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
- **Long sleep**: sleeping 9 hours or more in 24 hours, which is usually un-refreshing
- **Sleep drunkenness** (i.e., severe sleep inertia): extreme and prolonged difficulty fully awakening, associated with an uncontrollable desire to go back to sleep, 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
- **Cognitive dysfunction**: deficits in memory, attention, and concentration
- **Sleep hallucinations**: hallucinations at sleep onset and/or offset
- **Sleep paralysis**: a transitional state between wakefulness and sleep, in which one is aware but cannot move, speak, or react
- **Additional potential symptoms**: headaches, automatic behaviors, problems with balance, and difficulties with temperature regulation
- **Unique anesthesia needs**: see [http://www.hypersomniafoundation.org/anesthesia-and-ih](http://www.hypersomniafoundation.org/anesthesia-and-ih)

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. See [www.hypersomniafoundation.org/treatment](http://www.hypersomniafoundation.org/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

  o ____________________________________________
  o ____________________________________________
  o ____________________________________________

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

  o ____________________________________________
  o ____________________________________________
  o ____________________________________________
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.

**See www.hypersomniafoundation.org/IHSummary.

Additional Resources for K-12 Education Accommodations Terms

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