

The Idiopathic Hypersomnia Severity Scale (IHSS) was developed and validated by sleep experts with feedback from patients.

This reliable 14-item questionnaire is the only clinical tool designed specifically to measure your patients' Idiopathic Hypersomnia (IH) symptoms and provide a touchpoint that might be useful for patient identification, follow-up visits, and IH management.

The scale below measures aspects of nighttime and daytime sleep symptoms and the sleep inertia related to each, as well as impaired daytime functioning due to hypersomnolence. Symptom frequency, intensity, and consequences are rated using a 3- or 4-point scale, with higher scores indicating more severe and frequent symptoms.¹

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

Name: _____ DOB: _____ Date: _____

On the basis of your symptoms during the past month²:

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 |

Subtotal

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

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

(3) very sleepy

(2) sleepy

(1) awake

(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)

(3) often (4-7 times a week)

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

(1) rarely (once a week or less)

(0) never

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

(3) significant

(2) moderate

(1) minor

(0) no impact

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

(3) significant

(2) moderate

(1) minor

(0) no problem

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

(4) very severely

(3) severely

(2) moderately

(1) slightly

(0) not at all

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

(3) significantly

(2) moderately

(1) slightly

(0) not at all

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

(4) very significant

(3) significant

(2) moderate

(1) minor

(0) no problem/I do not drive

Interpreting IHSS Scores

Patients' IHSS scores will range from 0 to 50, with higher scores indicating more severe IH symptoms. A score of 22 or below is typical for people without any sleep disorder. Additionally, a cutoff score of 26 can reliably discriminate between treated and untreated patients with IH. A 4-point change in the IHSS represents a minimum clinically important difference.^{1,3}

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

TOTAL SCORE

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> 3. Rasmussen AL, Evangelista E, Barateau L, et al. Idiopathic Hypersomnia Severity Scale to better quantify symptoms severity and their consequences in idiopathic hypersomnia. *J Clin Sleep Med*. 2022;18(2):617-629.