

IDIOPATHIC HYPERSOMNIA

Idiopathic Hypersomnia (IH) is a neurological sleep/wake disorder

that 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, disorientated, 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 ie: problems with memory, automatic behaviour, concentration and attention.



Most people can feel tired, fatigued and at times, excessively sleepy, particularly when they do not get enough sleep. However what sets people with IH apart is that they experience 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. Some say they don't ever feel fully awake.

SYMPTOMS

The main symptom of IH is excessive deep sleep. Despite adequate and often extraordinary amounts of good quality sleep (eg: 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.
- Extreme and prolonged difficulty waking up with an uncontrollable desire to go back to sleep. Accompanied by confusion, irritability and poor coordination eg: drop things, walk into doorways or bounce off walls. Speech may also be slow or slurred. It can also include automatic behaviour, ie: performing tasks without consciously knowing it and not remembering you have done them eg: turning off alarm clocks or answering your phone.
- Cognitive dysfunction (commonly referred to as 'brain fog'): problems with memory, automatic behaviour, concentration and attention.
- People with IH can develop ADHD like symptoms, eg: fidgeting & talking a lot, to help cope with the immense sleep pressure.
- People with IH may also experience headaches, and problems with autonomic dysfunction, eg: dizziness on standing, and temperature regulation.

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

FACTS ABOUT TREATMENT

- Very little is known about the cause so there is no cure.
- The medications that are used are not ideal as they don't target the cause.
- Current medications only partly assist in managing symptoms and may be completely ineffective for some people.
- Medications often cause unpleasant side effects and they are typically not effective long term.
- Medications such as modafinil/armodafinil can interact with hormonal birth control making it less effective.

WHO DOES IH AFFECT?

The pathogenesis of IH is unknown. An autosomal dominant mode of inheritance has been considered by researchers 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 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 15–30 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 Idiopathic Hypersomnia (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 that truly do know what it is like living 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.



IDIOPATHIC HYPERSOMNIA AWARENESS WEEK®

Hypersomnolence Australia hosts the Worldwide Idiopathic Hypersomnia Awareness Week. It is held annually in the first full week in September. [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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