



## Frequently Asked Questions (FAQ)

### **1. Does a MSLT (Multiple Sleep Latency Test) diagnose idiopathic hypersomnia?**

No. There are several limitations to the MSLT. It can not confirm idiopathic hypersomnia or narcolepsy type 2 (without cataplexy). Please read the document [MULTIPLE SLEEP LATENCY TEST \(MSLT\) What it does and doesn't tell a sleep physician](#) for more information.

### **2. Does falling asleep quickly mean your idiopathic hypersomnia is severe (or worse than someone else with IH who had a longer sleep latency)?**

No. While people with idiopathic hypersomnia do tend to fall asleep quicker than healthy people falling asleep quickly is not a typical trait of idiopathic hypersomnia. Consistent research has shown that people with idiopathic hypersomnia do not necessarily fall asleep quickly. [1, 2] The primary symptom of IH is excessive sleep. Spontaneous sleep periods of up to 19 hours are common in idiopathic hypersomnia, despite a normal MSL (> 10 min) ie: despite not falling asleep quickly. [3]

1. Vernet C, Arnulf I, Idiopathic hypersomnia with and without long sleep time: a controlled series of 75 patients, Sleep 2009 Jun; 32(6): pp.753-9
2. Anderson KN, Pilsworth S, Sharples LD, Smith IE, Shneerson JM. Idiopathic hypersomnia: a study of 77 cases. Sleep. 2007 Oct; 30(10):1274-81.
3. Voderholzer U, Backhaus J, Hornyak M, et al. A 19-h spontaneous sleep period in idiopathic central nervous system hypersomnia J Sleep Res, 19, 1998, pp. 219–223.

### **3. Why do I have narcolepsy on my medical records however my doctor has told me I have idiopathic hypersomnia?**

There are currently no medications on the PBS for idiopathic hypersomnia. Doctors access medications for people with idiopathic hypersomnia by recording their diagnosis as narcolepsy, providing their patient meets the PBS criteria for narcolepsy which includes a Multiple Sleep Latency Test (MSLT) of <10mins. This means if your MSLT was <10mins your doctor has recorded your diagnosis as narcolepsy to enable you to have access to PBS listed medication.

### **4. Why do some people with idiopathic hypersomnia have access to modafinil and armodafinil on the PBS whereas others don't?**

Modafinil/armodafinil are PBS approved for narcolepsy only. The only way someone with idiopathic hypersomnia (or any other medical condition that causes EDS) can access affordable (via the PBS) modafinil/armodafinil is if their doctor submits the PBS application form as if they have narcolepsy. So, you must first meet the PBS criteria for narcolepsy which includes a MSLT <10 mins.

Secondly, the only way a doctor can access modafinil or armodafinil at all, whether it is for a patient with narcolepsy, idiopathic hypersomnia or any other medical condition that causes excessive daytime sleepiness (providing they achieve <10mins on a MSLT) is if they have a medical or mental reason that makes taking dexamphetamine (the first line treatment option) unsuitable. Therefore, the person with idiopathic hypersomnia who has access to PBS listed modafinil or armodafinil,

- a) has narcolepsy recorded as their medical diagnosis for the purpose of the PBS application for modafinil/armodafinil, and
- b) has a medical or mental reason\* that makes taking dexamphetamine unsuitable.

\*reasons include:

- Psychiatric Disorder
- Cardiovascular Disorder
- History of substances abuse
- Glaucoma
- Other absolute contraindication as specified in the Therapeutic Goods Administration (TGA) approved Product Information (doctors need to provide details of the contraindication)

## **5. I have idiopathic hypersomnia and I am prescribed modafinil/armodafinil on the PBS and I don't have any of those contraindications.**

This is not uncommon. We cannot say exactly why one individual has access to PBS listed medication whereas another does not (when neither have one of the above listed contraindications) however we do know that some doctors will write on a PBS application that their patient has one (typically 'Psychiatric Disorder') of the above contraindications (whether their patient has it or not).

## **6. Modafinil/Armodafinil - Birth Control and Pregnancy**

We hear from a number of women who are unaware of the potential failure of combined hormonal contraception, such as birth control pills, patches and implants when taken together with modafinil or armodafinil. Even more alarming are the number of doctors who also seem to be unaware of this information.

Please read this article for information relating to taking these medications and contraceptives as well as taking them while pregnant.

<https://www.hypersomnolenceaustralia.org.au/single-post/2018/03/13/modafinilarmodafinil-birth-control-and-pregnancy>

## **7. Will medication eradicate my idiopathic hypersomnia symptoms?**

No. As the cause of IH is unknown the medication prescribed for idiopathic hypersomnia will at best help you manage your symptoms.

Important note about medication:

While it may be tempting to try to use medication to enable you to participate a lot more in life it is important to remember that people with idiopathic hypersomnia generally do not operate very well on less sleep. While you may get away with sleeping as much as an average person would (eg: 7-8 hours in 24 hours) for a day or so most people find that any more than 2-3 consecutive days of this catches up with them and they eventually crash. Sleep is therefore very important to people with idiopathic hypersomnia. Most people who have learnt to manage their symptoms will tell you that they still sleep excessively despite medication, they just sleep a little less excessively.

## **8. What does “drug holiday” mean?**

Stimulant and wake-promoting medications can be helpful to relieve sleepiness for some people however they are rarely effective long term. One reason for this is because people build up a tolerance to their medication. A drug holiday is when you take a break from your medication. This can help prevent tolerance to your medication. It can also help you re-set yourself if you have built up a tolerance. To prevent building up a tolerance some people do not take their medication on

weekends. Some people may also take less medication on days that do not require them to be as awake and focused as other days might. If you have already built up a tolerance to your medication it may take a week or two off medication to reset. Always discuss drug holidays with your doctor.

## **9. Any tips on how to get going in the morning?**

This question or variations of it is by far the most common question and the answer is, yes, just one tip. Put your morning dose of medication on your nightstand (or table next to your bed). Putting it in a small medication cup or similar will help you find it in the morning. Put a pop top lid type water bottle next to your medication. Pop top is suggested because you don't want something that requires unscrewing the lid. Set all of your alarms for about an hour before you actually need to be awake. If you have someone that can wake you that's even better, get them to do that an hour before you need to be awake. When you wake (an hour before you need to) take your medication and go back to sleep (make sure you have alarms set for when you actually need to be awake). You should find waking up when you need to a little easier and it may even reduce the impact of the sleep drunkenness. Note: an hour before you need to be awake is just a suggestion. You may find a shorter or longer period works better for you.

## **10. Why is my Dex (or other amphetamine based medication eg: Ritalin) not working?**

This is another very common question. Go to our blog post for the answer.

<https://www.hypersomnolenceaustralia.org.au/single-post/2018/03/13/why-is-my-dex-not-working>

## **11. Why do others I have spoken to have symptoms I don't experience? Does this mean I do not have idiopathic hypersomnia?**

a) It may mean that. Idiopathic hypersomnia is one of the most over diagnosed sleep disorders due to ignorance and convenience (convenience because it can enable doctors to prescribe PBS listed medication). Hypersomnolence Australia has helped a number of people get to the bottom of their symptoms ie: they were diagnosed with idiopathic hypersomnia however they later found they did not have idiopathic hypersomnia. Some of these people have been fortunate enough to find answers for their symptoms and they have resolved them completely while others have found the right diagnosis (they have a different medical condition) so we know that not everyone diagnosed with idiopathic hypersomnia has idiopathic hypersomnia.

Please note that misdiagnosis is not always due to ignorance or convenience. The list of possible causes of excessive daytime sleepiness spans virtually every major area of medicine, neurology and psychiatry, therefore finding the right cause can be extremely difficult. To assist patients and doctors when considering the cause of daytime sleepiness, we [compiled a list](#) of known causes and routine tests. There are numerous possible causes so this list is by no means a complete. It is only intended as a guide to assist people and their doctor find the cause of excessive daytime sleepiness.

b) It could also mean you do not have the 'complete' form of idiopathic hypersomnia. When Bedrich Roth coined the term "Idiopathic Hypersomnia" he defined two forms of the disease, Monosymptomatic and Polysymptomatic. While the terms polysymptomatic and monosymptomatic

are no longer used, recent research supports the findings of previous studies that show there are different forms of idiopathic hypersomnia. These studies show a subgroup of patients with “a complete form” of idiopathic hypersomnia with symptoms that are unique to this group ('complete' means they typically experience all of the [key symptoms](#) of idiopathic hypersomnia). This group is often referred to as idiopathic hypersomnia "with long sleep".

The research suggests that 'complete' idiopathic hypersomnia is, in fact, a separate sleep disorder of 'incomplete' idiopathic hypersomnia (previously referred to as 'without long sleep'). In 2020, 21 of the world's narcolepsy and idiopathic hypersomnia researchers wrote in two papers that the

complete form of idiopathic hypersomnia (with long sleep) should be recognised as an independent clinic entity (a medical disorder separate from idiopathic hypersomnia without long sleep). As a result of the overwhelming research both groups also support the merging of narcolepsy type 2 (without cataplexy) and idiopathic hypersomnia without long sleep into one group (narcolepsy without cataplexy is more similar to IH without long sleep than it is genuine narcolepsy). The majority suggest renaming this group "Idiopathic Excessive Sleepiness" to reflect the primary symptom of the group, ie: excessive daytime sleepiness (EDS).

So, if you don't experience some of the symptoms that other people with IH experience this could also be why, ie: you may fall into the group of people that researchers have recently referred to as Idiopathic Excessive Sleepiness. Click [here](#) for references to this information.

c) It is important to remember that while IH symptoms are fairly standard across sufferers the way they affect us and our ability to manage them are influenced by many individual things including response to medication, level of support, other health issues and other environmental factors. This can sometimes make it appear as though symptoms are different. So, you may have genuine IH, but your ability to manage your symptoms just may be different to other people.

## **12. Is idiopathic hypersomnia rare? Also, Is idiopathic hypersomnia a real medical condition?**

Yes, and yes. Idiopathic hypersomnia is a rare disease. It is also one of the most misunderstood and under researched sleep disorders. Many (including doctors) incorrectly think it refers to any case of excessive daytime sleepiness (EDS) that cannot be explained by another preexisting medical condition or sleep disorder or by lifestyle or behavior. This is not correct; idiopathic hypersomnia is a rare neurological sleep/wake disorder. EDS is just one symptom of idiopathic hypersomnia. Idiopathic hypersomnia is characterised by a [number of symptoms and clinical features](#) first defined by Bedrich Roth more than 40 years ago\*. Roth's years of extensive research that led to his description of idiopathic hypersomnia as a separate disease entity was accepted and included in the first ICSD (International Classification of Sleep Disorders), the Diagnostic Classification of Sleep and Arousal Disorders in 1979. Since then it has been included as a “Rare Disease” on the Genetic and Rare Diseases Information Center (GARD) register and Orphanet.

\*[Bedřich Roth: pioneer in Sleep Medicine](#)

\*[Bedřich Roth, His Life's Work and the 35th anniversary of the book “Narcolepsy and Hypersomnia”](#)

## **13. Who is Hypersomnolence Australia?**

Hypersomnolence Australia (HA) is the world's first not for profit charity created especially for idiopathic hypersomnia. It was founded in 2013 by Michelle Chadwick. In the same year Michelle created the worldwide Idiopathic Hypersomnia Awareness Week. HA hosts this annual event every year in the first full week in September. HA's primary purpose is to support the medical community work towards a better understanding of idiopathic hypersomnia, better access to effective treatment options, and identifying biomarkers that will lead to more appropriate diagnostic

tools and ultimately a cure for idiopathic hypersomnia. We are committed to being a strong advocacy, raising awareness and educating others about idiopathic hypersomnia. Our goal is to not just change the process to diagnosis but also the level of care and services available to people post diagnosis. You can read more about us [here](#) and more about the history of HA [here](#).

#### **14. How can I support the work HA does?**

There are several ways you can help HA. Check out the Get Involved page on our website for more information. <https://www.hypersomnolenceaustralia.org.au/getinvolved>

#### **15. What is HA's Patient Registry?**

The patient registry is the Idiopathic Hypersomnia Patient Registry. It is the only patient registry of people diagnosed with Idiopathic Hypersomnia in Australia. It is used for the purpose of aiding research and to assist us to identify key areas of concern that 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.

It is open to people diagnosed with IH in Australia and NZ.

For more information about the registry

<https://www.hypersomnolenceaustralia.org.au/patientregistry>

To complete the survey and join the registry

[https://docs.google.com/forms/d/e/1FAIpQLSe6CFRk\\_UvrodMqjGwwi\\_azAOFoqgkJ4at42MLow\\_U8hGursA/viewform?c=0&w=1](https://docs.google.com/forms/d/e/1FAIpQLSe6CFRk_UvrodMqjGwwi_azAOFoqgkJ4at42MLow_U8hGursA/viewform?c=0&w=1)

#### **FOR MORE INFORMATION, PLEASE CLICK ON THE LINKS BELOW**

RESOURCES - <https://www.hypersomnolenceaustralia.org.au/resources>

Go to the Resources page on our website to view our Factsheets on stimulant medication (eg: dexamphetamine), modafinil/armodafinil, our Top 12 Tips for Living with IH and more.

WHAT IS IH?

<https://www.hypersomnolenceaustralia.org.au/what-is-idiopathic-hypersomnia>

DIAGNOSIS AND MANAGEMENT OF IDIOPATHIC HYPERSOMNIA

<https://www.hypersomnolenceaustralia.org.au/diagnosisandmanagement>

SYMPTOMS OF IDIOPATHIC HYPERSOMNIA

<https://www.hypersomnolenceaustralia.org.au/symptoms>

HYPERSOMNOLENCE AUSTRALIA'S IDIOPATHIC HYPERSOMNIA FACTSHEET

[https://www.hypersomnolenceaustralia.org.au/files/ugd/a1218b\\_b589f86ef1874e129d59ce9c95ce2e90.pdf](https://www.hypersomnolenceaustralia.org.au/files/ugd/a1218b_b589f86ef1874e129d59ce9c95ce2e90.pdf)

If you would like a hard copy of this factsheet in a trifold brochure sent to you (or copies sent to your doctor) please email us at [info@hypersomnolenceaustralia.org.au](mailto:info@hypersomnolenceaustralia.org.au).

WORLDWIDE IDIOPATHIC HYPERSOMNIA AWARENESS WEEK

<https://www.hypersomnolenceaustralia.org.au/ihawarenessweek>

## LIVING WITH IDIOPATHIC HYPERSOMNIA SUPPORT GROUP

<https://www.hypersomnolenceaustralia.org.au/supportgroup>

## LIVING WITH IDIOPATHIC HYPERSOMNIA – People’s perspectives

Having a rare neurological sleep disorder like idiopathic hypersomnia usually means going through life never meeting another person you can relate to or who understands what life is like for you.

This can be very isolating and lonely. Our Living with IH page is a place where you will find stories and other expressions by people living with idiopathic hypersomnia. We hope that their stories will help you on your journey.

<https://www.hypersomnolenceaustralia.org.au/livingwithih>

## ABOUT HA

<https://www.hypersomnolenceaustralia.org.au/aboutus>

## HA’s HISTORY

<https://www.hypersomnolenceaustralia.org.au/our-history>