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Narcolepsy and Cataplexy: Information for Adults and Families

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Summary: Narcolepsy is a sleep condition with excessive, sometimes (or often) disabling sleepiness, no matter how much sleep one gets. People with narcolepsy can have irresistible sleep attacks where they end up falling asleep at school, work, and in public places, which can cause severe problems with all aspects of life. The good news, is that effective treatments exist.

Case

Jennifer is in her 20's and has extreme problems with sleepiness. This is extremely frustrating, because when younger, she was extremely active and athletic. Nowadays however, no matter how much sleep she gets at night, she is always exhausted. The sleepiness is so bad that she'll fall asleep on public transit, and even while talking with friends. It is so bad that she couldn't finish high school, and hasn't been able to keep any job due to her fatigue and inability to wake up on time for work. She has seen doctors and been tested for hormone, vitamin deficiencies and diet issues, but no one has found anything.

Could I Have Narcolepsy?

Do you:

- Feel excessive sleepiness all the time, even when you have gotten an appropriate amount of sleep in the night?
- Find that if you experience strong emotions (e.g. someone tells you something funny, surprised, angry or sad), your muscles get weak? (e.g. like neck might droop, dropping something, or your knees might buckle if you don't grab on to something?)
- Ever see or hear things while falling asleep or waking up? (e.g. bugs on the walls, hearing voices)
- Ever feel paralyzed when waking or falling asleep?

If you have answered YES to more than a few questions, read on because you might have narcolepsy…

What is Narcolepsy?

Narcolepsy is a sleep disorder where people may notice:

- Excessive daytime sleepiness: It can range from mild "mental cloudiness" to irresistible sleepiness that makes it impossible to function.
- Unrefreshing sleep: Even when they appear to get what seems to be enough hours of sleep, it is not refreshing. And despite feeling sleepy throughout the day, people have poor night-time sleep, with repeated

awakenings, sometimes with vivid dreams. “A whole night’s sleep can feel like a five minute nap -- and a five-minute nap can feel like a whole night’s sleep.”
- Uncontrollable “sleep attacks”: Sleep attacks are irresistible urges to sleep, and one simply falls asleep during any activity, at anytime during the day. Understandably, this can cause severe problems with school, work and home life.

In addition, people may also have:

- Cataplexy: Sudden brief episodes of muscle weakness that occur with a strong emotional trigger. Triggers include laughter, surprise, anger, extreme happiness or sadness. Examples of muscle weakness include knees buckling, or the head drooping, or even speech becoming slurred because of an inability to move muscles necessary for speech. Some people experience full-body episodes where they are unable to move or verbally communicate. These attacks last from a few seconds to several minutes. People may fall to the ground because of the knees buckling, misleading some observers to believe that the person has fainted or had a seizure, but unlike these disorders, consciousness is maintained throughout the spell. Cataplexy is thought to be related to the muscle paralysis of REM sleep intruding abnormally in wakefulness. Up to 70% of those with narcolepsy have cataplexy, which can manifest together with daytime sleepiness, or develop later, even 5-10 years after sleepiness occurs. Cataplexy is very specific to narcolepsy -- it is rarely seen in those without narcolepsy.
- Sleep paralysis: Periods where one feels suddenly unable to move, or speak, or sometimes even breathe for seconds or minutes, though it often feels much longer. It can be a terrifying experience, and usually occurs often upon awakening from sleep, or just before sleep. The paralysis is thought to be REM muscle paralysis intruding upon wakefulness. Most people with narcolepsy (i.e. 60%) will experience this symptom, but this can also occur in those without narcolepsy.
- Hallucinations: Vivid and frightening hallucinations, e.g. seeing bugs on the walls, or hearing noises in the home. People often worry that they are going “crazy” and are worried to mention these symptoms. Hallucinations may happen upon falling asleep (hypnagogic), or upon awakening from sleep (hypnopompic). These are also thought to be examples of REM sleep (in this case dream content) intruding upon wakefulness. Up to 60% of those with narcolepsy have these experiences, often frightening. People without narcolepsy sometimes have sleep paralysis and/or hypnagogic / hypnopompic hallucinations especially if they are extremely sleep deprived. These people, however, will not have cataplexy.

As a result, narcolepsy can cause significant problems with all aspects of life including school, work, relationships and home life.

How Common is Narcolepsy?

Narcolepsy affects approximately 1 in 2000 people (0.05% of the population). Symptoms can start at any age. Usually symptoms start in childhood to teenage years.
Narcolepsy is often unrecognized and undiagnosed
Unfortunately, studies suggest that most (about 90%) of those with narcolepsy are not diagnosed.

Those with untreated narcolepsy struggle with functioning at school, work and home. They are at a high risk of being fired or getting into motor vehicle accidents. As a result, they are at a high risk of developing stress, anxiety and depression.

Even when people see health professionals, they are often misdiagnosed or told they are lazy and inattentive, or that they have conditions such as epilepsy, substance use problems, attention deficit disorder, depression, anxiety or even schizophrenia. These stigmas can often continue to persist by friends, family and colleagues after diagnosis.

Even if patients receive a diagnosis, they often struggle for an average of 10 or more years before symptoms are identified and diagnosed.

What Causes Narcolepsy?

Narcolepsy is most likely an autoimmune disorder. It may start with a viral infection, or other stress on the body’s immune system. In certain cases, the body’s immune system ends up attacking the brain cells that produce hypocretin (aka orexin), which is a neurotransmitter involved in sleep. As a result, the brain lacks hypocretin, and

has trouble regulating sleep.
Narcolepsy may also be genetic in the case of 1-2% of family members who have this condition.

I Think I Have Narcolepsy… What Now?

- **See your primary care provider**, and ask about the possibility of narcolepsy. Your doctor will help ensure that your symptoms of sleepiness and fatigue are not due to other causes, such as insufficient sleep, inconsistent sleep schedule, anemia, thyroid issues, diabetes, or other medical conditions.
- **Sleep testing:** If appropriate, your primary care provider might refer you for testing at a sleep clinic. The main test for narcolepsy is a test called the Multiple Sleep Latency Test (MSLT) that is performed after an overnight sleep study (PSG or polysomnogram). The MSLT is a daytime test, where people are given 4-5 opportunities to have a nap (lasting up to 35 minutes), each separated by 2 hour intervals. Depending on how quickly you fall asleep, and whether or not you reach REM sleep, the physician can determine if you have narcolepsy.

How is Narcolepsy and Cataplexy Treated?

For narcolepsy, stimulant medications are used to treat excessive daytime sleepiness, such as:

- Modafinil (Alertec),
- Methylphenidate (Ritalin), or
- Dextroamphetamine (Dexedrine).

Treatment helps with managing daytime sleepiness, and preventing the REM sleep intrusion phenomena (cataplexy, sleep paralysis and hallucinations) during wakefulness.
For cataplexy, medications can be used such as:

- Sodium oxybate (sodium salt of gamma hydroxybutyrate, GHB), which is felt to be the most effective. This medication has significant potential for side effects and requires special licensing privileges to prescribe.
- Antidepressants, such as
    - Venlafaxine (Effexor),
    - Atomoxetine (Strattera),
    - Fluoxetine (Prozac)
- Baclofen, an antispasmodic medication. It works in a similar way as sodium oxybate. Both baclofen and sodium oxybate act to consolidate nighttime sleep to help with excessive daytime sleepiness in addition to cataplexy.

There is no cure for narcolepsy yet; however medications can be very successful with dealing with the symptoms. Research in narcolepsy are yielding exciting breakthroughs that continue to improve our understanding and treatment.

Self-Help and Other Strategies for Narcolepsy

- Keep a regular sleep-wake schedule;
- Don’t stay up late, even on weekends;
- Avoid alcohol and other central nervous system depressants;
- Take intentional short naps (10-30 minutes) as needed to avoid unintentional sleep attacks;
- Use modest amounts of caffeine to promote alertness as needed;
- Operate motor vehicles and other heavy machinery only with the approval of your health care provider.
- Educate parents, family and friends about narcolepsy.

School Accommodations for Narcolepsy

Consider the following accommodations for narcolepsy:

- Ensuring that educators learn about narcolepsy.
- Flexibility over absences. Be understanding that the student may arrive often late for school, or have absences due to narcolepsy symptoms.
- Designate an area where the student can go for:
    - Scheduled nap times, as well as
    - Nap times as needed in the case of a 'sleep attack'.
- Allow the student to leave the classroom as needed.
- For any missed classes due to narcolepsy, have a way for the student to be provided with notes from other students.
- Workload accommodations. Being sensitive to the student's limited stamina, and thus limiting homework in the evenings.
- Testing accommodations. Allowing for breaks during testing times. Keeping testing times short enough as to not exhaust the student's stamina, i.e. at most 3-hrs of testing a day. Extra time for deadlines and writing tests.

For more information, please see the following classroom resources on narcolepsy
https://narcolepsynetwork.org/resources/for-students/

Workplace Accommodations

- Educate managers about narcolepsy.
- Workplace accommodations and career counselling suggestions include:
- Avoid jobs requiring sustained optimal alertness such as driving or using heavy machinery.
- Avoid rotating or long shift work or long work hours.
- Have strategically timed daytime naps (10-30 minutes) in order to avoid unintentional sleep attacks.
- Consider jobs that involve cognitive work with flexible hours.

For More Information

Canadian Resources
Canadian Sleep Society (CSS)
https://css-scs.ca
Narcolepsy Canada
www.narcolepsycanada.ca
Narcolepsy Awareness Programs and Services
https://www.facebook.com/pg/narcolepsycanada.ca/posts/

American Resources
Narcolepsy Network
http://www.narcolepsynetwork.org/
National Sleep Foundation
http://www.sleepfoundation.org/

About this Article

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