Idiopathic Hypersomnia Fact Sheet

Are you finding it difficult to understand Idiopathic Hypersomnia or having trouble explaining it to others? This fact sheet is a brief overview of what Idiopathic Hypersomnia (IH) is, what the typical symptoms are, and where you can go for help and further information.

What is Idiopathic Hypersomnia/Hypersomnolence?

Idiopathic Hypersomnia is a rare neurological sleep disorder characterised by excessive sleep. Traditionally it was described in two forms, Monosymptomatic (previously referred to as “without long sleep”) manifested by excessive daytime sleep/sleepiness, and Polysymptomatic (previously referred to as “with long sleep”). This is characterised by exceptionally deep and abnormally long nocturnal and daytime sleep, great difficulty awakening and "sleep drunkenness" (sleep inertia). Recent research supports the findings of previous studies that suggest Polysymptomatic Hypersomnia is distinct and unique and is in fact an independent sleep disorder of Monosymptomatic Hypersomnia. The research showed that the clinical features of Monosymptomatic Hypersomnia were more closely related to those found in Narcolepsy without cataplexy (Type 2 Narcolepsy).

Despite adequate or even excessive amounts of good quality sleep patients with both sleep disorders, Polysymptomatic and Monosymptomatic Hypersomnia are in an almost constant state of sleepiness.

What are the Symptoms?

Polysymptomatic Hypersomnia

Excessive nocturnal and daytime sleep with excessive daytime sleepiness are the major symptoms

People with Polysymptomatic Hypersomnia sleep in excess of 10 hours each day. It is not uncommon for them to sleep as much as 16+ hours in a 24 hour period. Unlike in other sleep disorders (eg: Narcolepsy) the sleep quality is normal and usually very deep.
Long and unrefreshing naps
People with Polysymptomatic Hypersomnia usually sleep longer than a normal daytime nap, their naps can be many hours in duration and yet they still wake up feeling unrefreshed. Regardless of how much sleep they get during the day people with will Polysymptomatic Hypersomnia still fall asleep without any difficulty at night and sleep solidly usually without arousal.

Difficulty awakening from sleep
People with Polysymptomatic Hypersomnia find it extremely difficult to arouse from sleep, they can sleep through many alarms and even physical attempts to wake them by other people can sometimes fail despite normal quality and more than normal quantity of sleep.

Sleep inertia/sleep drunkenness
Most people with Polysymptomatic Hypersomnia experience an impaired physiological state after awakening which usually involves confusion, disorientation and poor coordination. This causes significant difficulty and prolonged time in transitioning from sleep to wakefulness which often leads to many returns to sleep.

Cognitive (Executive) Dysfunction
People with Polysymptomatic Hypersomnia can have problems with memory, automatic behaviour, concentration and attention due to sleep drunkenness upon awakening and constant chronic sleepiness. This is commonly referred to as 'brain fog'

Unlike in other sleep disorders the sleep in patients with Polysymptomatic Hypersomnia is normal; there are no disturbances that can account for the excessive daytime sleepiness and prolonged daytime naps.

Polysymptomatic Hypersomnia is a lifelong disorder. Symptoms typically begin in adolescence or young adulthood. It is debilitating often profoundly affecting work, education and relationships. The cause of Polysymptomatic Hypersomnia is unknown however it is thought to be caused by a dysfunction in the part of the brain that regulates sleep and wake. Some researchers also believe there is a genetic link. Further research is necessary.

Monosymptomatic Hypersomnia
The main symptom of Monosymptomatic Hypersomnia is excessive daytime sleepiness. People with Monosymptomatic Hypersomnia may experience some difficulty awakening in the morning however they generally do not experience sleep drunkenness. They may or may not sleep longer than normal during the night however
irresistible naps during the day are common making their overall sleep time longer than normal. Unlike the unrefreshing sleep in Polysymptomatic Hypersomnia the naps in Monosymptomatic Hypersomnia can sometimes be refreshing.

Research shows that Monosymptomatic Hypersomnia and Narcolepsy without Cataplexy (Type 2 Narcolepsy) are more similar. It is thought that they are either a single entity or more likely made up of a number of other conditions, some of which may not yet be known. Further research is required.

How is Idiopathic Hypersomnia Diagnosed?

Diagnosing Idiopathic Hypersomnia can be difficult as excessive daytime sleepiness can be caused by various disorders and/or conditions as well as numerous medications. When diagnosing Idiopathic Hypersomnia all other possible causes of excessive daytime sleepiness must be excluded including insufficient sleep. Sleep studies involving a combined Polysomnography (PSG) and Multiple Sleep Latency Test (MSLT) are also carried out to exclude other sleep disorders such as narcolepsy and sleep apnoea.

How is Idiopathic Hypersomnia Treated?

While Polysymptomatic Hypersomnia is thought to be caused by a dysfunction of part of the brain that regulates sleep and wake an exact cause is not known. Therefore treatment involves targeting the symptoms, not the underlying cause. There are no approved medications in Australia specifically for Idiopathic Hypersomnia. Medications used to treat Narcolepsy including stimulants and wake-promoting medications are prescribed to counter daytime sleepiness however there are no medications that assist with the extreme difficulty waking up or the sleep drunkenness that people with Polysymptomatic Hypersomnia find so difficult to manage. Stimulant and wake promoting medications can be helpful to relieve sleepiness for some patients however they are rarely effective long term.

Monosymptomatic Hypersomnia and Narcolepsy without Cataplexy (Type 2 Narcolepsy) are thought to be either a single entity of which a single cause is not known or more likely made up of a number of other conditions, some of which may not yet be known. Therefore treating Monosymptomatic Hypersomnia also involves treating the symptom. Stimulants and wake-promoting medications can be effective in treating excessive daytime sleepiness/sleep however it should be noted that some people with Monosymptomatic Hypersomnia are known to have refreshing naps so it is important to take this into consideration. Sometimes taking a brief nap can be more beneficial particularly for those who find naps refreshing.
Who is Hypersomnolence Australia?

Hypersomnolence Australia is Australia's only Health Promotion Charity registered with the Australian Charities and Not for Profit Commission (ACNC) specifically dedicated to being a strong advocate, to raising awareness and educating others about Idiopathic Hypersomnia.

Please visit our website for more information, to sign up to our newsletter and to complete the survey for our Patient Registry. You can “Like” our Facebook page to keep up to date with relevant information, and you can also follow us on Twitter, Instagram and Pinterest.

We hope you have found this Fact Sheet informative. Support and information for people with Idiopathic Hypersomnia is important. Just as people with Idiopathic Hypersomnia need a reliable source of information and support, we need funding to provide this information and to hopefully fund vital research. Hypersomnolence Australia currently receives no funding.

We need your help!
Donations can be made via cheque mailed to the address above or through our ANZ bank account in the name of:

Hypersomnolence Australia
BSB: 014286
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References
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