

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.



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.

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.
- 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.
- Cognitive dysfunction (commonly referred to as 'brain fog'): problems with memory, concentration and attention, and automatic behaviour.

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.

DIAGNOSIS

Diagnosing IH can be difficult, as excessive daytime sleepiness can be caused by various disorders and/or conditions as well as numerous medications. A comprehensive medical history and proper clinical evaluation, including a thorough physical examination and medical tests, are necessary to rule out all other possible causes, including insufficient sleep, psychiatric disorders, the effects of medications, and medical illness.

Sleep studies involving a polysomnography (PSG) followed immediately by a multiple sleep latency test (MSLT) are also carried out to exclude other sleep disorders such as sleep apnoea.

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

TREATMENT & MANAGEMENT

As the cause of IH is unknown, there is no cure nor medication specifically designed to treat it. Medications used to treat narcolepsy, including stimulants and wake-promoting medications, are prescribed to help manage daytime sleepiness. Unfortunately, these medications don't address all symptoms, such as cognitive dysfunction or the extreme difficulty waking up and sleep drunkenness.

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.

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.

IMPORTANT: 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.

For more information, visit the [Resources](#) page on our website to view our factsheets on stimulant medication (eg: dexamphetamine), modafinil/armodafinil, our tips for living with hypersomnia, and more.

Diagnosed with Idiopathic Hypersomnia?

Hypersomnolence Australia holds the only register in Australia of people diagnosed with IH. It is used for the purpose of aiding research and to assist us in identifying key areas of concern which need addressing. It also gives you the opportunity to tell us what your biggest concerns are, the hurdles you face, or issues you think need attention. Please visit our [website](#) for more information.

Living with Idiopathic Hypersomnia?

Meet others you can relate to at our Living with IH community catch ups. We meet monthly via Google Meet.

Please visit the [Support Group](#) page on our website for more information.



ABOUT US

Hypersomnolence Australia is a not for profit health promotion charity dedicated to advocating, raising awareness and providing support for central disorders of hypersomnolence, eg; Narcolepsy and Idiopathic Hypersomnia.

We do not receive funding, and we do not charge membership fees. Our small team work on a volunteer basis. Your support is vital to our continued operation.



Help make a difference! Go to the [Get Involved](#) page on our website for ways to donate or scan to support us today.



Hypersomnolence Australia has full DGR Item 1 status. Donations are tax deductible. ABN: 19662120036



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