

HALF ASLEEP



HALF AWAKE

Idiopathic Hypersomnia (IH) can feel like you're stuck between the two—from the moment your alarm first goes off in the morning until you go to bed at night. **But did you know that the quality of your nighttime sleep could be part of the problem?**

FOR MANY, IDIOPATHIC HYPERSOMNIA IS A 24-HOUR SLEEP DISORDER WITH MULTIPLE SYMPTOMS



MORNING
WAKEUP



SLEEP INERTIA

Severe/prolonged grogginess or confusion when waking up



DAYTIME
& EVENING



EXCESSIVE DAYTIME SLEEPINESS (EDS)

Feeling very sleepy or tired during the day



LONG UNREFRESHING NAPS

Not feeling refreshed or better/rested after a nap (may even feel worse)



BRAIN FOG

Difficulty focusing, trouble thinking clearly, or memory problems due to EDS



NIGHTTIME SLEEP



LONG SLEEP TIME

Ability to sleep for many hours, sometimes for 11 hours or more



Scan this code to learn more about managing your Idiopathic Hypersomnia.

Turn over to take the **IH SYMPTOMS QUIZ!** →

IH Symptoms Quiz

Complete this 6-question quiz and share your answers with your doctor to help track your symptoms and discuss Idiopathic Hypersomnia (IH).

As you complete this quiz, think about your typical day from morning until nighttime—how your symptoms affect your activities, lifestyle, and relationships. Try to answer as truthfully as possible to paint a clear picture of how IH may be affecting you. **Keep your answers handy so you can refer to them the next time you are speaking with your doctor about your symptoms.**

REMEMBER: It's vital that you keep your doctor informed about all of your IH symptoms, so use this at your next appointment to talk to your doctor. If there have been changes in your sleepiness or how you feel, speak up!

MORNING WAKEUP

HOW DO YOU FIND WAKING UP IN THE MORNING?

QUESTION 1: I find waking up is...

- Pretty easy Somewhat hard Really hard Impossible

QUESTION 2: I need multiple alarms or help from someone else to wake up...

- Never Sometimes Often Every time

QUESTION 3: Based on the previous night's sleep, I typically wake up feeling...

- Rested Not rested

DAYTIME & EVENING

NOW THAT YOU'RE UP, HOW DO YOU FEEL THE REST OF THE DAY AND INTO THE EVENING?

QUESTION 4: After taking a nap, I usually wake up feeling...

- Rested Like I never even slept Actually, I don't take naps

QUESTION 5: The following things in my life are negatively affected by my sleepiness during the day:
(select all that apply)

- My energy level and motivation to do things Household chores
 Driving a vehicle safely My performance at school or work
 Being able to remember things and/or focus on tasks My relationships with others
 Other: _____

(Be sure to discuss with your doctor)

NIGHTTIME SLEEP

HOW LONG IS YOUR NIGHTTIME SLEEP?

QUESTION 6: On a weekend or a holiday, my ideal nighttime sleep is...

- 11+ hours 9-11 hours 7-9 hours Less than 7 hours

Get tips for talking to your doctor at [TalkAboutIH.com](https://www.talkaboutih.com)

The Idiopathic Hypersomnia Severity Scale (IHSS) was created by sleep experts to help determine the severity of symptoms in people with Idiopathic Hypersomnia (IH) and provide a measurement that may be useful for follow-up visits with a sleep specialist.

The scale below measures both nighttime and daytime symptoms and the sleep inertia (or "sleep drunkenness") related to each, as well as impaired daytime functioning. Please rate your symptoms using the 3- or 4-point scale for each question and review your responses with your doctor.

IDIOPATHIC HYPERSOMNIA SEVERITY SCALE (IHSS) (1/2)

Name: _____

DOB: _____

Date: _____

On the basis of your symptoms during the past month:

Fill in your answers here



1. What for you is the ideal duration of night-time sleep (at the weekend or on holiday, for example)?

(3) 11 hours or more

(2) more than 9 hours and less than 11 hours

(1) between 7 hours and 9 hours

(0) less than 7 hours

2. When circumstances require that you get up at a particular time in the morning (for example for work or studies, or to take the children to school during the week), do you feel that you have not had enough sleep?

(3) always

(2) often

(1) sometimes

(0) never

3. Is it extremely difficult for you, or even impossible, to wake in the morning without several alarm calls or the help of someone close?

(3) always

(2) often

(1) sometimes

(0) never

4. After a night's sleep, how long does it take you to feel you are functioning properly after you get up (in other words fully functional, both physically and intellectually)?

(4) 2 hours or more

(3) more than 1 hour but less than 2 hours

(2) between 30 minutes and 1 hour

(1) less than 30 minutes

(0) I feel I am functioning properly as soon as I wake up

5. In the minutes after waking up, do you ever do irrational things and/or say irrational things, and/or are you very clumsy (for example, tripping up, breaking things or dropping things)?

(3) always

(2) often

(1) sometimes

(0) never

6. During the day, when circumstances allow, do you ever take a nap?

(4) very often (6-7 times a week)

(3) often (4-5 times a week)

(2) sometimes (2-3 times a week)

(1) rarely (once a week)

(0) never

7. What for you is the ideal length of your naps (at the weekend or on holiday, for example)? Note: if you take several naps, add them all together

(3) 2 hours or more

(2) more than 1 hour and less than 2 hours

(1) less than 1 hour

(0) no naps

IDIOPATHIC HYPERSOMNIA SEVERITY SCALE (IHSS) (2/2)

8. In general, how do you feel after a nap?

(3) very sleepy
(1) awake

(2) sleepy
(0) wide awake

9. During the day, while carrying out activities that are not very stimulating, do you ever struggle to stay awake?

(4) very often (at least twice a day)
(2) sometimes (2-3 times a week)
(0) never

(3) often (4-7 times a week)
(1) rarely (once a week or less)

10. Do you consider that your hypersomnolence has an impact on your general health (i.e. *lack of energy, no motivation to do things, physical fatigue on exertion, decrease in physical fitness*)?

(4) very significant
(2) moderate
(0) no impact

(3) significant
(1) minor

11. Do you consider that your hypersomnolence is a problem in terms of your proper intellectual functioning (i.e. *problems with concentration, memory problems, decrease in your intellectual performance*)?

(4) very significant
(2) moderate
(0) no problem

(3) significant
(1) minor

12. Do you consider that your hypersomnolence affects your mood (for example *sadness, anxiety, hypersensitivity, irritability*)?

(4) very severely
(2) moderately
(0) not at all

(3) severely
(1) slightly

13. Do you consider that your hypersomnolence prevents you from carrying out daily tasks properly (family-related or household tasks, school, leisure or job-related tasks)?

(4) very significantly
(2) moderately
(0) not at all

(3) significantly
(1) slightly

14. Do you consider that your hypersomnolence is a problem in terms of your driving a car?

(4) very significant
(2) moderate
(0) no problem/I do not drive

(3) significant
(1) minor

Interpreting Your IHSS Score

Your score will range from 0 to 50. A score of 22 or below is typical for people without any sleep disorder. Higher scores on the IHSS indicate more severe symptoms of IH.

This questionnaire is not intended to take the place of talking with a doctor. Regardless of the questionnaire results, if you have concerns about your symptoms, you are encouraged to discuss them with your doctor.

For any information on the use of the IHSS, please contact Mapi Research Trust, Lyon, France. Internet: <https://eprovide.mapi-trust.org>.

Sources: 1. Dauvilliers Y, Evangelista E, Barateau L, et al. Measurement of symptoms in idiopathic hypersomnia: the Idiopathic Hypersomnia Severity Scale. *Neurology*. 2019;92(15):e1754-e1762. 2. Dauvilliers Y. Idiopathic hypersomnia severity scale. 2018. Accessed October 3, 2022. <http://links.lww.com/WNL/A854>

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TOTAL SCORE