

IDIOPATHIC HYPERSOMNIA

Idiopathic Hypersomnia (IH), sometimes referred to as Idiopathic Hypersomnolence, is a neurological sleep/wake disorder which causes excessive sleep and daytime sleepiness.

People with IH often struggle to wake up; they sleep through multiple alarms and may even fall back to sleep several times (this is known as sleep inertia). They may start the day feeling extremely groggy, confused and disoriented, with poor motor coordination and slowness (referred to as sleep drunkenness). They can also experience cognitive dysfunction (commonly known as 'brain fog') throughout the day, i.e., problems with memory, concentration, attention, and automatic behaviour.



Most people can feel tired, fatigued and, at times, excessively sleepy, particularly when they do not get enough sleep. However, people with IH are different; they suffer from extreme sleepiness despite getting adequate or typically more than adequate hours of sleep.

Their sleep may be deep and uninterrupted, but it is not refreshing. Despite extraordinary amounts of good quality sleep, people with IH are in an almost constant state of sleepiness.

SYMPTOMS

- Overwhelming need for excessive sleep. Despite adequate and often extraordinary amounts of good quality sleep (e.g., 10–11 hours or more per night), people with IH still feel excessively sleepy during the day.
- Chronic excessive daytime sleepiness, often resulting in long daytime naps.
- Long and unrefreshing naps. Naps are usually more than one hour long and are typically not refreshing.
- Cognitive dysfunction (commonly referred to as 'brain fog'): problems with memory, concentration and attention, and automatic behavior.
- Sleep Inertia and Sleep Drunkenness; Extreme and prolonged difficulty waking up with an uncontrollable desire to go back to sleep. It is accompanied by confusion, irritability, and poor coordination, e.g., dropping things, walking into doorways. Speech may also be slow or slurred. It can also include automatic behaviour, i.e., performing tasks without consciously knowing it and not remembering you have done them, e.g., turning off alarm clocks or answering your phone.

In an attempt to combat the overwhelming sleep pressure, people with IH may develop ADHD-like symptoms such as fidgeting and talking a lot.

Additionally, autonomic dysfunction, a condition affecting the nervous systems control of automatic functions, is common in IH. This can manifest as headaches, dizziness upon standing, and trouble regulating body temperature.

Unlike in other sleep disorders, the sleep in people with Idiopathic Hypersomnia is normal; there are no disturbances that can account for these symptoms.

IH is usually a debilitating, often lifelong, condition which profoundly affects work, education, relationships, and mental health. This is particularly the case for those without support.

FACTS ABOUT TREATMENT

- Very little is known about the cause, so there is no cure.
- Current medications often only partly assist in managing symptoms and may be completely ineffective or intolerable for some people.
- Stimulant and wake-promoting medications can be helpful to relieve sleepiness for some people, but they are rarely effective long-term and generally don't provide quality wakefulness. There are also potentially unpleasant side effects, which can include sleep deprivation, heart problems and anxiety.
- Modafinil and armodafinil can interact with hormonal contraception, such as birth control pills, patches, and vaginal rings, making them less effective. If you take modafinil or armodafinil and use hormonal birth control, please speak with your doctor for more advice.

Many people with IH benefit from a combination of medication and lifestyle changes. Lifestyle changes can be difficult to initiate and maintain for people with chronic illnesses and may require the assistance of a specialist therapist and peer support.

WHO DOES IH AFFECT?

The pathogenesis of IH is unknown. Researchers have considered an autosomal dominant mode of inheritance because around 50% of people with IH have at least one family member who also has symptoms. It appears IH may be more common in females.

The prevalence of IH is thought to be 0.005%–0.3%, but due to a lack of epidemiological studies, biological markers, and misdiagnosis of the disease, the real prevalence is unclear.

Though the symptoms mainly begin in adolescence or young adulthood (typically between 15 and 30 years of age), it is not uncommon for there to be a delay of many years before an accurate diagnosis is made.

LOOKING FOR SUPPORT?

There are online Living with IH (LWIH) Community Groups in the USA, Canada, Australia/NZ, and the EMEA (Europe/UK, Middle East, and Africa)*. Meetings are held every month via Google Meet or other similar video conferencing.

The aim of the meetings is to provide people diagnosed with IH with a community where they can offer and receive peer support and to assist with the isolation that many people with IH experience. Living with IH community groups are an informal monthly catch-up where people diagnosed with IH can feel relaxed among others who truly know what it is like to live with IH.

**If you live outside of the USA, Canada or Australia/NZ feel free to join the EMEA group.*

Go to the IH AWARENESS WEEK [WEBPAGE](#) for contact details of the LWIH community in your country/region.

Hypersomnolence Australia first launched the IH Awareness Week in 2013. Since its inception, the IHAW has united the IH community across 15 countries, fostering awareness and promoting education about IH. The IHAW has translated awareness infographics into 13 different languages. [Join us!](#)


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This factsheet was prepared by Hypersomnolence Australia and was vetted and approved by sleep clinicians.

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