

#7 In Their Own Voices

This guide is one of personal stories shared by college students, including some who participated in the Higher Ed Conversations Project. Some graduated from college, some “stopped out” for a while, and others dropped out of college. The stories were written intentionally by them in the hope of informing your college experience in ways that make a difference. These students are pioneers in their own right, never having had the opportunity to learn or hear from other college students with IH.

The Hypersomnia Foundation is providing these stories as information, and in so doing, the publication of these stories should not be interpreted as endorsing the viewpoints of the students.

Student Life with IH

The onset of idiopathic hypersomnia hit me during the second semester of my freshman year and, for better or worse, shaped my college experience from then on. There were many ups and downs and numerous misdiagnoses before finally landing on IH 2 years after its onset. During that time I was constantly negotiating with teachers about what I could complete, deadlines that could be more flexible and allowances that could be made because of my mysterious illness. It was only after withdrawing from school, staying home a semester, and then getting the IH diagnosis that I started coordinating with the ADA office on campus. In the end I graduated with honors in four years. Looking back I do not know how I did it but one thing is for certain, I would not have been able to make it through college without accommodations and the support I received from understanding professors.

One of my greatest concerns when I got sick was that I would be penalized for the things that were now out of my control. A very major part of the accommodations that I received was flexibility on class attendance and making sure that I was able to get the class materials and assignments remotely. Some of my professors did not fully understand that my absence was not a result of my choices as it was with other students and the accommodation letter truly helped on that front.

One of the major things about the experience of a student with IH, and living with IH in general, is the uncertainty. Not knowing when you will be able to wake up or how much energy you will have when you do constantly affects your ability to plan anything. During my college years, there was always that moment when I woke up and had to tally up what I missed and take an inventory of what was left to be done. Needless to say, adhering to a schedule when your body has other plans is a losing battle. All of this is not to say that attending classes cannot be done, but for many of us attending every single class is not a realistic expectation, especially morning classes.

The fatigue that we experience during our waking hours presents its own set of challenges. Fighting to stay awake during class and being alert enough to be attentive and productive often takes more energy than we have in our reserves. Sometimes that manifests by simply slowing us down so that it takes longer to complete a task. At other

times it prevents us from focusing on a page or a screen and comes paired with a headache. Each of these is quite prohibitive when it comes to completing work in a tight time frame.

This extends beyond academics to everyday tasks, when energy is low you have to budget it so the amount of things that you can accomplish in a day gets severely limited. Going to the bathroom or to the kitchen to feed yourself become monumental tasks that require the use of all the energy you have to give so your to-do list goes to the wayside. On campus eating is an even bigger challenge especially if you are not awake when the cafeterias are open.

Because this illness is hard to see in the moments that we are alert (or skillfully faking alertness) and even harder for others to distinguish from their own tiredness having the accommodations letter was truly key in reaching an understanding with teachers unfamiliar with true fatigue.

Undiagnosed IH and College

I was undiagnosed in college. The most important thing that I did in order to graduate on time was communicate with people, friends, professors, and classmates. I took the time to get to know a handful of people and let them get to know me. This built relationships and trust which went a long way at a small school.

When I did somewhat disruptive things, like set my alarm early with the optimism that I would actually wake up and snoozed it 25 times, my roommates (and neighbors, the walls were pretty thin) would be annoyed, but I think they learned to live with it because they cared about me. They didn't necessarily "know" me considering I had just met them at college, but the human connection that I had with them seems to have made my "quirks" tolerable.

I unfortunately had an 8:30am class one semester. The professor was strict, and there was a penalty on your grade for being late more than three times. I was late more often than not, but I spoke with my professor candidly, and simply apologized and let him know that I wasn't trying to be disruptive or disrespectful.

No one knew that I had a legitimate debilitating condition at the time (not even me!). I've taken some time to reflect on my experience with school, and I believe that making it clear to people that were depending on me that my intentions were good and being sincere was the key to graduating.

College & Hypersomnia

As my high school senior year ended, the anticipation of college grew. I would listen to my peers as their excitement grew. College, the first step in adulthood and independence. Making your own choices and selecting your own schedules. Living life to the fullest, while working hard on your education. For me, newly diagnosed with hypersomnia but suffering for years, I had a different focus. When was I going to nap? How can I get through an entire day of school, complete homework, a part-time job and then socialize with friends? I had a routine, I went to high school, rushed home to sleep,

woke up for a bit and slept the night away. I was able to get through teenage life being a slave to my sleep needs.

My concern and anxiety were well founded. College life was not a friend to my sleep disorder. Each day of college was a challenge. Not only fighting my extreme need to sleep but how to function with debilitating brain fog. College professors and administrators were uneducated on what hypersomnia was and how it affected a student. I was on my own to find a way to navigate college life. It was difficult, but I did it. Attendance was a struggle. Both sleep and doctor appointments kept me away from classes often.

Without a visible physical disability or one that is commonly understood, it is very hard to receive accommodations and understanding by college administrators, even with a doctor's note. Once they heard "hypersomnia" their reaction was "we are all sleepy" and the conversation was over along with the willingness to understand the illness.

With support from family and understanding friends, I was able to complete college.

Adjustments in College: *Academic and Personal*

By Olivia Robbins, BA*

Academic Adjustments

- **Working with the Office of Student Services** (*i.e., office providing disability services on this student's campus*)
 - Allowed to make up tests and examinations when absent from class
 - Extended time to hand in assignments
 - Copies of notes, lectures and PowerPoint presentations
 - Excused absences (this varied based by professor/course and what was deemed 'reasonable')
 - When I had especially long bouts of sleep, the office of student services would send out a letter to my professors that officially covered the affected dates
 - Priority registration for classes so that I could better craft a schedule more agreeable with my sleep schedule
 - When I needed to adjust my schedule, the office of student services would provide a letter to help facilitate the change
- **Working with the Professors**
 - For many of my classes, the work produced and the testing became the bases of my grades instead of weighing class participation and attendance
 - I coordinated Incomplete grade statuses and guidelines for the completion of those grades directly with the professors

Personal Adjustments

- **For Academic Work**
 - In group projects, I made sure to have my contribution on the front end of the projects and then helped out when I could later in the project

- I broke down large projects into smaller pieces and gave myself mini deadlines for each piece
 - My personal deadline was before the actual due date, still it did not always work with my sleep
- I looked ahead in the curricula and did as much reading or prep work as I could ahead of time when I was awake
 - This minimized the feeling of having to play catch-up after sleep would take over but was not always possible
- I tested out of as many campus requirements as possible (math courses and foreign languages) so that I would not have to take extra courses
- **For Campus Living**
 - Having a large amount of cooked food that I could warm up in smaller portions so that I did not have to worry about being awake during a specific time or having to cook
 - Having places on campus where I could sleep and feel safe
 - For one year I had both on-campus and off-campus housing
 - Napping in a friends' room worked out sometimes
 - Napping in the building where I had many of my classes also happened often (pretty normal for architecture students, so I lucked out there)"

**Olivia Robbins, BA, was a participant on the panel Turning Hope into Success: The Journeys of Two Graduates at the 2017 Hypersomnia Foundation Regional Conference, Boston, MA.*

Approved by the Hypersomnia Foundation Board of Directors and Education Legal Counsel

Last Updated: 7.5.20

Copyright © 2017 Hypersomnia Foundation, All rights reserved.