

IDIOPATHIC HYPERSOMNIA SEVERITY SCALE (IHSS):

An Emerging Tool to Assess Disease Severity and Burden

IHSS, which was developed in 2019, is a 14-item self-assessment questionnaire that measures the severity, frequency, and functional impact of the 3 key IH symptoms.







Idiopathic Hypersomnia Severity Scale (IHSS)

On the basis of your symptoms during the past month:

 1. What for you is the ideal duration of nigh-time sleep (at the weekend or on holiday, for example)? (3) ☐ 11 hours or more (2) ☐ >9 hours and <11 hours (1) ☐ Between 7-9 hours (0) ☐ less than 7 hours
2. Do you feel that you have not had enough sleep? (3) always (2) often (1) sometimes (0) never
3. Is it extremely difficult, 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. How long does it take you to feel you are functioning properly after you get up? (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'm functioning properly as soon as I wake up
 5. After waking up, do you ever do or say irrational things, and/or are you very clumsy? (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/week (3) often, 4-5 times/week (2) sometimes, 2-3 times/week (1) rarely, once a week (0) never
7. What for you is the ideal length of naps? (3) 2 hours or more (2) more than 1 hour and less than 2 hours (1) less than 1 hour (0) no naps
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 2x/day (3) ☐ often, 4-7x/week (2) ☐ sometimes, 2-3x/week (1) ☐ rarely, 1x/week or less (0) ☐ never
 10. Do you consider that your hypersomnolence has an impact on your general health? (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? (4) Very significant (3) significant (2) moderate (1) minor (0) no problem
12. Do you consider that your hypersomnolence affects your mood? (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? (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 THE IHSS SCALE

CLINICALLY RELEVANT SCORE RANGES Moderate = 13-25Mild = 0-12**Severe = 26-38** Very severe = 39-50