What to know about Narcolepsy

<u>Narcolepsy</u> is a chronic neurological disorder characterized by the brain's inability to regulate sleep-wake cycles properly. People with narcolepsy have random urges to sleep throughout the day. If the urge becomes overwhelming, people will fall asleep for few seconds to several minutes. In some cases, people may stay asleep for an hour or more.

What causes Narcolepsy?

The exact cause of narcolepsy is unknown, but it is typically associated with abnormally low hypocretin levels in the brain. Hypocretin is a chemical that controls the sleep-wake cycle. It is unclear why some people have low hypocretin levels which leads to narcolepsy.

Types of Narcolepsies

Narcolepsy type 1 is caused by damage to a specific part of the brain (the hypothalamus), which results in decreased production of orexin, a hormone that helps maintain wakefulness. Narcolepsy type 2 does not have low orexin levels, and the cause is unknown.

Signs and Symptoms of narcolepsy

Narcolepsy symptoms usually show up between the ages of 15 and 25, but they can appear much earlier or later in life. The symptoms usually worsen after the first few years. You may encounter the following:

• Excessive daytime sleepiness

The main symptom of narcolepsy is excessive daytime sleepiness. Even if you slept well the night before, you may still feel tired during the day. This sleepiness is difficult to control and may vary throughout the day. After a brief nap, you may feel alert, but sleepiness will return within an hour or two.

• Fragmented sleep

Nearly fifty percent of people with narcolepsy have trouble sleeping through the night. You may wake up frequently and have difficulty returning to sleep. This can cause fatigue, difficulty concentrating and other issues. It can also have an impact on your mood, making it difficult to cope with stress and anxiety.

• Memory problems

You may have difficulty remembering what others tell you because you were not fully awake at the time. Memory lapses can also occur when you become sleepy while performing activities that require little thought. Getting enough sleep is critical to memory retention. Lack of sleep can impair our ability to form new memories and retrieve old ones, resulting in memory lapses and difficulty retaining information.

• Sudden loss in muscle tone (cataplexy)

This happens only if you have narcolepsy type 1. Cataplexy is a sudden episode of muscle weakness caused by a strong emotion. This can happen when you are surprised, elated, or intimate with your partner. You may slur your speech, lose control of your limbs, or be completely paralyzed.

How is narcolepsy diagnosed?

Your healthcare provider will ask about your medical history and perform a physical exam. Based on the results of the physical exam and lab tests, your healthcare provider will be able to determine the best course of action for your treatment.

Some of the tests include:

- **Overnight** <u>polysomnogram (PSG)</u>. A sleep specialist will keep track of your sleep patterns throughout the night.
- <u>Multiple sleep latency test</u> (MSLT). This test, administered during the day after a full night's sleep, determines when you fall asleep and how quickly rapid eye movement (REM) sleep takes place.

How is narcolepsy treated?

Narcolepsy treatment aims to keep you as alert as possible throughout the day. It's also critical to limit times when you lose muscle control. Ideally, this can be accomplished with just a little of medication.

Medications to treat excessive daytime sleepiness and cataplexy in adults with narcolepsy include: Sodium oxybate and pitollisant.

Treatments for excessive sleepiness include modafinil, armodafinil, and solriamfetol, as well as moderate to high doses of amphetamines or methylphenidate.

Antidepressants such as fluoxetine or venlafaxine may be used to treat cataplexy and disturbed REM sleep. Clinical trials are currently underway to investigate drugs that can replace orexin.

A number of lifestyle changes may help manage narcolepsy. Some of these include:

- Sticking to the same sleep schedule 7 days a week. This can help you sleep better.
- Not having a large meal just before bed. A large meal can make it hard to sleep.
- Sleeping in a cool, comfortable room
- Doing relaxing activities such as a warm bath before bedtime
- Sticking to a prescribed medicine schedule. If you aren't getting treatment or consistently taking your medicines as prescribed, you are more likely to suffer serious injuries or death.

While new information about narcolepsy and other sleep disorders is being discovered, many people who suffer from the condition continue to struggle. In many ways, narcolepsy is an invisible disability. The person with narcolepsy appears to have nothing wrong with her or him, but the EDS (Excessive daytime sleepiness) and other symptoms, even for diagnosed and treated people with narcolepsy, can make it almost impossible to do even simple tasks.