



IDIOPATHIC HYPERMOMNIA

- People with idiopathic hypersomnia (IH) sleep a lot during the day.
- They often also sleep longer than usual at night.
- Waking up is difficult.
- Other possible causes of excessive sleepiness need to be ruled out for a IH diagnosis.
- It often starts as a teenager or young adult.
- If you think you have it, you should see a sleep specialist.
- Medication may help with wakefulness.

Note: All words that are underlined relate to topics in the Sleep Health Foundation Information Library at www.sleephealthfoundation.org.au

1. What is idiopathic hypersomnia (IH)?

IH is a neurological disorder with the following key signs and symptoms,

- feeling sleepy during the day and/or taking long naps
- sleeping for longer than usual at night (e.g. 12-14 hours or longer)
- difficulty waking up
- problem making the transition from being asleep to being awake (termed sleep inertia or sleep drunkenness)
- sleep feels unrefreshing and non-restorative

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.

IH may also be called 'Hypersomnolence Disorder'.

2. What else might cause the symptoms?

There are many possible reasons for feeling sleepy or tired. If you have some or all of the above signs and symptoms the first step is to see if there might be another reason for your sleep/wake problems. (See the fact sheet on [Excessive Daytime Sleepiness](#).) If your sleep problem is unexplained or suggests a sleep disorder, you should talk to your doctor. IH is often diagnosed by ruling out other causes of sleepiness. Doctors need to be sure that people diagnosed with IH are not sleepy because of some other problem related to sleep or general health.

3. What causes IH?

IH is quite rare, with only 1 or 2 people with IH for every 10,000. The cause is not well understood, but it is probably related to chemical imbalances in the parts of the brain that regulate sleep and wakefulness. IH usually starts in younger people, with the average of onset being 22 years.



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4. How does it affect people?

People with IH have difficulty with being able to work or study normally because of their symptoms. 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. People with IH, especially young people, are vulnerable across multiple aspects of life – including academic, emotional, behavioural and quality of life areas. Psychologists may be able to help individuals cope with some of these problems.

5. 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.

6. 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. Some clinics may also monitor your sleep-wake behaviour for 24 hours or more. Sleeping for more than 11 hours every 24 hours would indicate a problem that might be IH.

7. 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. A medication that increases dopamine and norepinephrine in the wake promoting centres of the brain, Modafanil, will help some people with IH symptoms. In most cases, IH persists but it seems that in 10-15% of cases it will resolve by itself.

8. 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 in being sleepy, such as driving (see [Drowsy Driving](#)). If you can 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 the IH symptoms make you feel depressed, 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.hypersomnolenceaustralia.org.au

Advocating, raising awareness, educating & providing support for Idiopathic Hypersomnolence (Idiopathic Hypersomnia).

For information on over 70 different sleep related topics, written by professionals, visit the Sleep Health Foundation Information Library at www.sleephealthfoundation.org.au. The underlined topics in this article are covered in detail there.



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Sleep Health Foundation ABN 91 138 737 854

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

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Version 2: August 2020