

#3 Guide to Requesting Academic Adjustments for College Students with Idiopathic Hypersomnia

This document is intended to guide students, their supporters, and physicians in discussions with campus Disability Service Providers about potential academic adjustments for this chronic illness. We recommend that the student and their physician work together to determine which academic adjustments would be appropriate, with the physician initialing each requested adjustment, and both physician and student signing this completed guide. In addition, the student may need to request that their physician document the student's disability. Information for the physician (including a template for that request) is provided here:*

<http://www.hypersomniafoundation.org/document/physicians-guide-to-college-student-acc-ess> and <http://www.hypersomniafoundation.org/document/documentation-of-disability>.

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 countermeasure 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
- **Unique anesthesia needs:** see 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.

* 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

REQUESTS FOR ACADEMIC ADJUSTMENTS AND CAMPUS SUPPORTS

All decisions by the office providing disability services on campus regarding requests for academic adjustments must be made in compliance with the American Disabilities Act (ADA), under the oversight of the Department of Education and its Office of Civil Rights.

The college professionals who make the determinations of academic adjustments for students are disability resource and services specialists known as *Disability Service Providers*. They are affiliated with the campus office that provides services to those with disabilities. The term “vocational counselor/rehabilitation office” is also mentioned in this guide and refers to the vocational rehabilitation agencies located off-campus in all 50 states and US Territories in state rehabilitation offices.

The *Guide* reflects a compilation of academic adjustments (aids and services) identified by college students with IH who participated in the Hypersomnia Foundation’s *Higher Ed Conversation’s Project*. They determined that those academic adjustments listed below are important to the college experience of those with IH—academically and on campus. The list reflects typical academic adjustments. Others are possible, and they can be determined in discussions with the Disability Service Provider. Keep in mind that by law, academic adjustments cannot alter the curriculum of the course.

In instances where actual assistance is needed for the academic adjustments (aids and services) listed below, support could be provided by the instructor or the instructor’s assistant (e.g., Graduate Assistant [GA] or Teaching Assistant [TA]), or by a Personal Coach (PC). **Note:** *Colleges are not required to provide personal coaches. Vocational counselor offices may provide personal coaches; policies regarding such support vary across vocational and state rehabilitation offices.*

This document is considered a guide and not a mandate, and as such is intended to be a helpful tool for students, their supporters, physicians, and Disability Service Providers. A

hallmark of the ADA is that each student and their needs are viewed on a case-by-case basis, so what may be appropriate and “reasonable” for one student with IH may not be for another student with IH.

Note to Students:

Disability Service Providers encourage students to have conversations with their professors about the necessary academic adjustments, without necessarily disclosing the disability.

The Disability Service Provider is not permitted to share the nature of your disability/ies with professors unless you sign a release of information form permitting the exchange of such information. If you believe that disclosing the nature of your disability would be beneficial to you, then you are encouraged to do so by setting up an appointment with the professor during their office advising hours. If you need guidance in doing so, talk with the Disability Service Provider.

Disclosing your diagnosis may be beneficial to the professor in recognizing, for example, that your challenges with class attendance or staying awake are a symptom of your diagnosis, rather than a weakness as a student.

None of the academic adjustments identified below are “approved.” Academic adjustments are flexible on a case by case basis, and this guide is intended to list possible adjustments that may be helpful to the college student with idiopathic hypersomnia.

REQUESTS FOR ACADEMIC ADJUSTMENTS

ATTENTION/LEARNING DURING CLASS

Accessible Seating Location

- Near exit
- Near instructor
- Near front of room
- Permission to sit where student would create as little disruption as possible

Accessible Seating Type

- Standing desk
- Stand

Class Summaries (to ensure that loss of focus doesn't compromise understanding)

Note: Professors, GAs, and TAs are not required to recap the material with students. Some may provide that service during office hours, but it is not required. Many students with this chronic illness receive this assistance through tutoring services on college campuses; although many vocational rehabilitation agencies may provide personal tutors, that policy varies across states and agencies.

- Review instructions

- ___ Review class notes
- ___ Others:

Alternative Formatting of Learning Materials

- ___ Access to digital copies (class syllabus, professor's class notes, PowerPoint Presentations (PPPs), all writing assignments
- ___ Access to digital recordings of class lectures
- ___ Access to electronic textbooks
- ___ Others:

Prompts to Maintain Alertness

- ___ Access to Notes version of PPP during class (3 slides per page with areas for notes)
- ___ Redirect inconspicuously if inattentive, unfocused, or sleepy
- ___ Prod gently if needed at regular intervals to ensure alertness
- ___ Wake inconspicuously (as shown by student) if sleepy or asleep

Note: *Professors, GAs, and TAs are not required to perform prompts and, in most cases, don't. Some vocational rehabilitation agencies will provide personal aides to perform these functions, but that policy varies across states and agencies. It is at the professor's discretion whether to allow the student to designate a trusted classmate to perform this function.*

- ___ Allow discreet and non-disruptive movement during class
- ___ Allow discreet and non-disruptive breaks during class
- ___ Permit use of tactile object, such as a stress ball or fidgeting object, to ensure wakefulness
- ___ Permit beverages, gum chewing, and non-disruptive food consumption during class
- ___ Others:

ASSISTIVE TECHNOLOGY (AT) (Not available on all campuses)

Note: *Colleges are required to provide equal access to all learning materials via alternate formats. Although that sometimes can include assistive technology, there is no requirement to allow specific devices or software within the language of the law in the college setting. The requirement of creating equal access is attainable without AT. Some campuses have some of the AT listed below; others may have none. Students may need to purchase their own AT.*

See #4 *Guide to Academic Resources for College Students with IH* (Section3) for additional and detailed information about assistive technology:

<http://www.hypersomniafoundation.org/document/college-students-academic-resources>.

- ___ Access to live streaming

- ___ Permission to record classes, e.g., Sonocent notes, Live Scribe Pen, Audacity, audio recording feature of Microsoft Word, generic recording device, etc.
- ___ Access to dictation (speech-to-text) software for essay exams
- ___ Access to text-to-speech software (Note: most computers and tablets come with built in text-to-speech software)
- ___ Permission to use personal computer in-class, as well as access to a computer for essay exams
- ___ Permission to use dictation (speech-to-text) for essay exams
- ___ Permission to use own laptop in class (portable word processor and internet)
- ___ Alternative formatting for text books
 - Note:** *This is usually done through digital texts, which can be “read” to students through the use of text-to-speech software. There is always text to speech software built into the operating system of computers and Tablets, but there are better programs, such as Premier or Read and Write Gold, that provide more functions. And don’t forget Apps! There are plenty of Apps, such as Natural Reader and Voice Dream, that help students to read, write, study, create study guides, and read calculators.*
- ___ Access to word prediction software (built into iPads)
- ___ Others:

ASSIGNMENTS

- ___ Access to class lectures/presentations remotely, including PPPs, etc.
- ___ Access to assignments ahead of time
- ___ Access to class notes
- ___ Access to in-class materials following absences
- ___ Allowing early/front-end contributions to group projects
- ___ Option of non-participation in group projects
 - Note:** *This may be an option if the objective of the assignment can be met with an alternative assignment, but if group projects are tied into the learning outcomes of the course, this may not be an option.*
- ___ Others:

Structure for Timelines

- Note:** *College students are expected to develop their own time management plan. Professors, GAs, and TAs do not usually get involved with this. A Disability Service Provider may be a good resource for this.*
- ___ Short-term timelines for shorter sections of longer assignments
- ___ Checklists for long assignments and projects
- ___ Timelines for long assignments and projects
- ___ Flagging yet-to-be submitted work
- ___ Others:

Extended Time on Assignments

Note: All assignments have deadlines. Students with disabilities are expected to keep up with the pace and rigor of a college level course. Many colleges will not approve extended time on assignments. Everybody has emergencies, and students with this chronic illness are encouraged to reach out to professors in the event of a hospitalization that prohibits the completion of the assignment; however, each case is handled individually. This is a typical high school curriculum modification; however, when requested at the college level, it is often denied.

- Take-home quizzes
- Take-home exams
- Assignments
- Reading assignments
- Projects
- Others:

LEARNING ASSESSMENT

- Permit exam/quiz to be taken on a different day/time

Note: College students are expected to schedule exams at the same time as the rest of the class, unless the additional time they are entitled to runs into another class. In that case, the professors may require them to complete the exam before the next scheduled class.

- Permit verbal responses on exams/quizzes
- Extended time for quizzes, examinations, projects, etc.
- Others:

Alternative Assessment Methods

This section speaks to the teaching and assessment methods of the class. Most college professors maintain the academic freedom to choose which approaches and methods they use, though department or campus policies may also determine them. This is not a common academic adjustment, and being given it would depend on the professor's and the institution's policies.

- Portfolios
- Internships
- Field-based learning
- Capstone projects
- Course projects
- Faculty-created exams (e.g., instead of standardized tests, etc.)
- Others:

ATTENDANCE (Absences, Late Arrivals, Participation)

- ___ Provide additional excused absences
- ___ Provide some flexibility with arrival and attendance allowances
 - Note:** *In the event that absences and late arrivals create an inability for the student with this chronic disease to demonstrate an understanding of the material on learning assessments, a withdrawal may be necessary. The Disability Services Provider is a good resource for determining parameters and expectations for this academic adjustment and will generally act as liaison between the student and the professor if the student requests it.*
- ___ Permission to take breaks, especially if the class is long
 - Note:** *Students are still held responsible for the material covered in class during their absence(s).*
- ___ Others:

REQUESTS FOR CAMPUS SUPPORTS

This section identifies potential requests for administrative support and campus services.

REQUESTS FOR ADMINISTRATIVE SUPPORT

- ___ Access to on-going support by an Assistive Technology Specialist, Learning Disability Specialist, or Disability Service Provider/staff member
- ___ Class notes-provided (class note-taker is an academic adjustment)
 - Note:** *This adjustment may be provided by digital recorders, SmartPens, student note takers, notes posted to learning platforms by the professor, etc.*
- ___ Access to “early scheduling” to select classes when apt to be most alert
 - Note:** *All students are encouraged to register for classes as early as possible to maximize their options for available courses. This request differs from the usual procedure in that it would allow the student with IH to register with the group of students who are given first access to course registration.*
- ___ Permit flexibility in academic status, e.g., full-time, part-time, single course
- ___ Permit on-line class option if offered by own campus, campus in academic system, or by a campus having an articulation agreement with your campus.
- ___ Academic adjustments by way of an alternative class, project option, or an experience for a class required for graduation, if that class is offered only at a time when the student is not physically able to attend
- ___ Permit flexible use of the option of a grade of Incomplete to fulfill course requirements
- ___ Flexible access to faculty for advising, if physically not able to attend early morning advising hours

- ____ Student shall expect a response within a reasonable timeframe when the student informs a professor of or invokes requests for an academic adjustment. Unless otherwise specified by campus policies, the response should be within the first week of classes (when notification is at the beginning of the semester) and within 24 but no later than 48 hours (if an accommodation is invoked or the professor is notified of a change in accommodations during the term).
- ____ Student shall have the right to an appeal of any denial of accommodations through the institution's published grievance process.
- ____ Others:

REQUESTS FOR CAMPUS SERVICES

- ____ Access to parking space close to classes to prevent onset of fatigue due to the distance to class
 - Note:** *If the college is a public institution, it is required to provide accessible parking for people with disabilities. If the walk from a vehicle or bus stop to campus is unduly burdensome for the student, the student is encouraged to seek accommodations.*
- ____ Wellness checks by Residence Assistants (RAs) or Campus Security at family's request
- ____ Allowed to live in close proximity to a friend who can provide wake-up interventions when needed
- ____ Single room so that a roommate's schedule does not interfere with student's schedule and vice versa, e.g., so that the student can turn off all of the lights and take a nap from 2-7 p.m. without inconveniencing or being woken by a roommate
- ____ Campus living arrangement with access to a refrigerator and microwave oven, so there could be access to food 24/7 for when the student wakes after sleeping through dining hall hours
- ____ Others:

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

Date _____

Signatures:

Student _____

Physician _____

Medical Specialty _____

Medical Affiliation/Office _____

Contact Information _____

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