UNDERSTANDING narcolepsy

American Academy of SLEEP MEDICINE™
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DO YOU ALWAYS FEEL tired?

HAVE YOU . . .

Had the sudden urge to sleep during the day even though you’re getting enough sleep at night?

Fallen asleep while working, eating, or speaking with someone?

Felt alert after a brief nap but then the alertness quickly changes to sleepiness?

YOU MAY HAVE NARCOLEPSY.

Symptoms usually begin when patients are between 10 and 20 years old. The main symptom of narcolepsy is excessive daytime sleepiness.

EXCESSIVE DAYTIME SLEEPINESS: People with excessive daytime sleepiness are tired during the day even when they have had a full night’s sleep. Sleepiness may occur during many different activities, including talking with others or driving. The sleepiness is difficult to prevent and may vary over the course of the day. After a brief nap, people will feel alert, but the sleepiness usually returns after one or two hours.
There are other symptoms that may be present in narcolepsy.

**CATAPLEXY:** Cataplexy is muscle weakness that can range from barely noticeable to severe and is often triggered by strong emotions. When people who have narcolepsy with cataplexy are laughing or angry, their cataplexy might show up as slight pressure on their eyelids, or it could be more serious and cause them to fall down.

**HALLUCINATIONS:** While falling asleep or waking up, people with narcolepsy may have intense, dream-like hallucinations.

**SLEEP PARALYSIS:** People with sleep paralysis lose the ability to move and feel paralyzed when they’re falling asleep or waking up.
WHAT CAUSES NARCOLEPSY?
Narcolepsy runs in some families, but most cases are not genetic. Recent studies suggest that people with narcolepsy with cataplexy often are missing a substance called hypocretin.

HOW LONG WILL I HAVE NARCOLEPSY?
Narcolepsy is a lifelong condition. However, with the right treatment, most people can manage their narcolepsy well.

CAN I DRIVE IF I HAVE NARCOLEPSY?
Driving when your narcolepsy is untreated can be very dangerous. The laws about driving with narcolepsy are different in each state. Ask your health care provider about the laws in your state.

Studies show that people with untreated narcolepsy are ten times more likely to get into car accidents than people with treated narcolepsy.
TRUE OR FALSE?

I CAN’T HAVE NARCOLEPSY BECAUSE I’M NOT SPENDING THE WHOLE DAY ASLEEP.

*This is FALSE.*

When the total amount of sleep per day is added up, people with narcolepsy may not sleep more than people without narcolepsy.

I CAN’T HAVE NARCOLEPSY BECAUSE I HAVE TROUBLE SLEEPING AT NIGHT.

*This is FALSE.*

Most people with narcolepsy have trouble sleeping and may wake up repeatedly during the night.

I CAN’T HAVE NARCOLEPSY BECAUSE I HAVE OBSTRUCTIVE SLEEP APNEA.

*This is FALSE.*

Many people with narcolepsy have more than one sleep disorder.
HOW DO I KNOW IF I HAVE NARCOLEPSY?

Many people do not know that they have narcolepsy. If you think that you have this disorder, speak with your health care provider. He or she may refer you to a sleep specialist. There are tests that can help determine if you have narcolepsy.

IN-LAB SLEEP STUDY: You may be referred to a sleep center for an overnight stay to monitor your sleep. Data is collected about your sleep that will let the sleep physician make a diagnosis.

MULTIPLE SLEEP LATENCY TEST (MSLT): This test takes place in a sleep lab where you take naps at set times during the day. Data is collected on how quickly you fall asleep.

HYPOCRETIN LEVEL MEASUREMENT: In rare cases, the level of hypocretin is measured in a sample of cerebrospinal fluid. This requires a lumbar puncture (spinal tap).
COULD I HAVE ANOTHER SLEEP DISORDER?
Many sleep disorders can cause people to be tired during the day. It may be difficult to determine if you have narcolepsy, another sleep disorder, or a combination of narcolepsy and other sleep disorders.

Sleep disorders that may cause excessive daytime sleepiness include:
- Insufficient Sleep
- Circadian Rhythm Sleep Disorders
- Restless Legs Syndrome
- Obstructive Sleep Apnea

HOW IS NARCOLEPSY TREATED?
Medication is often used to treat narcolepsy. Many people take stimulating medications that help them stay awake during the day. Some people take certain types of antidepressants to help with cataplexy. Changes in lifestyle can help make sure that you have the best schedule for controlling your narcolepsy.

If you think you may have a narcolepsy or another sleep disorder, please talk with your health care provider.