

# IDIOPATHIC HYPERSOMNIA

## WHAT IS IDIOPATHIC HYPERSOMNIA?

**Idiopathic hypersomnia (IH) is a chronic neurological sleep disorder. People with IH are very sleepy despite getting normal or longer amounts of sleep, but the exact cause is not known.**

## WHAT ARE THE SYMPTOMS OF IDIOPATHIC HYPERSOMNIA?

- Trouble staying awake and alert during the day (excessive daytime sleepiness)
- Sleeping longer than average (more than 11 hours per 24 hours, typically 12-14 hours)
- Extreme difficulty waking from sleep
- Feeling very groggy, confused, or disoriented when waking up from an overnight sleep or nap (called sleep inertia or sleep drunkenness), which may last for hours after waking.
- Not feeling refreshed even after sleeping an average amount (7-9 hours) or after a nap
- Falling asleep accidentally, e.g. while driving or working
- Difficulty coping with social life, work, or study because of sleepiness (can also lead to depression)
- Some people have trouble with memory and brain fog
- Some people with IH also experience headaches, dizziness, or cold hands and feet

BECAUSE OF LOW AWARENESS,  
IH SYMPTOMS ARE OFTEN  
UNDIAGNOSED OR MISDIAGNOSED.

## HOW IS IDIOPATHIC HYPERSOMNIA DIAGNOSED?

Diagnosis usually involves medical tests to check for other potential causes of sleepiness, such as narcolepsy or other sleep disorders. **Seeing a sleep specialist is recommended.**

- A healthcare provider will ask questions about symptoms and sleep. Some healthcare providers may ask people to monitor their sleep and wake activity for several days by keeping a **sleep diary** or wearing a clinical device (e.g. an **actigraph**).
- To check for other sleep disorders, an overnight **sleep study** (also called polysomnography) is done followed by a **multiple sleep latency test** the next day, where the person is asked to nap for 20 minutes every 2 hours. People who fall asleep very quickly but don't enter REM sleep may have idiopathic hypersomnia. Both tests are done in a sleep center/lab, with stick-on sensors that measure breathing, heart rate, brain activity, and body movements while asleep.

## HOW IS IDIOPATHIC HYPERSOMNIA TREATED?

As there is currently no cure for IH, the goal of treatment is to live well by managing alertness.

- **Medications** may be prescribed to help people feel more alert and active when awake and to sleep more deeply at night, including stimulants, non-stimulant wake-promoting agents, oxybates, antidepressants, and medications that target the GABA system. Only one medication is approved by the FDA specifically for IH, the other medications are known to be effective for treating sleepiness in other disorders such as narcolepsy and are used “off-label” to treat IH.
- **Treating other sleep disorders** and avoiding certain medications is helpful to reduce other potential causes of sleepiness.
- Helpful **lifestyle strategies** include keeping healthy sleep habits, getting light in the morning, using more than one alarm, asking friends and family to help with waking for appointments, and avoiding driving when sleepy.
- **Counselors** can help people navigate the challenges of living with IH.
- **Social support** from patient organizations can help people with IH and their families live well with IH.

★ PROPER DIAGNOSIS, TREATMENT,  
AND SOCIAL SUPPORT CAN HELP  
PEOPLE LIVE WELL WITH IH. ★