiagnosis of sleep disorders in patients with multiple sclerosis. *J Clin Sleep Med* 2014;10:1025-31.
2. Bøe Lunde HM, Aae TF, Indrevåg W, et al. Poor sleep in patients with multiple sclerosis. *PLoS One* 2012;7:e49996.
3. Merlino G, Fratticci L, Lenchig C, et al. Prevalence of 'poor sleep' among patients with multiple sclerosis: an independent predictor of mental and physical status. *Sleep Med* 2009;10:26-34.
4. Siengasukon CF, Aldughmi M, Kahya M, et al. Individuals with mild MS with poor sleep quality have impaired visuospatial memory and lower perceived functional abilities. *Disabil Health J* 2018;11:116-21.
5. Braley TJ, Chervin RD. A practical approach to the diagnosis and management of sleep disorders in patients with multiple sclerosis. *Ther Adv Neurol Disord* 2015;8:294-310.
6. DiGerolamo T. Let's find better sleep. *MS Focus Magazine*. Available at: <https://msfocusmagazine.org/Magazine/Magazine-Items/Posted/Let-s-Find-Better-Sleep>.
7. Siengasukon CF, Alshehri M, Williams C, Drerup M, Lynch S. Feasibility and treatment effect of cognitive behavioral therapy for insomnia in individuals with multiple sclerosis: A pilot randomized controlled trial. *Mult Scler Relat Disord* 2020;40:101958.
8. Siengasukon CF, Al-Dughmi M, Stevens S. Sleep health promotion: practical information for physical therapists. *Phys Ther* 2017;97:826-36.