

#2 College Student Access: Physicians Can Make an Important Difference

The medical consultant to the college may not be well informed about the diagnosis of IH, so the diagnosing or treating physician's* input is **critical**. In order for physicians to **best support their college students with idiopathic hypersomnia (IH)**, the Hypersomnia Foundation recommends that physicians: (1) engage their college students with IH during every office visit about their symptoms and medications and how they affect academic performance and life on campus; and (2) be forthcoming in their correspondence with college personnel. Below are ways in which physicians can help patients with idiopathic hypersomnia.¹

During Office Visits, Discuss:

- **Functional Capacity:** Help patient articulate how **symptoms and medications affect academic performance and campus life** (e.g., "Tell me how your sleepiness/ability to stay focused is affecting you in classes, doing assignments, and on campus in general." "Tell me how your medications affect how you do your academic work.")
- **Academic Adjustments:** Initiate a discussion about how the patient is managing coursework (e.g., "Tell me what problems you are having with your academic work."). Ask about accommodations (i.e., academic adjustments) and what might be most helpful to ensure access to learning, including changes to current accommodations. (See #3 Guide to Requesting Academic Adjustments for College Students with Idiopathic Hypersomnia: <http://www.hypersomniafoundation.org/document/requesting-academic-adjustments-in-college>).
- **Medical Alerts:** Ensure patient is aware of available **medical alert options** (e.g., if patient experiences frequent automatic behaviors). These options now include medical alerts available on many smartphone lock screens, in addition to traditional alert bracelets or wallet cards. Campuses may request that students with IH carry such identification so that first responders who may find them sleeping and not very responsive understand what the medical issue is. For further information and to get HF's IH-specific card, see www.hypersomniafoundation.org/medical-alert-card.
- **Legal Consultation:** If appropriate, make referral (e.g., www.medical-legalpartnership.org).

When Communicating with College Personnel

The physicians' role is to **educate** and provide **input into the student's request for academic adjustments**, which could include **a letter**.¹ Serious problems can result for the student when college personnel** know little about this diagnosis, such as believing that students with IH have control over their symptoms and misinterpreting the students' behaviors as partying all night, not caring about academics, using drugs, etc. Specifically, physicians can help to:

- **Educate About Diagnosis and Symptoms:** IH in general, its effects on the patient in particular, and current treatment options, quality of life/functionality, etc. See www.hypersomniafoundation.org/treatment, www.hypersomniafoundation.org/healthcare-providers and *IH Characteristics and Diagnostic Criteria*: <http://www.hypersomniafoundation.org/IHSummary>.
- **Provide Safety Recommendations:** Make recommendations regarding the student's ability to safely participate in **potentially dangerous coursework**, such as in nursing, STEM, or psychology lab classes, sports, etc. (e.g., "My patient J.L. experiences frequent microsleeps that are currently uncontrolled by medication, so I recommend that this student not (do X) without close supervision.")

- **Describe Functional Limitations:** Note possible effects on attendance (absences, tardiness, need to leave class), participation in class and related activities (focused, engaged), and assignments (punctuality/volume in and outside of class). When describing the functional limitations, physicians may want to note the following in their letters:
 - That idiopathic hypersomnia is a central disorder of hypersomnolence, like its better-known cousin narcolepsy;
 - That symptoms and functional limitations of IH can vary across patients, with severity fluctuating and progressive downward trends, the latter resulting in reassessments for accommodations over time.
- **Make Recommendations:** Highlight the student's unique struggles with coursework and life on campus and recommend **specific academic adjustments** to best help the student access learning. See #3 *Guide to Requesting Academic Adjustments for College Students with Idiopathic Hypersomnia* (<http://www.hypersomniafoundation.org/document/requesting-academic-adjustments-in-college>) for a vetted list of possible academic adjustments, such as adaptive devices, assistive services, compensatory strategies, and/or collateral support services to help guide their choices. Academic adjustments requests should not fundamentally alter the basic nature or essential elements of an institution's courses or programs. Physicians are encouraged to especially note academic adjustments which have been successfully utilized by their students in the past or currently.
- **Write a Letter:** Physicians may be asked to write a letter supporting requests for academic adjustments. The following template may be used as a guide for that letter (it is intended to be cut and pasted to the physician's letterhead and completed/modified as they see fit):² <http://www.hypersomniafoundation.org/document/documentation-of-disability>. The physician's letter should include **verification of authenticity**, with an official clinic stamp, original letterhead, fax cover sheet, and/or equivalent.

* The term physician is used in this context to refer to the health care provider or medical practitioner authorized to diagnose and/or treat a patient with this diagnosis and sign off on related college forms.

** E.g., Disability Service Providers, Infirmary/Medical Staff, Administrators (Provosts, Vice Presidents of Student Affairs or Academic Affairs, Deans) Academic Advisers, Registrars, Admissions Advisers, Resident Life Managers, Campus First Responders, Campus Security/Police, Faculty, etc.

1 Flygare, J. (2016). Succeeding in school and in the workplace with narcolepsy. In Goswami, Thorpy, & Pandi-Perumal, (Eds.), *Narcolepsy: A Clinical Guide* (2nd ed.) (Pp. 395-405). New York: Springer.

2 Minnesota State University's Disability Documentation Guidelines (<http://www.mnsu.edu/access/current/guidelines.html>)

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

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