Idiopathic Hypersomnia: What You Need to Know

Idiopathic Hypersomnia (IH) is a rare, lifelong neurological sleep disorder that often goes unrecognized and undiagnosed. People living with IH are constantly thinking about, craving, or fighting sleep, which can severely impact their quality of life.

WHAT ARE THE SYMPTOMS OF IH?



Excessive Daytime Sleepiness (EDS): Feeling very sleepy or tired during the day



Sleep Inertia: Severe/prolonged grogginess or confusion when waking up



Long, Unrefreshing Naps: Not feeling better/rested after a nap (patients may even feel worse)



Non-restorative Sleep: Not feeling rested or refreshed when waking up, even after a full night's sleep



Cognitive Impairment: Difficulty focusing, trouble thinking clearly, or memory problems due to excessive daytime sleepiness



Long Sleep Time/Duration: Ability to sleep for many hours, sometimes for 11 hours or more



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HOW IS IH DIAGNOSED?

People who are experiencing IH symptoms should report them to their doctor. A sleep specialist must conduct a careful clinical evaluation to support the diagnosis of idiopathic hypersomnia, including:

- ▶ The presence of excessive daytime sleepiness for at least 3 months
- A comprehensive medical history, physical examination, and medical tests to rule out other conditions or medications as a cause
- Excluding disturbances in sleep rhythms (e.g., circadian sleep disorders) and insufficient sleep
- An overnight sleep test or polysomnography (PSG), followed immediately by a daytime Multiple Sleep Latency Test (MSLT)

HOW DOES IH IMPACT EVERYDAY LIFE?



IH is a 24-hour sleep disorder—from **struggling to wake up in the morning** to fighting the **need to sleep during day** and getting non-restorative sleep at night.



People living with IH are **consumed by sleep**, day and night.



People living with IH **feel exhausted during the day**, even after a full night's sleep.



Living with IH feels like being **stuck between being asleep** and awake all day long.

