

# Diagnosing and Treating Hypersomnia in Youth

## Sleep Disorders Are Common in People Who Have Disabilities

by John Garcia, M.D.

The most common consequences of sleep disorders are fatigue and irritability. But in youth — especially children who have brain injuries or developmental disabilities — the consequences of sleep disorders can be more pervasive.

For example, in addition to exacerbating pain, sleep disorders can impair learning and complicate healing. As youth accumulate sleep debts, their quality of life, mood and memory often deteriorate significantly. Sleep deprivation also can harm a child's cardiovascular, immune and metabolic systems.

Although numerous types of sleep disorders exist, this article focuses on hypersomnia: daytime sleepiness that persists despite ad lib sleep. In cases of hypersomnia, neither nighttime sleep nor daytime napping is restorative. Something else gets in the way.

Diagnosing and treating that “something else” is the key to improving clinical outcomes.

### Signs and Symptoms

Although hypersomnia might seem uncommon, providers who routinely ask about patients' sleep patterns will find plentiful instances of the condition.

Some signs of hypersomnia are clear. Although many children give up naps at about age 5, that phenomenon is more culturally created than physiologically based. One red flag appears when children who have given up naps resume them. Such behavior points to a sleep disorder until proven otherwise. In addition, a child who is too sleepy to complete homework is similar to an adult who is unable to complete work. Such patients deserve evaluations by a physician specializing in sleep disorders.

Primary causes of hypersomnia are rare. They include:

- Narcolepsy, a deficiency of the neurotransmitter orexin/hypocretin; some syndromes — including myotonic dystrophy, Prader-Willi syndrome, Niemann-Pick disease

and brain injury — exhibit orexin/hypocretin deficiency as part of the disease

- Idiopathic hypersomnia, a condition that is associated with hypersomnia but does not meet diagnostic laboratory criteria for narcolepsy
- Kleine-Levin syndrome (recurrent hypersomnia), which is seen in teens and young adults, mostly males; between periods of hypersomnia, patients experience typical sleeping patterns

In patients with neuromuscular disorders, such as cerebral palsy or muscular dystrophy, daytime sleepiness also can be a symptom of hypercarbia. Hypercarbia is caused by restrictive lung disease, muscle weakness and difficulty managing secretions.

More often, primary-care providers will see hypersomnia resulting from secondary causes, such as brain injuries (see next section) and disorders that fragment nighttime sleep. Disorders that fragment sleep include restless leg syndrome, sleep apnea, nocturnal seizures, and periodic limb movement disorder.

In addition, sleep disorders often occur secondary to developmental disabilities. For example, sleep problems affect about 30 percent of children who have cerebral palsy, epilepsy, brain injuries and spina bifida. Between 25 and 50 percent of children who have attention deficit hyperactivity disorder also have sleep disorders. Brain tumors and their treatment also can cause brain injuries and subsequent hypersomnia.

### The Particular Case of Traumatic Brain Injuries

Sleep disorders are one of the main symptoms of minor brain trauma in children and young adults. One study found that 55 percent of patients reported daytime sleepiness one month after a traumatic brain injury (TBI). That compares to 41 percent of people who experienced trauma without a brain injury and 3 percent of a trauma-free control group.

One year later, 27 percent of the TBI patients continued to report sleepiness. The study divided groups into patients with mild, moderate and severe brain trauma. In people with severe brain trauma, 90 percent of respondents could not discuss their own sleep patterns (“self-report”) because of cognitive difficulties.

Researchers hypothesize that sleepiness following a TBI is caused by an injury to the posterolateral hypothalamus, which decreases levels of the excitatory hypothalamic neuropeptide hypocretin-1 (orexin). Orexin is an alerting neurotransmitter made in the lateral hypothalamus. Because orexin is broadly distributed both to the cortex and to the brainstem, it’s easy to see how the forces of a TBI could disrupt its production. One study found deficient levels of hypocretin in 95 percent of patients who experienced acute moderate to severe TBIs.

Studies have shown that long-term outcomes from severe brain injuries can be compromised when patients experience sleep disorders. Once you eliminate sleep disorders, cognitive deficits might improve or disappear.

## Diagnosing Hypersomnia

A clinical history and sleep logs will help a practitioner sort through the differential diagnosis of hypersomnia. Patients suspected of having a diagnosis manifesting as hypersomnia should undergo actigraphy, an overnight polysomnogram, and a multiple sleep latency test.

### The 24-Hour History

One initial way to uncover sleep disorders is to ask patients or families to describe their sleep patterns during 24 typical hours. Begin with the dinnertime hour, then continue by asking the nonthreatening question, “What happens next?”

Keep track of responses, including information about:

- Bedtime routine
- Frequency, character and duration of arousals
- Time it takes to wake patient (is awakening spontaneous or aided by a parent?)
- Routine necessary to get patient out of bed
- Daytime behavior
- Timing and duration of naps

Determine whether daytime behavior is consistent with excessive daytime sleepiness. Ask patients whether they are falling asleep in school. If they admit to resting their head on their desk, chances are they are falling asleep during the day.

In at least half of all cases, a 24-hour sleep history will uncover a sleep-disorder diagnosis.

## Sleep Log

Another helpful tool for measuring the effects of a sleep disorder is a sleep log. A sample is available online. The log is an easy way for patients, or their parents, to provide an overview of information concerning sleep habits.

To complete a sleep log, patients or their parents:

- Note the time they went to bed.
- Mark the hours during which they were asleep.
- Mark the time they got out of bed for the day.
- Indicate times they exercised, consumed caffeine or took medication.

A physician specializing in sleep medicine can use the information to diagnose and treat sleep disorders.

## Actigraphy

Actigraphy is useful in clinically evaluating excessive sleepiness. The patient wears an actimetry sensor, the size of a wristwatch, to measure gross motor activity for up to several weeks. A computer algorithm correlates inactivity with sleep. Actigraphy gathers data that helps unmask any night-to-night variability in sleep patterns.

One of the benefits of actigraphy is that it can be done at home, rather than in a sleep laboratory where sleep patterns can differ from a patient’s usual experiences. It is especially useful in evaluating insomnia.

## Multiple Sleep Latency Test

Ultimately, the diagnosis of hypersomnia as an entity separate from fatigue is best made with a multiple sleep latency test. Otherwise, it is nearly impossible to differentiate fatigue and sleepiness in clinic.

Fatigue is generally defined as a temporary loss of strength and energy. Hypersomnia is defined as the ability to fall asleep. Although fatigued people might describe themselves as sleepy, they cannot fall asleep when given the opportunity.

In a multiple sleep latency test, a patient is offered five opportunities to nap. Those opportunities are spaced two hours apart throughout the day. In prepubertal children, a mean sleep latency of fewer than 15 minutes is considered consistent with a diagnosis of objective hypersomnia. The multiple sleep latency test usually takes place after the overnight test, which rules out obstructive sleep apnea and other sleep disorders.

## Treatment and Prognosis

The goal of treatment should be to return patients to normal alertness. That means patients should feel better and not require naps. Treatment should include the judicious use of medication (beyond hypnotic drugs), with an emphasis on nonpharmacological management. Stimulant medications, including methylphenidate and amphetamine salts, are generally very effective. When side effects — including headache, stomach ache, appetite suppression and tics — are troublesome, modafinil can be an effective option.

If an overnight sleep exam confirms the existence of a disorder fragmenting sleep, that disorder, too, can be treated. For example, patients who have restless leg syndrome receive iron or pramipexole. Patients who have seizures need evaluations and treatments from a neurology team. Patients who have obstructive sleep apnea receive surgery or use a device to deliver continuous positive airway pressure. Patients with a primary hypersomnia are treated with stimulant medication or modafinil.

The prognosis for patients with hypersomnia is good. This is one of the most satisfying areas of sleep medicine because a diagnosis is generally identified and effective treatments are available. (The exception is Kleine-Levin syndrome, for which there is no known effective treatment.) Treatment nearly always improves the patient's quality of life dramatically.

## References

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## Hypersomnia: A Case Study

A 10-year-old girl sustained a traumatic brain injury after a motor vehicle accident. She displayed slow responses and showed trouble processing information. Because obstructive sleep apnea and hypersomnia were suspected, she had a consultation with a sleep-medicine specialist.

A polysomnogram showed that she fell into rapid-eye-movement (REM) sleep immediately upon falling asleep. That symptom is common in patients with narcolepsy. Typically, REM sleep occurs later in the night; seeing it in the first hour of sleep is abnormal. A multiple sleep latency test showed that her mean sleep latency averaged 10 minutes. (Sleep latency of less than 15 minutes is considered abnormal in children.)

Further investigation found that a nutritional supplement, which the family was giving the girl, had caffeine in it. When that supplement was replaced with a stimulant medication, the girl's sleep improved

## **Gillette Sleep Health Clinic Receives Accreditation**

The American Academy of Sleep Medicine (AASM) has granted accreditation to the Sleep Health Clinic at Gillette Children's Specialty Healthcare. AASM is committed to ensuring that sleep-medicine specialists provide excellent health care and enhance the awareness of sleep as an important element of health, public safety, and quality of life.

Gillette's sleep health team works with children and adults who have disabilities. The team works closely with neurologists to identify issues, such as seizures, that might be affecting sleep. Using electroencephalograms, Gillette's sleep medicine specialists record electrical currents in the brain and identify the cause of sleep disruption. The team also measures heart rate, limb movements, and oxygen and carbon dioxide levels to better understand a patient's unique situation.

Sleep clinic appointments are available at Gillette's St. Paul campus, Burnsville Clinic, and the Gillette Lifetime Specialty Healthcare St. Paul – Phalen Clinic. For more information about Gillette's sleep services, call 651-726-2899. To schedule an appointment, call 651-229-3995.

## Author's PROFILE



**John Garcia, M.D.**

**John Garcia, M.D.**, is a board-certified sleep specialist at Gillette Children's Specialty Healthcare in St. Paul, Minn., and director of Gillette's Sleep Health Clinic. He works with patients who have disabilities and associated sleep disorders, including obstructive sleep apnea, sleepwalking, circadian rhythm disorders, and restless leg syndrome.

Dr. Garcia is a graduate of the University of Iowa School of Medicine. He completed a residency in pediatrics and one year of fellowship training in behavioral/developmental pediatrics at Riley Hospital for Children in Indianapolis, Ind. He then completed a sleep fellowship equivalent at the Minnesota Regional Sleep Disorders Center in Minneapolis. Dr. Garcia holds clinics at Gillette's main campus in St. Paul and at its Burnsville Clinic.

His professional associations include the American Board of Sleep Medicine and the American Board of Pediatrics.

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## Referral Information

Gillette accepts referrals from physicians, community professionals and outside agencies. To schedule an outpatient appointment, contact Patient Appointments at 651-290-8707, Monday through Friday between 8 a.m. and 5 p.m. Physicians who are on staff can admit patients by calling 651-229-3890.

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## Gillette Opens Brainerd Lakes Clinic

Gillette has opened a permanent hub for assistive-technology services in the Brainerd Lakes area. Our Brainerd Lakes Clinic, located in Baxter, Minn., offers services tailored to children, teens and adults who have:

- Bone and muscle problems, including spasticity
- Brain and spinal cord injuries
- Cerebral palsy

The new clinic houses an on-site assistive-technology laboratory for fittings, fabrication and adjustments. The clinic offers full custom orthoses (braces); adjustments to the Gillette CranioCap® orthosis; custom seating and mobility systems; augmentative and alternative communication consultations and devices; and consultations regarding computer access.

Gillette will continue to partner with Brainerd Medical Center to provide rehabilitation medicine services to children, teens and adults.

To make an appointment or to refer a patient to the Brainerd Lakes Clinic, call 218-824-5001 or 800-578-4266. You also can visit Gillette online at [www.gillettechildrens.org](http://www.gillettechildrens.org).

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