

# Sleepy Patients? Use HF's "HINT" Test!

There are many reasons why your patients could be falling asleep during the day, including being overcommitted, stress, irregular work hours, a new baby or young children in the household, acting as a caretaker for an elderly family member, poor sleep habits, etc.

But excessive daytime sleepiness can also indicate a serious medical condition, such as depression, side effects from medication, or **IDIOPATHIC HYPERSOMNIA (IH)**, a chronic neurological sleep disorder.

How can you help your sleepy patients? Consider applying the Hypersomnia Foundation's "HINT" test to determine whether a particular patient might have IH or a related sleep disorder.

Simply ask:



HYPERSOMNOLENCE (the symptom of long sleep and/or excessive daytime sleepiness)?

People with IH remain excessively sleepy throughout the day despite getting enough (or even too much) sleep. Many sleep more than 9-10 hours in a 24-hour period.



#### INERTIA or grogginess upon waking up?

Many people with IH are very groggy when they try to wake up (sleep inertia), and their sleep can be very deep, thereby resulting in the need for multiple alarms, reminders or rituals to actually get out of bed. Even when they do awaken, their cognitive skills may be affected.



#### NAPS - Are they refreshing or not?

Most people with IH do not find naps refreshing (in contrast to people with narcolepsy).



### TIMELINE - Sleepiness lasting more than 3 months?

If ANY sleepiness/hypersomnolence (regardless of other symptoms) persists for more than 3 months, then the person should probably see a sleep specialist for further evaluation.

For additional signs of IH, see **HypersomniaFoundation.org/IHSummary** Approved by HF's Medical Advisory Board

Patients also may want to seek academic or workplace accommodations or apply for disability, if needed, even while they are pursuing a diagnosis for their persistent sleepiness. The Hypersomnia Foundation has free resources on our website (www.HypersomniaFoundation.org) that can help with these processes, along with many other free resources for healthcare professionals and people with IH and related disorders.





# A Case Study... from a Parent's Perspective

In 2014, my daughter came home from college for Thanksgiving, and, as usual, every time I gathered the family for an outing or a meal, she was "missing" – asleep on the couch or in bed.

She had developed an insatiable craving for sleep at age 13, and although she had been examined and tested several times over her teen years by her pediatrician, there was no satisfactory explanation. A sleep disorder wasn't mentioned. This time, I insisted that she see her college health physician when she returned to school. I knew that she liked and respected him. This physician listened to her carefully and concluded: "You do sleep far too much, you have had these symptoms over a long period, and there is nothing in your health history to explain it." He sent her for a sleep study at a local hospital.

A night-time sleep study, followed by a daytime test called the MSLT (Multiple Sleep Latency Test) resulted in her diagnosis of idiopathic hypersomnia. It had taken nearly seven years to get a correct diagnosis. We later learned this is not unusual. She began treatment with a local sleep specialist. Eventually, we took her to see Dr. David Rye at Emory University, one of the top IH researchers in the country, to explore cutting-edge treatments.

Through off-label prescriptions of medications (normally used to treat related sleep disorders like narcolepsy), my daughter is able to work full-time, drive safely, and have a fuller social life.

I didn't realize my daughter had been blaming herself for her sleepy symptoms until after she was diagnosed. She told me, "I always thought everyone else felt as sleepy as I did; [and that] I just didn't handle it as well." So my advice to other parents is, if your child is having problems with their sleep – don't wait. See your child's physician, and keep asking questions until your child gets a correct diagnosis.

- Name withheld to protect her daughter's privacy

## **About HF**

The Hypersomnia Foundation (www.hypersomniafoundation.org) is a nonprofit patient advocacy organization, with a distinguished panel of Medical and Scientific Advisory Board members, that provides free resources and information for patients as well as medical providers, researchers and educators. You can learn about treatments and current research studies, view our Medical Provider Directory (which lists sleep medicine specialists familiar with IH and other rare sleep disorders), find Education Essentials Guides to help students with IH succeed academically, and much more.

