throughout the spell. Cataplexy is thought to be related to the muscle paralysis of REM sleep intruding abnormally into wakefulness.
Up to 70% of patients 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 for narcolepsy; it is rarely seen among patients without narcolepsy.

2 Sleep Paralysis is a frequent terrifying experience that occurs either just before sleep, or more often upon awakening from sleep. Patients perceive themselves suddenly unable to move, or speak, or sometimes even breathe for seconds or minutes, though it often feels much longer. This frightening experience can be accompanied by equally frightening hallucinations (see #3). The paralysis is thought to be REM muscle paralysis intruding in wakefulness. Up to 60% of patients with narcolepsy will experience this symptom, but this can also occur in 5% of people without narcolepsy.

3 Hypnagogic/Hypnopompic Hallucinations are vivid dreamlike experiences that occur upon falling asleep (hypnagogic), or upon waking up from sleep (hypnopompic).
Patients sometimes describe seeing bugs on the walls, or hearing noises in the home and may worry that they are "going crazy". Some patients will even avoid reporting these symptoms for fear of being perceived as "crazy".
These experiences are also thought to be REM sleep characteristics (in this case dream content) intruding upon wakefulness. Up to 60% of patients with narcolepsy have these experiences, which are 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.

WHAT CAUSES NARCOLEPSY?

Narcolepsy is a neurochemical disorder but the exact cause is unknown. Inherited factors account for 1-2% of family members having this condition. Although this is a small number, this is 40-50 times higher than the normal population suggesting that genetics plays a significant role. Research has shown that several brain chemicals are involved. The most important of these is a brain chemical called hypocretin (also known as orexin). In 90% of patients with narcolepsy and cataplexy, hypocretin is deficient. Sometimes, other medical conditions affect hypocretin and consequently cause narcolepsy, although this is rare.
Further research suggests the body's own immune system in many instances is triggered to selectively attack the brain cells that produce hypocretin (i.e. an autoimmune response), leading to hypocretin deficiency.

WHAT CAUSES NARCOLEPSY?

Unfortunately, diagnosis is often delayed because of poor symptom recognition, sometimes by 10 years or more. Patients who are suspected to have narcolepsy should be referred for an evaluation at a sleep clinic.
The main test for narcolepsy is a nap test called the Multiple Sleep Latency Test (MSLT) that is performed after an overnight sleep study. The MSLT is a daytime test, where patients are given 4 to 5 nap opportunities (lasting up to 35 minutes), each separated by 2 hour intervals. It is the key test for the diagnosis of narcolepsy along with the clinical evaluation by the sleep specialist. Technologists measure how quickly patients fall asleep and whether or not they achieve REM sleep in those naps. Physicians then determine if a diagnosis of narcolepsy is appropriate.
It is advisable for patients to be off many medications prior to performing the MSLT, due to the sensitivity of the test. In particular, psychiatric medications, sleeping medications, and stimulant medications can interfere with interpretation of the test results.
It is also important to consult with the sleep doctor regarding several other sleep hygiene issues that should be addressed prior to taking this test.

HOW IS NARCOLEPSY TREATED?

Once narcolepsy is diagnosed, treatment is symptomatic, being aimed at managing daytime sleepiness, and preventing the other associated symptoms (e.g., cataplexy, sleep paralysis and hallucinations). There is no cure for narcolepsy yet. With appropriate recognition and treatment, up to 80% of patients return to almost normal functioning.

Société Canadienne du Sommeil
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Narcolepsy and Cataplexy

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WHAT IS NARCOLEPSY?

Narcolepsy is a sleep disorder characterized by excessive daytime sleepiness. This sleepiness can vary significantly in severity, experienced in mild cases as “mental cloudiness” or a lack of energy, to extreme cases where irrepressible sleep attacks interrupt the day.

In some cases this can be a major concern for school, work, social relationships, or even driving. Patients with narcolepsy are sometimes perceived to be ‘lazy’, ‘sleep deprived’ or have ‘memory problems’. This can result in depression, poor performance at work or school, job dismissal or motor vehicle accidents, making this an important condition to recognize and treat.

Recognition is very challenging, as patients with narcolepsy can frequently be misdiagnosed as having epilepsy, a substance use disorder, attention deficit disorder, or other major psychiatric disorders such as a mood, anxiety or even psychotic disorder. Although patients with narcolepsy feel sleepy during the day, their night-time sleep is often poor, being interrupted by repeated awakenings, sometimes with vivid dreams.

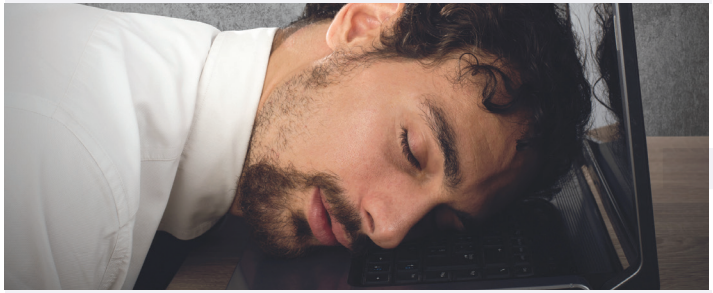
Normal sleep is typically divided in two broad categories – Rapid Eye Movement (REM) sleep, also known as the dreaming sleep, and Non-REM (NREM) sleep, which is made up of light and deep sleep. In normal REM sleep two important features occur. Firstly, about 85% of our dreams occur in REM sleep. Secondly, almost all of the muscles of the body become almost paralyzed except for the muscles of the eyes, and the diaphragm.

HOW COMMON IS NARCOLEPSY?

The onset of symptoms occurs most commonly in the teenage years or the 30 to 40 year age group, but onset can range from birth, to even late adulthood in rare instances.

Unfortunately, patients typically are diagnosed 10 or more years after symptom onset.

Narcolepsy affects approximately 1 in 2000 people (0.05% of the population).



ARE THERE OTHER SYMPTOMS OF NARCOLEPSY?

Yes. Excessive daytime sleepiness (EDS) is most characteristic of this condition which may be accompanied by three other symptoms, namely cataplexy, sleep paralysis and hypnagogic or hypnopompic hallucinations.

1 **Cataplexy** is the sudden, brief, bilateral and reversible episodes of muscle weakness that typically occur with a strong emotional trigger. Such triggers are most commonly laughter, surprise, anger, extreme happiness or sadness. Examples of the loss of muscle tone include knees buckling, or the head drooping, or even speech becoming slurred because of an inability to move muscles necessary for speech.

These attacks last a few seconds to several minutes. Patients 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 usually maintained

Educating parents, family, friends, teachers and employers is essential. Career counselling is helpful to avoid jobs requiring optimal alertness such as driving or using heavy machinery. Rotating or long shift work should be avoided. Strategically timed daytime naps can be helpful.

Stimulant medications are used to treat the excessive daytime sleepiness, such as Modafinil, Methylphenidate, or Dextroamphetamine. Treatment can be effective for many patients, and should be monitored by a doctor.

For cataplexy, several antidepressant medictions are effective. These include Venlafaxine, Atomoxetine, or Fluoxetine, and others. Currently, the most effective drug for the treatment of cataplexy is Sodium Oxybate (Gamma Hydroxybutyrate, GHB). Use of these medications should be followed by a physician.

Unfortunately, while treatment lasts indefinitely, there are new and exciting treatment breakthroughs currently being made, which are contributing to our understanding of this often neglected and socially disabling condition.

ADDITIONAL PATIENT BROCHURES BY SLEEP EXPERTS

- Dental Appliances
- Sleep in Aging
- Sleep Bruxism
- Drowsy Driving
- Insomnia
- Human Circadian Rhythms
- Strategies for Night Shift Workers
- Narcolepsy and Cataplexy
- Dreams and Nightmares
- Obstructive Sleep Apnea
- Patient Guide to Sleep Studies
- Positional Therapy for Obstructive Sleep Apnea
- Children
- Restless Legs Syndrome
- Sleep and Post- Traumatic Stress Disorder
- Normal Sleep

The Canadian Sleep Society is a national organization committed to improving sleep for all Canadians through: support for research, promotion of high quality clinical care, education of professionals and the public, and advocacy for sleep and sleep disorders medicine.

For more information visit **www.canadiansleepsociety.com** or email **info@css-scs.ca**

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