Understanding Narcolepsy
What is Narcolepsy?

Narcolepsy is a chronic neurological disorder that affects the brain’s ability to regulate sleep-wake cycles. It results in persistent and excessive daytime sleepiness (EDS) and in many cases, cataplexy. Individuals with narcolepsy may also experience disturbed nighttime sleep, sleep-related hallucinations, temporary sleep paralysis, memory issues, and difficulties concentrating. The exact cause of narcolepsy is unknown.

Cataplexy is sudden change in muscle tone in one or more parts of the body that can be triggered by strong emotions (e.g., fear, anger, stress, joy, laughter), resulting in weakness or involuntary movements.

The severity, duration, and frequency of cataplexy attacks vary from person to person. While they typically result in a loss of muscle tone, pediatric patients and individuals with newly developed disease might experience an activation of muscle movements or attacks that occur independent of emotions.

130,000 to 200,000 individuals in the U.S. have narcolepsy.

Narcolepsy Sleep Patterns

With a normal sleep pattern, it takes 60-90 minutes to transition from the non-REM stages to the REM stage, providing sufficient opportunity for restorative sleep (stage 3), which promotes immunity, cognition, and memory. A person with narcolepsy, however, transitions rapidly from non-REM to REM stages, blocking the ability to achieve “rest” even after a full night’s sleep.
Types of Narcolepsy

There are two types of narcolepsy. **Narcolepsy Type 1 (NT1)** occurs with excessive daytime sleepiness and cataplexy, whereas **Narcolepsy Type 2 (NT2)** occurs without cataplexy.

NT1 is 2-3x more common than NT2\(^{10}\)

While the exact cause of narcolepsy is unknown, NT1 is thought to result from a combination of genetic, autoimmune, and environmental factors. Individuals with NT1 show a loss of up to 90% of the neurons (brain cells) that produce a protein called **hypocretin**, though it is unclear what triggers the immune system to attack these neurons. Individuals with NT2 tend to have normal levels of **hypocretin**.

NT1 can be diagnosed in individuals who do not have cataplexy but present with low levels of **hypocretin**. Hypocretin, also known as **orexin**, is a protein produced in the brain that helps regulate sleep-wake cycles.
RISK FACTORS AND COMMON SYMPTOMS

Narcolepsy symptoms often begin to show up during adolescence, but can go unrecognized for many years before a diagnosis is made. On average, women are diagnosed with narcolepsy 28 years after symptom onset – 12 years longer than it takes for men to be diagnosed.\textsuperscript{11}

Risk factors for narcolepsy include:

- Age (10-20 years old)
- Family history
- Immune or environmental triggers
- Brain trauma or infection

Common symptoms of narcolepsy include:

- Excessive daytime sleepiness (EDS)
- Sudden attacks of sleep
- Sleep paralysis
- Changes in rapid eye movement (REM) sleep
- Hallucinations
- Disturbed nighttime sleep or insomnia
- Cataplexy (in NT1)

Secondary narcolepsy is a form of narcolepsy that occurs after injury to the hypothalamus in the brain, as a result of brain trauma or infection.

Symptoms of narcolepsy present similarly in adults and adolescents; however, EDS is often mischaracterized in teens as a behavioral problem, such as restlessness or irritability. Some symptoms are also commonly mistaken for other conditions, such as depression or idiopathic hypersomnia, leading to an incorrect or delayed in diagnosis. In women, especially, narcolepsy is frequently misdiagnosed as a psychiatric condition.\textsuperscript{11,13}
Individuals with narcolepsy often tend to have other health conditions, such as:

- Sleep disorders (e.g., sleep apnea, insomnia)
- Mental health disorders (e.g., mood disorders, depression, anxiety)
- Cardiovascular disease
- Metabolic disorders (e.g., diabetes)
- Neurologic disorders (e.g., epilepsy, Alzheimer's disease)

57% of individuals with narcolepsy experience depression related to narcolepsy

Narcolepsy is associated with increased risk of serious accidents and injuries, and over time, narcolepsy may also impact relationships, work, cognition, and overall quality of life. Women who are diagnosed with narcolepsy also have higher associations with mental health and metabolic disorders, and other chronic conditions over the long term.

If you have been diagnosed with narcolepsy, talk to your health care provider about a personalized plan for your care. For more information, see the Managing Your Narcolepsy Care section of the SWHR Narcolepsy Toolkit.