# Do you know Narcolepsy

Narcolepsy is commonly portrayed in the media as a comedic event where people suddenly fall asleep in the middle of important or humorous situations. Sudden sleepiness, however, is just one among many characteristics of Narcolepsy. The symptoms of Narcolepsy are often much more subtle than in media depictions.

The symptoms of Narcolepsy may impact many areas of a patient's life. Due to Narcolepsy being poorly understood and largely invisible, many people experience feelings of isolation, loss of self-confidence, depression and anxiety. To avoid embarrassment, individuals with Narcolepsy sometimes avoid situations that could trigger or exacerbate their symptoms, further impacting quality of life.



# Narcolepsy does not always look SLEEPY







Narcolepsy may also look like memory loss, poor concentration, irritability, and automatic behaviors, which can lead to psycho-social impairments and affect relationships, academic performance, professional success, and leisure activities.



Narcolepsy is a life-long neurological sleep disorder characterized by the brain's inability to regulate sleep-wake cycles.

Narcolepsy affects 1 in every 2,000 individuals. Typical onset of Narcolepsy occurs between the ages of 10 and 20; but can also occur in young children.

64% of children and adolescents with Narcolepsy are originally misdiagnosed.

Only 42% of sleep specialists and 9% of clinical doctors feel comfortable diagnosing Narcolepsy.

Only 22% of sleep specialists are able to identify the 5 key symptoms of Narcolepsy. As a result, it can take 2-10 years to diagnose Narcolepsy.

### **Excessive Daytime Sleepiness**

- **Excessive Daytime Sleepiness (EDS) is the inability to stay awake and alert during the day.**
- **Even with sleep, an individual with Narcolepsy can feel as though he or she has been awake for 72 hours straight.**
- ❖ Sometimes, individuals with Narcolepsy can have instances of automatic behavior, in which they continue an activity with little conscious awareness of the activity occurring.
- **EDS** is one of the first symptoms to develop in individuals with Narcolepsy.



# Sleep Disruption

- Sleep Disruption is the breaking up of sleep by frequent awakenings, also known as fragmented sleep
- Individuals with Narcolepsy often transition quickly to REM sleep but then wake often, causing many more transitions from deep sleep into light sleep or wake



### **Sleep Paralyisis**

- A brief inability to move or speak while falling asleep or upon waking up
- ❖ This is most likely caused by an intrusion into wakefulness of the normal paralysis that occurs during REM sleep.



### **Cataplexy**

- ❖ A sudden, uncontrollable, and usually brief loss of muscle tone caused by experiencing strong or intense emotions.
- **❖** Cataplexy only occurs in type 1 Narcolepsy.
- Cataplexy can vary from partial cataplexy, which may involve the slurring of speech to full cataplexy where an individual may experience weakness of the face, limbs, and trunk, which causes them to slump to the ground, awake but unable to talk or move.



## Hallucination

- ❖ Individuals with Narcolepsy may experience vivid dreamlike experiences while falling asleep or upon waking up. ◢
- Hallucinations when falling asleep are known as hypnagogic; when waking up, hypnopompic.
- These hallucinations can be experienced as multisensory and can feel extremely real.
- People with Narcolepsy often transition directly from wake into REM sleep, which may underlie this experience.



Source: Rosenberg R, Kim AY. The AWAKEN survey: knowledge of Narcolepsy among physicians and the general population. Postgrad Med. 2014;126(1):78-86. doi:10.3810/pgm.2014.01.2727. FTI CONSULTING Presentation to Wake Up Narcolepsy "Narcolepsy Awareness Survey" September 2022.

