

What is Idiopathic Hypersomnia



Idiopathic Hypersomnia (IH), sometimes referred to as Idiopathic Hypersomnolence, is a neurological sleep/wake disorder characterised by excessive sleep and daytime sleepiness. It is a debilitating condition often profoundly affecting work, education and relationships.

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.


**IDIOPATHIC HYPERSOMNIA®
AWARENESS WEEK**

Hypersomnolence Australia hosts the Worldwide Idiopathic Hypersomnia Awareness Week. Held annually in the first full week in September. Join us!

About us

Hypersomnolence Australia is Australia's only registered Health Promotion Charity specifically dedicated to being a strong advocate, to raising awareness and educating others about Idiopathic Hypersomnia.

Diagnosed with Idiopathic Hypersomnia?

Hypersomnolence Australia holds the only register in Australia of people diagnosed with IH. For more information please visit our website.

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



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


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Idiopathic Hypersomnia



I sleep a lot. I always have.
10+ hours a night. Every night.
I nap a lot too. 2 hour naps.
More than once a day. Everyday.
This is my normal.




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Symptoms

The main symptom of IH is excessive deep sleep. Despite adequate and often extraordinary amounts of good quality sleep (eg: 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 awakening from sleep, accompanied by confusion, disorientation, irritability and poor coordination with an uncontrollable desire to go back to sleep. 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. This is known as “sleep drunkenness”.
- Cognitive dysfunction (commonly referred to as ‘brain fog’): problems with memory, automatic behaviour, concentration and attention.

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

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.

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.

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Treatment and Management

There are no medications specifically for IH. Medications used to treat Narcolepsy including stimulants and wake-promoting medications are prescribed to counter daytime sleepiness, however, there are no medications currently available that assist with cognitive dysfunction or extreme difficulty waking up and sleep drunkenness.

Stimulant and wake-promoting medications can be helpful to relieve sleepiness for some people however they are rarely effective long term and can have unpleasant side effects. Some people with IH find a combination of medication and lifestyle changes are helpful in managing their symptoms.

Lifestyles changes can be difficult to initiate (and maintain) for people with chronic illness and may need the assistance of a specialist therapist.



DISCLAIMER - The content of this pamphlet is for information purposes only and is not a substitute for professional medical advice. Any concerns you may have about your health should be discussed with your doctor.

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