Narcolepsy Fast Facts

What is Narcolepsy?
Narcolepsy is a life-long disorder of the central nervous system characterized by the brain's inability to control sleep-wake cycles. At various times throughout the day, people with narcolepsy experience irresistible and sudden bouts of sleep, which can last from a few seconds to several minutes. This sleepiness is similar to how non-narcoleptics feel when going without sleep for 48-72 hours.

Sleep episodes can occur at any time: at work or school, during a conversation, playing a game, eating a meal, or, most dangerously, when driving an automobile or operating other types of machinery.

Other major symptoms may include:
• Cataplexy, a sudden loss of voluntary muscle tone, usually triggered by strong emotions, often laughter.
• Vivid dream-like images or hallucinations during sleep onset or when waking.
• Brief episodes of total paralysis, also during sleep onset or when waking.
• Some individuals with narcolepsy have no difficulties falling asleep at night. Most, however, experience difficulties staying asleep.

Narcolepsy often affects sufferers’ quality of life. Social, career, and other choices may be compromised. Especially for young people, the condition can cause embarrassment, anxiety, and depression, particularly if peers and loved ones are not supportive.

Who Gets Narcolepsy?
Narcolepsy affects both males and female equally and appears throughout the world. It most often starts in childhood or adolescence. Narcolepsy is not rare, but it is an under-recognized and under-diagnosed condition. More than 200,000 Americans and 3 million people worldwide are living with narcolepsy.

Causes
Narcolepsy may have several causes. Narcolepsy is almost always caused by the lack of a neurotransmitter called hypocretin, or orexin. Neurotransmitters are brain chemicals that neurons produce to communicate with each other and to regulate biological processes. Loss of hypocretin results in the inability to regulate sleep.
Research has shown that narcolepsy is caused by the loss of brain cells that produce hypocretin. The reason for such cell loss remains unknown but appears to be autoimmune in nature. That is, the body’s immune system selectively attacks hypocretin-containing brain cells. In rare cases, narcolepsy is caused by a genetic defect that prevents normal production of hypocretin molecules.

Recent research points to two infectious agents that may be involved in triggering the condition. Frequently, narcolepsy onset follows a seasonal pattern of higher rates in spring and early summer, following winter upper airway infection season. Researchers are investigating a possible link between narcolepsy onset and streptococcus infection, such as strep throat.

**Diagnosis**
Unfortunately, many physicians are unfamiliar with the symptoms of narcolepsy. Likewise teachers and athletic coaches, individuals who often can observe symptoms most directly.

Many people experience symptoms for three to five years before getting an accurate diagnosis. Delays of 10-15 years are not uncommon.

**Treatment**
Currently, narcolepsy cannot be cured, and intensive research to find a cure continues. The loss of hypocretin is believed to be irreversible and lifelong. But the condition can be controlled in most individuals with drug treatment. The leading medications are Xyrem®, Provigil® and Nuvigil®.

Drug therapy should accompany various behavioral strategies according to the needs of the affected individual, such as:
• Take short, regularly scheduled naps at times when sufferers tend to feel sleepiest.
• Maintain a regular sleep schedule.
• Avoid alcohol and caffeine-containing beverages for several hours before bedtime.
• Avoid smoking, especially at night.
• Maintain a comfortable, adequately warmed bedroom
• Engage in relaxing activities such as a warm bath before bedtime.
• Exercising for at least 20 minutes per day no closer than four to five hours before bedtime.

Source: National Institutes of Health
www.ninds.nih.gov/disorders/narcolepsy/detail_narcolepsy.htm