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A Disease of Dignity

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From my old report cards I know I overslept and missed the bus fifty-eight times in my junior and senior years of high school. It got to where I bought five alarm clocks, including one old-timey one with twin bells and the little hammer between them, because Amazon advertised it as exceptionally loud. One Amazon review said the clock woke the reviewer's 90-year-old grandfather, who had hearing problems. Another reviewer wrote, "This alarm will wake the dead!"

It never woke me, though. Sometimes I'd wake up two or three hours after my five alarm clocks had gone off. I'd reset my alarms, realize I was beyond late for school, then hate myself as much as I'd ever hated anyone. Then I'd sneak into my closet and go back to sleep. I'd lay out my blankets and pillows on the closet floor, curl up my body, knees to my chest, and close the closet door. I'd doze off two feet under my jackets' sleeves and jeans' legs, as comfortable as I could be. When my mother came home from working the graveyard shift, she'd think I was gone. Then I'd wake up at



whatever time in the afternoon, after my mother had already gone to sleep herself.

I was always tired. When I did make it to school, I'd fall asleep, head on desk, in most classes. I'd stumble off the school bus steps around 3:00 P.M., drop onto the bed or couch or floor, and wake up around eight or nine or ten the next morning. I sucked down coffee, a taste I hated. I downed energy drinks and energy shots until I shook. Then I bought pure caffeine on the internet to mix into everything I drank. But I still slept entire days away.

I chalked it up to my workload, at first. I had taken ten Advanced Placement (AP) classes and played two sports. My grades had put me at the top of my class in sophomore year, though that class rank plummeted by the end of the next. I had always been academically successful, moving up classes, skipping a grade. Even with my sleeping problems, I would graduate high school at sixteen, so part of me figured daily exhaustion was par for this course.

My voice lowered and became monotone, and my gait slowed. I lost weight, because I ate only once every two or three days, and I wore the same clothes, dusty gray thermals with fat wool socks, for weeks without showering. No one who noticed, no teacher, classmate nor coach, neither my mother nor any other family member, ever asked me, "Are you alright?". No one inquired about my health or suggested I see a doctor. Instead, I heard jokes, rumors, and accusations, even from my mother, that I must be skipping school on purpose.



Maybe I just wanted to lounge around all day, suggested my AP Chemistry teacher.

Or maybe I was on drugs. I mentioned to my AP Biology teacher how tired I was. He scoffed, “You’re clearly smoking a lot of weed.”

The vice-principal called me down to her office to discuss my absences. I explained that I felt tired all the time. She said, “Look, I know it’s hard to get up in the morning, but we’re all tired.”

When I confided my exhaustion to my mother, she said, “You’re just lazy.”

Little bits of me still showed up in standardized tests, even though my grades tanked. I could cut through a two-hour-long AP test, even if I couldn’t function for a seven-hour school day. They gave me awards: National Merit Scholar, AP Scholar with Distinction. I had 99th percentile SAT scores. Some schools mailed me offers of full scholarships, despite my grades. I was approached by faraway schools—Florida State, UC San Diego— and I received a generous offer with a foreign travel stipend and a free iPad from the University of Arizona.

I accepted their offer. Coming from chillier New Jersey, I figured the sizzling Tucson sun would spark me awake. But at the U of A, my sleep trouble persisted. I overslept entire days of classes. Then I started to wake up nervous. In my dorm room I had little breakdowns, feelings like bones snapping, when I shot up every morning to check the clock. Was it 6:00 a.m., 8:00 a.m., 2:00 p.m.? Would I trudge to class, exhausted enough to cry, or silently hate myself for waking up too



late? If I saw something like 6:15 on the clock, my brain zapped itself. I refocused my eyes to see whether it was A.M. or P.M. I couldn't trust what day's half I woke up in.

Again I showered as if they were rationing water. I bought a burger maybe once every other day as my only food. My classmates, high-achievers in the U of A's Honors College, gave me funny looks and passive-aggressive insults. Angel from down the hall twisted his face and spoke slowly to me, to mock how distant I was, how detached, stupid, or high I must have seemed. After my second semester, the university rescinded my scholarship. I failed my favorite class, a senior-level honors psychology seminar that my adviser had recommended me for as a freshman. My professor wrote me a thousand-word email, describing how "unmotivated" I seemed, how my "priorities seemed to be elsewhere". After I'd had three poor semesters and a 10-day trip to the psychiatric ward, my mother bought me a plane ticket back to New Jersey.

For the next three years, I bounced from therapist to therapist for depression and anxiety. These people, who were always old, foreign to me, and soft-spoken, laid it out: it's problem with serotonin, obviously, or dopamine. No one mentioned sleeping too much as its own disease, but they were right about the mood disorders. I had gotten into cutting my arm with razors and, after I came back from Arizona, attempted suicide, hanging myself with a belt until I lost consciousness. Then the belt gave and I woke up, as usual, in a daze.



Every therapist I met said it must be due to my depression. If I could patch my mental state, then I would smooth over my sleeping problems. However, even in spots where my depression improved, when I felt motivated enough to work or return to Arizona, I still averaged almost sixteen hours a day asleep.

In January 2014, my primary physician referred me to a new psychiatrist. However, I was certain my problems originated in my sleep, rather than my mental outlook. I had been reading about different kinds of brain problems, including injuries that could lead to sleeping all the time. So I called my physician's office and finagled a referral to another specialist, a neurologist. After two appointments, this neurologist, recommended three sleep studies. One of these was a polysomnography, an overnight sleep study. My mother drove me to the sleep lab. A technician fitted me with electrodes and a finger pulse monitor, and ran through what must have been his usual "It might be hard to sleep in a new place" speech. I zonked out in their bed before I knew it.

Most adults spend about twenty percent of their sleep in the REM stage, the deepest stage, where most dreaming occurs. The healthy range is seventeen to twenty-three percent. If you wake up during REM sleep and need more, you might enter "REM rebound" next time, where you fall into REM sleep faster than normal. REM rebound is evidence of how biologically important REM sleep is; it's necessary for cognitive function. My polysomnogram, the charted result of my



polysomnography, told me I only spent 4.8 percent of my sleep in the REM stage. My body delayed entering REM sleep for more than three hours after I had fallen asleep. The neurologist suggested that my sleep failed to restore me, as if I were constantly sleep deprived even after being out for twelve or more hours. The neurologist and the testing physician who ran the polysomnography both agreed with a diagnosis of a rare sleep disorder called “idiopathic hypersomnia”.

Hypersomnia is sleeping too much, the opposite of insomnia, and idiopathic means there is no known cause. Idiopathic hypersomnia has an estimated prevalence of one in twenty thousand. Remission occurs in about ten to fifteen percent of cases. The hypersomnia remained regardless of the medications I was taking. I had no history of head injury or anything else that might have caused excessive sleeping. There was some strange neurology, something interfering with my sleep. But there was nothing we could find as a cause.

There’s no FDA-approved treatment, so my physicians and I went through off-label medications by the boatload. They prescribed antidepressants: citalopram, escitalopram, bupropion. Then there were stimulants: modafinil, armodafinil, and Adderall. I didn’t feel anything from the first two, and the Adderall gave me headaches that felt like little buzzings, or beads of sand whishing around my brain. There was lorazepam, because I also had panic attacks, and levothyroxine, to increase my levels of thyroid hormone, even though my tested levels were within normal range. I contin-



ued to see therapists for depression and anxiety, trying to fight the two-fronted battle. I wore down my mental gears more, fighting sleep problems and mood problems, with therapists, psychiatrists, and neurologists. I wanted all the tools, weapons, and resources I could gather. There's still, on top of my dresser, a sheet of sleep hygiene "tips and tricks", describing how I should force myself to sleep at certain times, wake up at the same time every morning, and not use my bed for anything other than sleeping or sex. But this was advice for a person whose problem originated in behavior, not neurology. I could sleep at almost any time, anywhere, in cars, or on park benches like a bum. It had been a joke in school that I could sleep standing up, just leaning on walls in the hallway. Waking up at the same time every morning was impossible as far as I could tell, because I had always slept through every alarm clock. My mother even put ice cubes down my shirt once to wake me up. She told me later that I had screamed and knocked the ice out my shirt, and that I screamed so loudly that she would never wake me up again, not for anything. She'd rather just let me sleep.

She still wanted me to be active, however. My single mother had grown up poor and angry in the ghetto, in Atlantic City, and had fended for herself for most of her life. When I asked her for food money, she told me, "Don't come asking me for money. I'm not giving you anything other than a room, and you should be grateful I'm giving you that at all." So I needed to work for my own



money, pay my bills, buy my food. For my part, I also ached to work. I saw being able to work full-time as a measure of functionality. If I could get up, shower, get dressed, and work for eight hours a day, without passing out the second I got home, then I would be healthy enough to return to university studies. From 2013 to 2016, I took on and lost more jobs than I can remember. I worked for two Walmarts, five pizzerias, a shoe store, a flower shop, a bookstore, a gutter repair contractor, a flag football league, and more. I lost all of these jobs, except one, due to oversleeping. I overslept some shifts entirely. The shoe store manager, who lived nearby, offered to give me a ride to work. On the first day he stopped by, I slept until noon and woke up with five missed calls and seven text messages. He had pulled up to the house, honked his horn, knocked, called, and texted me on my unmuted, full-volume phone. I snoozed through the whole thing.

I tried to mitigate my shame by being obsessive about the time I spent asleep. I recorded every hour I spend in any activity on an Excel spreadsheet. I recorded the times I fell asleep and woke up, in an effort to keep them consistent. I wrote down times on sticky notes, and later typed them in Excel. I recorded the times I spent working or looking for work, reading and studying, going to the gym, and so on. Sleep dominated, with an average of 13.9 hours a day spent asleep. After three months with no change, I slipped into another stay-at-home depression.



My mother berated me, in some way she thought was galvanizing, about how “worthless” and “useless” I was becoming. When that effort failed, she kicked me out the house, an attempt at “tough love”, to motivate me into keeping a job. I spent four months on friends’ couches, then the county homeless shelter, then the psych ward again, before my mother took me back in. I was crippled, non-functional. I spun into a mental cycle of fear, embarrassment, anger, and self-loathing over both my inability to do anything and the abandonment I felt from people I had believed were my support. My mother, I figured, only kept me because she was obliged. She gave me a room, because she couldn’t have people calling her a terrible person if I wound up homeless again.

Then my hypersomnia went away. I don’t have an explanation of how it improved. I didn’t change my diet or start taking a miracle plant extract. I just started sleeping less.

I remember the first week I spent sleeping fewer than ten hours every day. It was the last week of April, 2017. On May 2, I slept nine hours, a cool nine, like a normal person, not twelve or sixteen or twenty. Then on May 3, I slept eight hours. When I woke up, I felt fine, not tired, not dazed, not in a weird stupor like before, where I’d be falling over if I managed to wake up with this little sleep. That afternoon, I realized something was up, and I started jotting down my hours again.



It was just sleep, but that week I was on a roll. Every night gave me a restful eight or nine hours, without an alarm, without any drugs. And when I did set an alarm, it actually woke me. Then a week of normal sleep spun into a month. That summer, I found a job working at a local tennis center, attending to the courts and teaching tennis (I had played the sport competitively). I was late to work a few times, but I never had a problem with staying awake or with oversleeping entire days.

My improved sleep transformed my health. I took care of the normal things, showered, and ate at regular times. I gained healthy weight. I stopped having panic attacks. My hypersomnia diminished spontaneously. It was a downright miracle.

Now I'm 23, picking up my life where I dropped it at 19. My social network died: No one has kept in touch with me from high school or from Arizona. My frozen academic life is thawing out through community college classes.

My old depression has left, but now a new one comes when I think of how many people judged me as being stupid or lazy or drugged out. If I had not been my own advocate, and insisted on seeing a neurologist who brought up sleep studies, I have little doubt I would have ended my life. The anguish of being teased at school and reviled by my mother, the lack of support I needed at such a vulnerable time was closer to killing me than hypersomnia ever had. And though I'm still getting along, working and studying, something has left me. The people closest to me accused me of being a lazy, stupid person who probably smokes a lot of



weed, with the same blind, mobbing ostracism as if they had accused me of committing a robbery. Because of that, I lost a trust in people in the same manner as a person wrongfully convicted of a crime. I might sleep well now, but I think I'd feel most rested if I could ever find people to rebuild that trust.

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