



Important Things to Know About Idiopathic Hypersomnia

- People with idiopathic hypersomnia (IH) sleep a lot during the day.
- Some of them will also sleep longer than usual at night.
- It is often diagnosed by ruling out other possible causes of excessive sleepiness.
- It often starts as a teenager or young adult.
- If you think you have it, you should see a sleep specialist.

What is idiopathic hypersomnia (IH)?

The main symptom of IH is feeling sleepy during the day. There are two forms of IH. In one, the person has a normal amount of sleep at night (i.e. up to 9 hours). In the other, they sleep for longer than usual at night (e.g. 12-14 hours). In both forms, people also sleep during the day, usually in long naps of 1-2 hours. However these naps are not refreshing and they wake up still feeling tired. Many people with IH also have a lot of trouble waking up in the morning. They may feel quite groggy as they surface from being asleep.

What causes IH?

IH is quite rare. The cause is not well understood, but it is probably related to a problem in the parts of the brain that regulate sleep and wakefulness. Recent research suggests it may be to do with malfunction of the same systems in the brain that sleeping pills act on. People who have taken sleeping pills and wake up before they have worn off, tend to be groggy and confused. This is how people with IH often feel when they wake up.

How does it affect people?

IH usually starts in younger people, aged less than 30. It tends to come on gradually, over months or years. People have difficulty with being able to work normally because of excessive sleepiness. Others may mistake this for lack

of interest or motivation. Close friends and family need to understand how hard it is for sufferers to fight feeling sleepy. It may also cause depressed feelings. It is not safe to drive a car unless the symptoms are under control with medication.

Where and when should sufferers seek help?

If you are always feeling sleepy and cannot explain why, you should talk to your doctor (see [excessive daytime sleepiness](#)). You probably don't have IH if you feel tired or fatigued without the urge to sleep during the day. If you wake up refreshed after having a long sleep, then you probably don't have IH.

What might your doctor do?

If your GP feels you may have a sleep problem you will be referred to a [sleep specialist](#). Many patients have IH for many years without knowing it. To determine if you have IH or another sleep disorder (e.g. [narcolepsy](#)), you may have a "Multiple Sleep Latency Test" in a clinic that does [sleep studies](#).

What is the Multiple Sleep Latency Test?

After your sleep is monitored overnight, you will be asked to try to nap every two hours throughout the day. While you are doing this, your sleep is measured. You will be

given 20 minutes to sleep every two hours – often at times such as 9am, 11am, 1pm and 3pm. There are two things being looked at. One is how long it takes you to go to sleep. The other is what type of sleep you have when you go to sleep (See [Facts about Sleep](#) to read about REM sleep). If you go to sleep quickly, but not into REM sleep, you might have IH.

What else might cause the symptoms?

There are many possible reasons for feeling sleepy or tired (see [excessive daytime sleepiness](#)). IH is often diagnosed by ruling out other causes of sleepiness. This means that doctors need to be sure that people diagnosed with IH are not sleepy because of some other problem related to sleep or general health.

How can we treat IH?

There is no cure but many people can control the symptoms of IH symptoms (at least in part) with medication. As more is learnt about the systems in the brain that control sleeping and waking, there is the promise that new drugs will be developed for IH. In most cases, IH persists but it seems that in 10-15% of cases it will resolve by itself.

What can you do to help with symptoms?

You need to adapt your lifestyle. Try to work out a system for being able to wake up in time for things you need to do during the day (e.g. using more than one alarm, asking friends and family to help, morning light). Avoid situations where it is a danger to be sleepy, such as driving (see [drowsy driving](#)). If you plan your naps during the day, this may help. But how much this works varies from person to person. Keep the same sleep hours each night. If you feel depressed about being sleepy, then seek help.

Where can I find out more?

http://en.m.wikipedia.org/wiki/Idiopathic_hypersomnia

This is an excellent, very comprehensive and up-to-date guide to the disorder with a range of excellent links.

www.livingwithhypersomnia.com

www.sleepfoundation.org/article/sleep-related-problems/idiopathic-hypersomnia-and-sleep

www.facebook.com/groups/180483188757329

Australian Facebook page for people with Idiopathic Hypersomnia

www.hypersomnolenceaustralia.com

Hypersomnolence Australia: Advocating, raising awareness, educating & providing support for the rare neurological sleep disorder, Idiopathic Hypersomnolence (Idiopathic Hypersomnia)

This information is produced by:

Sleep Health Foundation

ABN 91 138 737 854

www.sleephealthfoundation.org.au

A national organisation devoted to education, advocacy and supporting research into sleep and its disorders

Sleep Disorders Australia

ABN 98 075 427 459

www.sleepoz.org.au

A voluntary group offering assistance and support to people and their families living with sleep disorders

Australasian Sleep Association

ABN 32 172 170 561

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The peak national association of clinicians and scientists devoted to investigation of sleep and its disorders

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Ongoing concerns about sleep or other medical conditions should be discussed with your local doctor.

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