

Guide to Requesting Accommodations for K-12 Students with Idiopathic Hypersomnia

This document is intended to guide students, parents, physicians and school personnel (including school nurse/medical practitioner) in discussions about potential accommodations.*

What Is Idiopathic Hypersomnia? **

Idiopathic hypersomnia (IH) is a chronic, usually lifelong, neurologic disorder, a **central disorder of hypersomnolence (CDH)** in the same category as **narcolepsy**. The hallmark symptom of IH is excessive daytime sleepiness, an uncontrollable need to sleep and/or daytime sleepiness that persists even with adequate or prolonged nighttime sleep. IH may be associated with some or all of the following characteristics:

- **Debilitating**, often significantly affecting social, school, and occupational functioning
- **Onset** usually in adolescence or early adulthood (but may be earlier or later)
- **Fluctuating severity**, with some time periods worse than others
- **Daytime naps**, which are generally long (over 1 hour) and usually not refreshing [*frequent*]
- **Long sleep**: sleeping 9 hours or more in 24 hours, which is usually un-refreshing [*frequent*]
- **Sleep drunkenness** (i.e., severe **sleep inertia**): extreme and prolonged difficulty fully awakening, associated with an uncontrollable desire to go back to sleep [*frequent*], which can be accompanied by **automatic behavior** (performing tasks without conscious self-control and not remembering what or if it was done), disorientation, confusion, irritability, and poor coordination
- **Motor hyperactivity** (e.g., "never stopping," "speaking a lot"), serving as a counter measure to boost alertness [*frequent*]
- **Cognitive dysfunction**: deficits in memory, attention, and concentration (sometimes referred to informally as "**brain fog**")
- **Sleep hallucinations**: hallucinations at sleep onset and/or offset [*occasional*]
- **Sleep paralysis**: a transitional state between wakefulness and sleep, in which one is aware but cannot move, speak, or react [*occasional*]
- **Additional potential symptoms**: headaches, automatic behaviors, problems with balance, and difficulties with temperature regulation

What Treatment Is Available? **

IH has no cure, and relatively little is understood about its cause. Physicians may prescribe stimulant medications or other treatments for IH. However, no currently available medications are completely effective or effective in all people with IH, so symptoms may persist in spite of treatment.

Name of Student: _____

Impact on My Learning

I really want to learn and be a good student, but my symptoms *may* make me appear:

- Tired
- Unmotivated
- Confused and foggy
- Disinterested
- Fidgety
- Inattentive
- Unable to concentrate
- A slow learner
- Irritable
- Prone to inappropriate outbursts/statements

Some of these are not true! And this isn't how I want to be!

I've worked with my doctor* to determine which accommodations would be appropriate for me. Below are some specific accommodations (chosen with and initialed by my doctor) that will help me perform as well as students without IH.

ATTENTION AND LEARNING

- ___ Sitting near the teacher
- ___ Reviewing instructions with me
- ___ Providing directions/instructions 1 step at a time
- ___ Redirecting me inconspicuously if I appear inattentive
- ___ Allowing me to wear a near silent electronic device (such as a watch) that will prompt me periodically so I may focus more fully
- ___ Periodically (e.g., every 15-20 minutes) gently prodding me (or allowing a friend to do it) to keep me alert
- ___ Waking me up if I fall asleep (We can discuss the best way to wake me.)
- ___ Giving me "walk breaks" so I'll be more alert
- ___ Providing a podium or standing desk for days when I need to stand to stay awake
- ___ Allowing me to use a tactile object, such as a stress ball, to help maintain alertness
- ___ Allowing me to do something with my hands during class (doodle, knit, use a stress ball, etc.)
- ___ Allowing me to use paper and pencil instead of a computer

ASSIGNMENTS

- Providing copies of teachers' presentations given in class
- Providing copies of teachers' class notes
- Collecting handouts/worksheets in a folder to give to me following an absence
- Giving me a checklist for multi-part or multi-day assignments
- Giving me daily deadlines for multi-part or multi-day assignments
- Reminding me if I have unsubmitted work
- Checking my understanding while I'm doing classwork
- Allowing extended time on assignments completed outside of class
- Reducing the length of assignments, but requiring enough for me to demonstrate my understanding
- Allowing me to write in bullet points instead of paragraphs
- Giving me access to audio and digital texts
- Allowing me to use a computer for note taking and writing
- Allowing me to use specialized software (text-to-speech, speech-to-text, word prediction) and the Internet

TESTING

- Requiring no more than two tests per day
- Giving me a study guide for all tests
- Checking in with me discreetly before a test/quiz to ask if I'm up to it
- Allowing me to take a test/quiz on a different day or different time of day so that I may perform my best
- Breaking long tests into shorter segments over multiple testing periods
- Allowing extended time on quizzes and tests
- Allowing take-home tests
- Allowing me to use the book/notes on tests
- Allowing me to stand up and/or move around during class or tests
- Allowing me to give verbal answers on tests/quizzes
- Allowing me to use word processing for essay tests
- Allowing me to use speech-to-text application software for essay tests

OTHER ACCOMMODATIONS

- Allowing me to eat snacks and drink bottled water or other beverages (including caffeinated) during class
- Providing an unlimited bathroom/clinic pass that I may use as needed
- Allowing me to have additional time to pass between classes without a penalty for tardiness
- Providing me with opportunities to take breaks/naps during the day (in the clinic or other predetermined place)
- Scheduling my classes at times when I'm most alert
- Providing a daily study hall to complete homework/make-up work/unfinished tests
- Providing an abbreviated school day consisting of core classes only
- OTHER supports specific to student's functionality as affected by symptoms of IH
 - _____
 - _____
 - _____

RECOMMENDATION FOR ASSISTIVE TECHNOLOGY CONSULT TO CONSIDER:

- Use of a portable word processor with productivity applications and Internet access
- Use of text to speech application to support reading comprehension
- Use of word prediction application to support written expression and spelling by reducing fatigue through minimizing key strokes and supporting thought completion through word prediction and floating word banks
- Use of speech to text application to support written expression by allowing oral responses to be dictated into text, particularly for longer writing responses
- OTHER supports specific to student's functionality as affected by symptoms of IH
 - _____
 - _____
 - _____

Date: _____

Please Note: Given the nature of this neurological disorder, this student may face challenges in the classroom and in class-related activities, e.g., attending classes as expected, arriving on time and staying through the school day, staying focused or awake in class, participating in class activities, keeping pace with the volume of assignments and completing them in timely ways.

Signatures:

Student _____

Parent _____

Physician _____

Medical Specialty _____

Medical Affiliation/Office _____

Contact Information _____

* The terms physician or doctor are used in this context to refer to the healthcare provider or medical practitioner authorized to diagnose and/or treat a patient with this diagnosis and sign off on related school forms.

****Sources:**

1. 2015 Review article in *Chest*, by Khan/Trotti et al, "Central Disorders of Hypersomnolence: Focus on the Narcolepsies and Idiopathic Hypersomnia" (**free download** at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4694150/>)
2. 2016 *Sleep Medicine Review* article, by Billiard/Sonka et al, "Idiopathic Hypersomnia" (request through a medical library: <https://www.ncbi.nlm.nih.gov/pubmed/26599679>)
3. International Classification of Sleep Disorders, Third Edition (ICSD-3): <http://www.aasmnet.org/store/product.aspx?pid=849>
4. Diagnostic and Statistical Manual of Mental Disorders (DSM-V) p. 368-372 Hypersomnolence Disorder: <https://www.psychiatry.org/psychiatrists/practice/dsm>

Additional Resources for K-12 Education Accommodations Terms

- <https://www.understood.org/en/school-learning/special-services/504-plan/504-plan-terms-to-know>
- <https://www.understood.org/en/learning-attention-issues/getting-started/disability-important-terms/terms-you-may-hear-and-what-they-mean>

Approved by Hypersomnia Foundation Board of Directors, Medical Advisory Board, and Education Legal Counsel

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