
I Need a Nap: Living with Idiopathic Hypersomnia in Sleepless Capitalism

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Abstract

This work of creative non-fiction makes use of auto-theory and personal journaling to unpack my experience of living with idiopathic hypersomnia in a hyperproductive capitalist context. My discussions are undergirded by my frustration that I must depend upon the medicalization of my body and products of capitalist pharmaceutical corporations to function. I centre my experiences around my reality as a graduate student. Success in academia requires a gross output of ideas beyond the grasp of many folk who live with various chronic conditions. Using affect theory, queer crip studies, queer phenomenology, and temporality, I meander through the ever-present burden of existing in a tired body with the yearning to change (destroy) a system that already makes us *all* feel far too tired.

Keywords

idiopathic hypersomnia, queer theory, crip theory, embodiment, affect theory, autotheory, creative non-fiction

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I have taken to getting up and staying out of bed once Margot's squeaky meow wakes me, usually around 6:30am or 7:00am. She's a hungry gal and it's breakfast time. If I don't shake out my limbs and walk around my apartment, I'll go right back to sleep. Some days, I feed Margot in a fog and return to bed: later, I check her bowl and my brain to recall if I have already gotten up that morning, noticing I have slept through at least four alarms.

I am learning to enjoy the mornings. Things still a little quiet, dew on the grass. With the prompting of my psychiatrist I have made a full list of morning activities I can do to keep me awake: a morning crossword puzzle, light tidying, sitting outside with coffee when it's warm out. Other days, I just make my bed and shift my tired body to a chair in the corner of my living room. Sometimes I start a crossword there. Often, I doze off again, for a few hours. This time with my neck a little craned in the dusty orange upholstery.

People like to comment on exhaustion:

you got how many hours of sleep?

last night I got (less/more) because
I (was working/haven't slept in weeks)

I am also *so exhausted* because
I have been *so busy*.

Etc., etc.

What about when I am so tired after days of doing nothing? It is not the *noble* pursuit of productivity but the blanket of lethargy that wraps me up tight. It is not the badge of honor worn only after burning ourselves out. 'Idiopathic' means 'we don't really know why,' and 'hypersomnia' means excessive sleepiness (Khan & Trotti, 2015). And, because these words form a 'diagnosis' given to me by a doctor, it is a thing I can point to and say *that's why I am so tired* (still without knowing really why). This diagnosis follows me into my career as a graduate student; it shapes my every move.

A professor discussing how to translate a PhD into the "non-academic" world once said how all work we do during graduate school should be directly related to our career goals. Another professor, after hearing I had been spending a lot of time working at my restaurant job lamented: "that's too bad, I wish you were working more on your *own* work."

Underlying this comment is the presumption that this is a simple choice. But academia does not privilege those short on time, energy, or money. It does not privilege those who cannot use every bit of their energy to produce, produce, produce (or, publish, publish, publish).

The comment suggests it is as if those summers I had spent lugging around jugs of chlorine at the swimming pool store was a purposeful, enjoyable, choice—while my middle-class peers were gallivanting from conference to conference, bulking up their CVs, making connections, starting new projects (I cringe and boil a little thinking back on the customer who—having pried into my personal life because a pool store worker is no career fit for a 'lady'—asked me if I was doing my PhD to find my husband).

As if coming home from nine-hour workdays to slump into my bed and sleep through my alarms most mornings was the career-building opportunity I had sought.

As if even the four-hour shifts at the fancy Italian restaurant, pretending to be a little straight to the hetero couples so I could try to earn tips while ignoring my co-workers' casual homophobia, was my idea of a relax and recharge, ready to dive back into theory upon returning home sweaty and smelling like old pasta.

(it wasn't how the professor meant it, but these jobs did turn out to be directly related to my research)

Our survival depends on capital (I write, as if that's news). And, we need to produce to earn money. You should be publishing in your undergrad to make it, we're told (but only in *prestigious* journals, of course). At least in your Master's. Regardless of your class status and the directly related student-debt accrued and lack of savings... *Publish or perish, publish or perish.*

I once let it slip to a new friend, despite trying to avoid the subject completely: I am feeling pretty tired today.

You're tired? That's me. I'm the one always tired. You're not allowed to feel tired.

Oh, okay.

I can't recall if I had told this friend about my idiopathic hypersomnia yet. But another time, after I am sure I had, she says to me on a particularly groggy day: how are you still tired from camping? (I camped for one night and I had to take two whole days to recover, I could have used three, but time is money, and I couldn't afford it).

It's not 'funny' that we are all tired. Not ha-ha. Not in a strange or coincidental way. It's purposeful. Once, in a graduate paper, I referenced a sentiment from Sarah Ahmed in a tweet that is no longer available. I stumbled upon a phrase with a similar intent in her online blog:

Exhaustion as a management technique: you tire people out so they are too tired to address what makes them too tired (Ahmed, May 30, 2018).

This paper talked about my queer and clumsy body. Still queer, and heavy limbs still clumsy. I used to write a lot about my clumsy body moving through the structure of academia. I appear able-bodied. Indeed, taking up crip theory feels tenuous to me. Is it really mine? I keep googling whether or not "idiopathic hypersomnia" is a disability. Is it an illness? A chronic condition? Why do I take Ritalin for it every single day, and still feel too tired to keep up with all of this required *output*?

Publish or perish, publish or perish or publish or perish or

Within the past year I have managed some sort of normalcy, I suppose. It has included serious sleep-hygiene. Only books before bed. Phone out of my room, far enough to have to walk to turn off the alarm, but not too far where I can't hear it. Lots of coffee. But not too late in the day. Morning work-outs (*trying not to spend too much time equating working-out with disordered eating habits*

and body dysmorphia, letting that thought come and go, or linger in the background again, whistling, waiting for its turn to come up the next morning when I then feel too groggy to go for my run). Sit on the uncomfortable loveseat if I want to watch any TV before bed (fall asleep with my back crunched again anyway). Great. Now I can wake up with my cat and choose from any of the list of activities I can do so that I don't fall back asleep. *Seven hours is not enough. Eleven is not enough. Nine, six, five, fourteen.*

I keep thinking it is not a disability because I am not registered with disability services at my institution. Because people tell each other everyday just how exhausted they are. And look at me, I've managed a decent routine. I think this while knowing that the concept of "disability" is shifting and contested (Kafer, 2013, p. 20). The medicalization of bodies is fraught, disability is socially constructed in many ways (p. 6). Yet, I am still bound to this body. I am so tired; everyone is so tired. It is impossible within me: we are all exhausted but every time I bring up having a chronic condition people respond with "oh my god I am also so tired," and I feel invalidated. The twisting of my lethargic limbs aches to defer to the medicalization, the nights at the sleep clinic and the following torturous days of napping in intervals, blood tests, and psychiatric evaluations: Yeah but *I* have a medically diagnosed condition. As if this somehow makes my exhaustion more real, without considering the privilege I had to have doctors believe my accounts and care enough to push further for an answer. I wonder how many folks I encounter daily may have an undiagnosed sleeping condition.

After explaining that I don't have a driver's license to a friend: yeah, but couldn't anyone just fall asleep at the wheel?

Isn't that a big part of the problem?

A direct consequence of my sleep disorder has been my interest in queer temporality (certainly in tandem with my queerness). Beyond my research, "chrononormativity" is in my daily vocabulary. Elizabeth Freeman conceptualizes chrononormativity as the dominant way in which our socio-economic and political systems are structured, giving specific value to temporal rhythms. She writes how it is the use of time to organize individual bodies toward maximum productivity. (Freeman, 2010, p. 3). Individual bodies toward maximum productivity. Every moment toward what we can contribute to

capitalism. Heteronormativity developed neatly alongside this, too. Freeman also shows how chrononormativity deeply affects queer subjects to the point of asynchronicity. When these temporal rhythms are expected to feel “natural” through constant policing and social discipline (p. 18), queers tend to fail when attempting to fit into gender/heterosexual/capitalist expectations (Halberstam, 2011; Muñoz, 2009). As queers do not line themselves up with traditional familial linearity, they start to veer away from the expectation of maximum labour and maximum efficiency in a capitalist context.

By virtue of existing in a ‘deviant’ body, attempting to conform to expectations of heteronormativity and capitalism can have a tangible, exhausting affect. In the jobs that I have mentioned, I was always expected to read ‘neutrally,’ which means adhering to gender roles and expectations under the precarity of capitalism. Ahmed writes that the “normative dimension can be redescribed in terms of the straight body, a body that appears ‘in line’” (2006, p. 66). Hiding what I think are markers of queerness, I work at femininity, trying to emulate my ‘female’ coworkers.

(Looking back on that time a co-worker was yammering on in expo about how he didn't understand how anyone could have gay sex. Not to me, directly. But I was there rolling silverware into napkins. I rolled so tightly they would have had to been ripped apart by the next customer. Another co-worker was fighting him on it, I could see her frustration. Too new to the restaurant, and already aslant from its gendered expectations, I remained tense and silent. I did not want to explain queer sex to a man I barely knew. I strained to hide my hurt as I brought my table their appetizers, pretending to be aligned). Following this ‘linearity’ means “to direct one’s desires toward marriage and reproduction; to direct one’s desires toward the reproduction of the family line” (Ahmed, 2006, p. 74). A heteronormative body may seem neutral because it aligns with what is considered the norm: “lines disappear through such processes of alignment” (p. 66). Anything aslant means that I deviate, an androgynous haircut, ungendered clothing, a sleep disorder. Yet in these jobs I contort myself to appear aligned because sometimes I lack the choice. It’s physical, it’s tiresome.

I think about these bodily contortions in relation to crip theory via Alison Kafer. She writes that both crip and queer times change our expectations of milestones and benchmarks, as well as our valuation of productivity and daily activities: “Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (Kafer, 2013, p. 27). Crip time acknowledges the ways current temporal frameworks are based on a very particular embodiment, that is, white, “able,” young, etc. For a person with a disability accounting for chronic pain and fatigue, temporality shifts:

the present moment must often be measured against the moment to come: if I go to this talk now, I will be too tired for that class later...this idea of conserving energy, of anticipating, can be read as queer in that it bucks American ideals of productivity at all costs...in other words, how might we begin to read these practices of self-care not as preserving one’s body for productive work, but as refusing such regimes in order to make room for pleasure? (p. 39)

A crip time, like a queer time, does not align with time-as-productivity models of capitalism. The root of my exhaustion is ever blurry. Circular: the snake eating its tail. Embodying and acting, craning, shifting, contorting straining, into a specific space and within a specific timeline under a very specific system. Yet, always aslant and consequently affected. Melissa Gregg and Gregory Seigworth (2009) discuss that affect can be a relational feeling, one which is comprised of both intimate experience and interrelated bodies, “becoming a palimpsest of force-encounters traversing the ebbs and swells of intensities that pass between ‘bodies’” (p. 2). *The negative space between my body and a soft surface is weighty, and if I let it take hold I am gone for an hour or more, only to wake up with despair and limbs full of fog. Mandatory shutdowns were announced in March of 2020, and I became laden with the shrinking of that negative space.* So much of whatever normalcy I had worked toward since my “diagnosis” (or medicalization of a deviancy) involved attention to time and space. After years of trial, work, which I am fortunate enough to do from the comfort of my home, has to be staged with attention to this space. Where is my desk situated? Can I work in my pajamas? With soft pants in a blanket cocoon, I fall asleep at my desk again. I must go

somewhere else and return. Move my body. Change into something a bit uncomfortable: tight, digging into my chubby belly when I sit. Makeup so I can't rub my eyes, maybe.

I've little spaces left to go, lucky that I can work from home.

I don't want to denounce the privilege I have working in academia. But things are complicated. I have spoken with some non-academic folx since the shut-down in March. "Was your work affected?" They ask. "I work from home" I respond quickly. But I don't say how I was deeply affected. How I had to continue to grade papers and defend my candidacy exams and continue to produce and produce because if I go any longer than my allotted funding, how will I pay for my school? How will I finish? I can't take a break now. Publish or perish or publish or perish or

Better check the number of COVID cases in my town (I can't). Better check what the new symptoms are now (Nope). I am so tired, and I am only sleeping because I've stopped checking the news. But then I can't stop. And I can't stop scrolling. And yelling and feeling angry because I have learned about Breonna Taylor's murder, and George Floyd and Dominique Rem'mie Fells. And Jacob Blake was shot seven times. And I am so tired, but I have a home and a room to work in and I am white. The brain power and embodied awareness of existing in a racialized body is an exhaustion I'll never know (Hersey, 2020). My queer body feels straight people like eyes on the back of my head. My whiteness fades into the background (Ahmed, 2007). My "medically validated diagnosis" cringes when people complain of exhaustion and wants to fight back calmly and sleepily and hold claim to exhaustion, when we are all at the mercy of sleepless capitalism. I remember walking from a bus to get coffee, cognizant of the frat bros nearby, maybe they are lovely but maybe they are queerphobic and I know I look like a dyke. A police officer smiles and nods. I'm a dyke but I'm white.

Tomorrow I am going to a protest. And then I am going to nap. I hope you do too.

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Author Biography

Amy Keating is a PhD candidate in the Department of Gender, Sexuality, and Women's Studies at Western University in the area known as London, Ontario - the land of the Chippewa of the Thames, the Oneida of the Thames, and the Muncey Delaware Nation. Forever searching for other queers and community connections, Amy noticed that many queer communities surround various forms of art and creation. Their research thus explores how queer art and aesthetics can foster spaces of belonging and joy for queer identified folk in a world that was not made for deviant bodies. As Amy lives with idiopathic hypersomnia, they are forced to interrogate the way the structures of capitalism value a temporal framework that privileges the able, hetero, cis, male, and white body. Outside of academia, Amy also loves learning and writing queer folk songs on the banjo and sharing freshly baked bread with their friends.