

#8 Tips for Supporters of College Students with Idiopathic Hypersomnia (IH)

This guide is intended to provide practical information, direction, and support to the parents, families, loved ones, and friends of college students with IH.

The Invisible Disability

"The term 'invisible disabilities' refers to symptoms such as debilitating pain, fatigue, dizziness, cognitive dysfunctions, brain injuries, learning differences and mental health disorders, as well as hearing and vision impairments. These are not always obvious to the onlooker, but can sometimes or always limit daily activities, range from mild challenges to severe limitations and vary from person to person. International Disability expert, Joni Eareckson Tada, explained it well when she told someone living with debilitating fatigue, 'People have such high expectations of folks like you [with invisible disabilities], like, "come on, get your act together" but they have such low expectations of folks like me in wheelchairs, as though it's expected that we can't do much' (Joni)."

Source: www.invisibledisabilities.org.

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GENERALLY SPEAKING¹

1. **Advocate for the Student.** Listen carefully to the student. Hear what they are saying. Guide them in advocating for themselves on campus, at the office of their primary care physician, and in the workplace.
2. **Make Sure It's the Right Physician.*** The physician needs to be willing to listen, support, and not discredit the experience the student describes, the symptoms that are affecting daily life, or the concerns expressed by the supporter. The physician's role in the student's life can be very important. Consequently, the physician needs to be provided with information about the diagnosis of IH. Refer the physician to the Foundation's website (<http://www.hypersomniafoundation.org/healthcare-providers>) and the following two documents:

Idiopathic Hypersomnia Characteristics and Diagnostic Criteria
<http://www.hypersomniafoundation.org/IHSummary>

and #2 *College Student Access: Physicians Can Make an Important Difference*
<http://www.hypersomniafoundation.org/document/physicians-guide-to-college-student-access>

If the current physician is not respectful of the symptoms, supportive of the student, and committed to an accurate diagnosis, find a new doctor!

3. **Consider Services Beyond Campus.** There are off-campus services that can help the college student with idiopathic hypersomnia. For example, because IH is a recognized disability, your state rehabilitation services office may arrange for a vocational counselor. The office provides supportive services to the student through all levels of schooling and through their career paths, including some services not provided on campus under ADA law. For example, campuses are not required to provide personal coaches or personal aides, but vocational rehabilitation offices may provide such services. The link below provides a list of your state's rehabilitation offices where you can find information to learn about, explore, and request services for the student.

<http://www.fda.gov/downloads/AboutFDA/WorkingatFDA/UCM277757.pdf>

4. **Be informed and Use IH Resources.** You and the student are not alone. Idiopathic hypersomnia is not a behavioral issue, and it's not something that can be fixed with a magic wand. This is a neurological medical condition that your student cannot help and needs support to manage.

- Sign up for the Hypersomnia Foundation's **SomnusNooze** newsletter and read past editions at www.hypersomniafoundation.org.
- Spend time on the **Hypersomnia Foundation** website to learn more about idiopathic hypersomnia.
- Participate in Hypersomnia Foundation events.
- Join support groups. Contact *Hypersomnia Alliance* (<https://www.hypersomniaalliance.com/> or <https://www.facebook.com/HypersomniaAlliance/>). This group encourages support and awareness through local and online groups and offers support retreats.

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MORE SPECIFICALLY²

5. **Stay Calm, and Be Supportive!** Help your student accept and adjust to their *current* symptoms.
6. **Choice of Campus Can Matter.** If it's possible to have a choice between campuses, then consider these factors:
 - **A campus where the living is "easier"** from the student's perspective, e.g., seasons, weather, campus layout (flat vs. hilly), access to personal necessities

after hours, transportation options, ease of parking if driving or being driven, etc.

- **A campus with availability of and accessibility to food at night** after the student wakes from long naps. For example, find out the operating hours of the dining halls on campus and access to them during late hours (**Alert:** possible campus safety and transportation issues). Encourage the student to seek an accommodation for living quarters that allows access to compact refrigerator and/or microwave oven in the room.
- **A campus with a flexible institutional culture and an advocacy approach used by the office providing disability services** (see #1 *Student Guide to Thinking About Academic Adjustments*, entry 11: Completion-Based Challenges—<http://www.hypersomniafoundation.org/document/guide-to-thinking-about-accommodations>).

7. Help the Student Strategize Daily Life on Campus

- **Accept** that others won't necessarily understand the student's symptoms—peers, faculty, administrators, accessibility services, campus staff, public safety or first responders.
- **Understand** their symptoms. For example, is the student a long sleeper? Does the student need naps during day? If so, are they predictable? Does the student often sleep through dinnertime and wake at 11PM famished, with no food in sight or available on campus? Does the student experience "brain fog" or "sleep drunkenness"?
- **Check in** about the strategies the student is using, how they are being managed (e.g., powering through or relying on friends to wake or for assignments), and what types of help they need.
- **Talk through and support** potential academic strategies with the student. For example, discuss the possibility of dropping a class, changing status from full-time to part-time student, requesting an Incomplete grade, joining a campus community group, seeking counseling for coping strategies, or checking in with the office providing disability services on a regular basis, etc.
- **Encourage the student** to choose an academic major and a campus that will work for them and for you. The choice of major must be worth what the student will go through to graduate.
- **Look into costs** associated with taking classes in summer and winter intercession semesters to reduce the student's course load during the academic year. Discuss options with the office that oversees those course schedules and determine whether those classes can be incorporated into the student's course-load during the traditional academic year and without additional costs.

8. Be Proactive in Developing Security Checks

- **Supporters feel a lot more confident** when the students demonstrate an ability to keep themselves safe. Otherwise, the supporters worry on a daily basis until they hear back after trying to make contact.
- **Find ways to monitor wellness and safety.** If living on campus, the students' dorm-mates could be contacted for a wellness check, although caution is advised not to pressure them inadvertently to "take care of" the student. Another option is to ask for the contact information of the dorm's Resident Assistant (RA) and reach out to the RA if you are concerned after not hearing from the student for some time. Many found it easier to determine the student's safety when living off-campus through friends. Friends tend to be more receptive than dorm-mates to being contacted for wellness checks. The dean's office overseeing student affairs, the disability services staff, and the campus police department can suggest available options on campus for wellness checks, as well as reputable, safe off-campus services for hire.
- **Check the smoke detectors** in the student's living quarters!
- **Make getting to campus less of an ordeal.** A major source of anxiety for supporters is the student driving an automobile to and from class. Additionally, once the student arrives on campus, a long walk to class can result in exhaustion or sleepiness. Encourage the student to seek an accommodation for accessible parking on campus if walking from the parking lots (or a bus stop) is unduly tiring, and set up your own system (e.g., a text, IM) to reassure you of safe arrivals. This also reassures the student that you are there for them and will know if something goes awry en route to campus or to their living quarters.

9. Keep in Mind That...

- **An invisible disability** such as idiopathic hypersomnia needs additional support and understanding from family, loved ones, and the staff providing disability services.
- **A cooperative mindset** on the part of supporters and campus personnel is the best fit for a student with idiopathic hypersomnia.
- **Presumptions** that faculty and disabilities services staff communicate frequently or effectively with each other may be erroneous. They may not connect at all.
- **A sense of community on-campus** can be empowering for all students, especially for those diagnosed with idiopathic hypersomnia. Encourage connections with others with whom the student has something in common.
- **Alternate transportation** to living quarters may be needed after a long or sleepy day (or night) on campus to ensure that the student doesn't sleep through the usual drop-off stop. The student may need help arranging this.

- **Requests for individual meetings** at the beginning of each semester between the student, disability services, and professors may be needed. *This is something the student must request. It won't happen otherwise.*
- **Request a letter** at the beginning of each semester be sent from the office providing disability services to faculty. This is strongly advised by supporters and students. *This is something the student must request. It won't happen otherwise.* The letter needs to note that the student may sleep during class, be late to class, not attend class, not be able to participate in class discussions or activities, or be late with assignments and that these behaviors are *consequences* of the symptoms of idiopathic hypersomnia, are *uncontrollable*, and *unpredictable*.

See #6 *Tips for College Students with Idiopathic Hypersomnia*

<http://www.hypersomniafoundation.org/document/tips-for-college-students-with-ih>

and #1 *Student Guide to Thinking About Academic Adjustments*

<http://www.hypersomniafoundation.org/document/guide-to-thinking-about-accommodations>

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ADDITIONAL CONSIDERATIONS³

10. Be informed about the *Education Essentials Program for College Students with Idiopathic Hypersomnia*

#1 *Student Guide to Thinking About Academic Adjustment*

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

#3 *Guide to Requesting Academic Adjustments for College Students with IH*

#4 *Guide to Academic Resources for College Students with Idiopathic Hypersomnia*

#5 *Advice from College Administrators, Faculty, and Disability Service Providers*

#6 *Tips for College Students with Idiopathic Hypersomnia*

#7 *In Their Own Voices*

#8 *Tips for Supporters of College Students with Idiopathic Hypersomnia*

#9 *Resources for College Students with Idiopathic Hypersomnia and Their Supporters*

11. **Be Informed About Medical Alert Safety Resources:** Supporters and students are advised to be aware of available medical alert options, which now include medical alerts available on many smartphone lock screens, in addition to traditional alert bracelets or wallet cards. Some campuses may require them so that if first responders or campus police are called to assist a student with IH, the student is not

treated for another medical condition with similar symptoms. (See #9 Resources for College Students with IH and Their Supporters, SAFETY MEASURES: <http://www.hypersomniafoundation.org/document/resources-for-college>).

12. **Encourage Health Services/Infirmary Contact:** The office of the campus medical practitioner(s) is located at the college infirmary/hospital or in health services. The student with IH is encouraged to:

(1) inform that office of their diagnosis and of their needs on campus and in class settings at the same time they inform the office providing services to those with disabilities

(2) provide information about the diagnosis, specifically the following:

- the Foundation's website www.hypersomniafoundation.org
- the document *Idiopathic Hypersomnia Characteristics and Diagnostic Criteria* <http://www.hypersomniafoundation.org/IHSummary>
- the *Education Essentials Directory of Guides for College Students with IH:* <http://www.hypersomniafoundation.org/ed-essentials>

(3) give permission for that office to provide medical information as needed to first responders and campus police, the offices of the Deans, and the disability services office

13. **Encourage Student to “Test Out of” Classes:** Many colleges, though not all, allow students to take examinations for course credit. For more information, see #4 *Guide to Academic Resources for College Students with IH* and/or #9 *Resources for College Students with IH and Their Supporters*.

14. **Encourage Working Ahead of Time.** As energy levels allow, encourage student to read, prepare assignments, and invest time in the work ahead of time. “Banking” is how one student described putting in extra hours during an internship for days when the student couldn’t be at the site.

15. **Read This Open Letter to Parents from Jane Jarrow**

https://www.pratt.edu/uploads/6445-open_letter_to_parents.pdf

Dr. Jane Jarrow is a widely-recognized authority on disability issues in higher education. She consults to universities and colleges on matters of accommodations and support for students with disabilities. She is the mother of a college student with disabilities. (Source: Pratt Institute)

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* The term physician is 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 **Generally Speaking:** Contributions by parents/supporters who were featured in the Hypersomnia Foundation *SnoozeTV* broadcasts (2015) or attended the 2015 Hypersomnia Foundation Conference, Atlanta

2 **More Specifically:** Contributions by parents/supporters who participated in the *Higher Ed Conversations Project*, an initiative created by the Hypersomnia Foundation to identify relevant academic adjustments for college students with idiopathic hypersomnia (IH)

3 **Additional Considerations:** Contributions by the Board of Directors (2017), Hypersomnia Foundation

**Approved by Hypersomnia Foundation Board of Directors and Education Legal Counsel.
Vetted by supporter participants in the *Higher Ed Conversations Project*.**

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