

STANDARD CHARACTERISTICS:

- **Neurological** disorder^{1, 3}
- **Chronic**, usually lifelong after onset^{1, 2, 3, 4}
- A **central disorder of hypersomnolence (CDH)**, in the same category as **narcolepsy**^{1, 3}
- Hallmark symptom: **excessive daytime sleepiness (EDS)**, an uncontrollable need to sleep or daytime sleepiness that persists for at least 3 months even with adequate or prolonged nighttime sleep^{1, 2, 3, 4}

POSSIBLE CHARACTERISTICS:

- **Debilitating**, often significantly affecting social, school, and occupational functioning^{1, 2, 3, 4}
- **Onset** usually in adolescence or early adulthood (but may be earlier or later)^{1, 2, 3, 4}
- Seems to affect more females than males^{2, 3}
- **Fluctuating severity**, with some time periods worse than others^{2, 4}
- **Daytime naps**, which are generally long (over 1 hour) and usually not refreshing [*frequent*]^{1, 2, 3, 4}
- **Long sleep**: sleeping 9 hours⁴ or more³ in 24 hours, which is usually un-refreshing [*frequent*]^{1, 2, 3, 4}
- **Sleep drunkenness** (i.e., severe **sleep inertia**): extreme and prolonged difficulty fully awakening, associated with an uncontrollable desire to go back to sleep [*frequent*], which can be accompanied by **automatic behavior** (performing tasks without conscious self-control and with partial or total loss of memory), disorientation, confusion, irritability, and poor coordination^{1, 2, 3, 4}
- **Motor hyperactivity** "e.g., "never stopping," "speaking a lot"), serving as a countermeasure to boost alertness [*frequent*]^{2, 3, 4}
- **Cognitive dysfunction**: deficits in memory, attention, and concentration (sometimes referred to informally as "brain fog")^{2, 4}
- **Sleep hallucinations**: hallucinations at sleep onset and/or offset [*occasional*]^{1, 3}
- **Sleep paralysis**: a transitional state between wakefulness and sleep, in which one is aware but cannot move, speak, or react [*occasional*]^{1, 3}
- **Additional potential symptoms**: headaches, automatic behaviors, problems with balance, and difficulties with temperature regulation [*occasional*]^{2, 3, 4}
- **Unique anesthesia needs**: see hypersomniafoundation.org/anesthesia-and-ih

Sources:

1. 2015 Review article in *Chest*, by Khan/Trotti et al, "Central Disorders of Hypersomnolence: Focus on the Narcolepsies and Idiopathic Hypersomnia" (free download at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4694150/>)
2. 2016 *Sleep Medicine Review* article, by Billiard/Sonka et al, "Idiopathic Hypersomnia" (request through a medical library: <https://www.ncbi.nlm.nih.gov/pubmed/26599679>)
3. International Classification of Sleep Disorders, Third Edition (ICSD-3): <http://www.aasmnet.org/store/product.aspx?pid=849>
4. Diagnostic and Statistical Manual of Mental Disorders (DSM-5) p. 368-372 Hypersomnolence Disorder: <https://www.psychiatry.org/psychiatrists/practice/dsm>

DIAGNOSTIC CRITERIA FOR IDIOPATHIC HYPERSOMNIA (IH) ACCORDING TO THE ICSD-3

The following 6 criteria must be met for a diagnosis of idiopathic hypersomnia (also termed idiopathic CNS hypersomnolence by the ICSD-3):

- 1. Daytime lapses into sleep or an irrepressible need to sleep** on a daily basis, for at least 3 months.
NOTE that additional supporting features are: a) sleep drunkenness; and/or b) naps that are unrefreshing and long (greater than 1 hour).
- 2. Insufficient sleep syndrome is confirmed absent**, preferably via at least a week of wrist actigraphy.
- MSLT (Multiple Sleep Latency Test) shows one of the following:
 - **Fewer than 2 sleep onset REM periods** (SOREMPs, which are REM sleep periods within 15 minutes of sleep onset); Or
 - No SOREMPs, if the REM latency on the preceding overnight sleep study was less than or equal to 15 minutes.
NOTE that an additional supportive finding is a high sleep efficiency (greater than or equal to 90%) on the preceding overnight sleep study.
- The presence of one or both of the following:
 - **Average sleep latency of less than or equal to 8 minutes** on MSLT;
 - **Total 24-hour sleep time is greater than or equal to 660 minutes** (more typically 12-14 hours) when measured in one of the following 2 ways:
 - a) a 24-hour sleep study that was performed after correcting any chronic sleep deprivation; or
 - b) wrist actigraphy recorded along with a sleep log and averaged over at least 7 days of unrestricted sleep.
NOTE that the appropriate total sleep time may need to be modified to account for normal changes in sleep time due to stages of development and cultural variability.
NOTE also that sometimes patients fulfilling other criteria may not meet this particular criteria, and clinical judgment should then be used to diagnose IH, taking great care to rule out other conditions. It is then advisable to repeat this testing at a later date.
- 5. No cataplexy** (a sudden muscle weakness brought about by a strong emotion).
6. Another condition (sleep disorder, medical or psychiatric disorder, or drug/medication use) does not better explain the hypersomnolence and test results.

DIAGNOSTIC CRITERIA FOR HYPERSOMNOLENCE DISORDER ACCORDING TO THE DSM-5

- Excessive daytime sleepiness (EDS or hypersomnolence) despite a main sleep period lasting at least 7 hours and also associated with one or more of the following:
 - Additional recurrent sleep periods or lapses during the day;
 - A main sleep period that is greater than 9 hours and unrefreshing;
 - Abrupt awakening leads to difficulty becoming fully awake.
- Significant impairment in occupational, cognitive, social, and/or other important functioning.
- EDS occurs at least 3 times a week and lasts for at least 3 months.
- Hypersomnolence is not better explained by another sleep disorder.
- When other mental and/or medical conditions coexist, they do not fully explain the hypersomnolence.
- Hypersomnolence is not caused by a medication or substance abuse.