
NON-FICTION | SPRING 2021

Sleep To Dream

By Jackie Mantey

Fatigue is my kryptonite. The never-ending scramble for sleep is simply part of who I am. That was the story I told myself, anyway. Then I fell asleep while alone in a late-night Uber ride and finally admitted that slogging through these onslaughts of exhaustion was cause for concern.

That's why I'm here, trying to make small talk with an uninterested sleep technologist pushing electrodes onto my head. It's 6 pm, and the doctor's office we're in overlooks Lake Michigan in Chicago, but you'd never guess it. This space looks more like a windowless hotel room. It's designed to eliminate natural light and reminds me of the underworld cave where *no light is cast by the sun or the moon*, home to Hypnos, the Greek deity of sleep. My "cave" has a full-sized bed, a TV atop a dresser, and a private bathroom.

During my consultation a week earlier, a specialist in this office asked questions about my sleep patterns. A bewildered "How did you know?!" was my response to most of them, as if she were a carnival act guessing my weight, age, and sign.

"Did you struggle with sleep as a teenager?"

I broke up with a high school boyfriend because he liked talking on the phone late into the night—much too late for me. That relationship is one of many sacrifices I've made for sleep, tapping out too soon because I was tired.

"Didn't everyone struggle with sleep as a teenager?" I responded.

"No."

Now, as the tech tucks me into bed, I think about how much a sleep disorder diagnosis might explain about my life. The rest of the night, a camera watches me from the ceiling, the man in the moon. In a room next door, my brain waves and eye movements dance across a screen, stars sleepwalking across the sky.

Growing up on a family farm, my physical reality demanded wakefulness. To be unalert on a farm is to risk a meal, risk a paycheck, risk getting yourself or someone else hurt. The dairy-farmer side of my family is, I told my doctor, "a sleepy people," but we assume it's because we're working so hard all day.

Farming *is* exhausting, but it's been a decade and a half since I've lived the farm life. The routine of work/ sleep/ work/ nap for relief/ work/ sleep is cemented in my psyche like cow pie on work boots. I've internalized this exhausting cycle so much that it has become the judge and jury in determining my self-worth. Sleep seems self-indulgent. My desperation for it, embarrassing. I think I must earn it. To earn it, I white-collar overwork myself in quiet compensation for what I consider to be a lack of willpower. This distracts me from a real physical problem. It gives me an excuse to ignore something I have always understood as a moral flaw.

My sleep test constitutes two parts:

1) First, an overnight stay. The electrodes now on my head are for a Polysomnogram (PSG). They electronically record my breathing and brain activity, as well as movement of my body and eyes. Sleeping here overnight ensures I get a distraction-free night's rest, and the PSG looks for signs of sleep apnea or restless leg syndrome.

2) Upon waking the next day, I stay in my Hypnos hotel room to take a Multiple Sleep Latency Test (MSLT). This requires me to take five 20-minute naps every two hours. The MSLT tracks how fast I fall asleep during those naps and if I enter the Rapid Eye Movement (REM) stage of sleep.

Most people need about 10 to 20 minutes to fall asleep; people with narcolepsy can fall asleep in less than five. Most people typically enter REM 90 minutes after falling asleep; people with narcolepsy can bypass non-REM sleep altogether. (They can even enter REM while they're still awake. These "dreams" are called hypnagogic hallucinations.) In the MSLT's five naps, if the patient falls asleep in less than eight minutes on average and enters the REM stage of sleep during two or more naps, narcolepsy can be diagnosed.

Narcolepsy is rare. Only one in 2,000 Americans have it, according to the Sleep Foundation. It usually starts in adolescence, and it's easily misdiagnosed, most commonly as psychiatric disorders, depression, or emotional issues. I've never been diagnosed with anything more than a concussion (I was my fifth-grade basketball team's eager secret weapon for securing loose balls), but I also never mentioned to my doctors that I needed almost 12 hours of sleep a night—plus at least one nap—to feel what might constitute as *good*. Why would I bring it up? I had been this tired for as long as I could remember. I felt ashamed of how much I slept as an adult. And... no one ever asked.

I also had an incomplete idea of what narcolepsy actually is. Everyone with narcolepsy suffers from excessive daytime sleepiness, but only a small percentage of these people experience every symptom during the course of their lives. That means someone could have narcolepsy but not have cataplexy. Surprised? I was. I understood Hollywood's punchline version of the disorder: Enter stage right, the Narcoleptic Argentinian in *Moulin Rouge*, falling asleep in his fancy frills at the most inopportune times.

The cause of type 1 narcolepsy (with cataplexy) is a shortage of the brain-stimulating protein hypocretin, also called orexin. The cause of type 2 narcolepsy (without cataplexy) is relatively unknown—except for the fact of relatives. It’s a bumner genetic-lottery ticket that slithers around family trees.

Narcolepsy is a rare diagnosis in the fact of its uncommon physical occurrence, but it’s also a rare diagnosis in the sense that it is *good* news. Diagnoses are usually dark and scary things, unwanted discoveries of something that’s been festering. A narcolepsy diagnosis is the opposite. It’s an answer. A relief. A language for formerly unreadable experiences. It’s a point in the story where everything makes sense.

I return to the sleep center a week after my tests. My PSG returned nothing of note, but my MSLT results held an answer: I fell asleep in under eight minutes in three of my five naps (I was out in less than three minutes for my first nap of the day at 10 am), and I went into REM sleep in two of those three naps.

When my doctor says that, without a doubt, I have type 2 narcolepsy, she does more than diagnose me. She changes my understanding of myself. I am not weak, not lazy, not self-indulgent, not undisciplined. I am tired for a reason—a reason that has nothing to do with my character.

I weep.

The sleep-themed lore I most relate to is the tale of Rip Van Winkle. Lured by mythical mountain creatures and then lulled to sleep with their liquor, Rip woke up 20 years later, seeing the truth of his world for the very first time. I think, based on his long-term blackout, as well as his punk rock disdain for the townsfolk and their “schedules,” that Ol’ Rip was also, in fact, ripped.

Like, all the time.

Wasted. Blitzed. Hammered.

Rip is an allegory of an alcoholic.

Takes one to know one.

I’m nearly four years sober from alcohol and cocaine when I’m diagnosed with narcolepsy. Going to a sleep specialist is an indirect result of my recovery. Two years sober, I was still getting inexplicable headaches that I once considered hangovers. I got tested for allergies (none!), quit caffeine for a year (in hindsight, a very unhelpful idea!), and tried a low-hormone birth control (helped a bit!). Sleep was next on my list of possible explanations for my lingering headaches and overwhelming exhaustion (ding, ding, ding!).

I tell my doctor about my sobriety because the treatment for narcolepsy, which has no cure, includes pharmaceuticals that keep you awake. That scares me. If there's anything I love more than sleep, it's—cough—party favors. I need my doctor to know she should ask me questions if I ever start to exhibit eagerness for pills. I'm surprised by her response. She says research is being conducted to study a possible connection between substance abuse, impulsivity, and narcolepsy.

I can see a correlation in my own lived experience. Booze helped me get excited to go out at night. And the promise of booze, booze, more booze, helped *keep* me out as 2 am approached. No sleep 'till Brooklyn! Coke around? Even better. I lived to come alive at night.

When I was in middle school, a friend took me to my first-ever concert. The Backstreet Boys! All five of them, right up in my sweet, innocent, never-left-the-farm face. It was a big moment for me. Not because of the Backstreet Boys, but because being in a city was like opening a door to a room I didn't even know was in my house. I loved being surrounded by thousands of people, the excitement, the noise, the buildings, the lights. I was hyped-up on adrenaline and the mystery of Nick Carter's pumping hips.

The next morning, I had to wake up early to milk the cows. I started crying. I was so tired. I didn't want to go to the farm. I wanted to go back to the city. Mom, frustrated, asked what was wrong. All I could muster, in a choking wail, was, "I'm not a *farm girl*. I'm a *Backstreet Boys girl*." I didn't have the language to say, "I don't know why I'm so uncomfortable here. I don't know why I am so very, very tired."

When my doctor told me I had narcolepsy, it was like I woke up 20 years later and could see the truth of my world for the very first time.

Undiagnosed narcolepsy isn't to blame for my substance abuse, but it is part of a bigger puzzle. I've come to think of my regular blackouts as a self-induced sleep. My increasingly righteous hangovers were excuses to sleep away the daylight and the shame.

I had become my own Maleficent in *Sleeping Beauty*, administering the poison myself so I could shut down. The village inside me was burning, and I held the torch. I was my own villain, my own worst nightmare. I was all the characters, and I needed to wake up. Sobriety was a choice to drop the torch, throw on the shining armor, and signal for the comatose cave giant to get a move on! Sobriety was a choice to save myself before it was too late.

I tell my doctor that my past substance abuse makes me afraid of accepting a stimulant's support. We rule out Adderall because of its potential addictiveness. There's a medicine people with narcolepsy can take that will help them get a better night's sleep, but I back away from that option too; numbing-out is a gingerbread house in the woods that I'm particularly vulnerable to.

I decide to try Modafinil, a eugeroic medication that promotes wakefulness. Both Modafinil and Adderall affect excitatory neurotransmitters in the brain, but Modafinil is ranked as a Schedule IV controlled substance, a classification lower than Adderall. I remember Adderall (a fellow French student used to share her *joies de vivre* with me in college) and it made me feel as hyper alert as an anxious dog. Research shows Adderall is a significantly more dangerous drug of abuse than the one I'm about to take.

My first week taking Modafinil, a small dose to start, I can't believe how much better I feel—and how *not* addicted. I describe my experience with Modafinil like this: When I was sober but still undiagnosed, waking up felt like I was in a river coming up for air. Then I would spend all day doggy-paddling in that river, trying as hard as I could to stay afloat. Fatigue felt like dipping in and out of a drowning state, and sleep felt like succumbing to the water. It was a daily struggle to fight the pull of going down.

With Modafinil, waking up now feels like surfacing above the water and finding a small raft floating nearby. I take my morning dose and climb on the raft. The river is still here, but the raft helps me appreciate its beauty and respect its power. I spend my day cautious of the possibility of being pulled under, but I'm not consumed by it. I don't wear myself out trying to stay safe, and I'm not so sky-high that I don't even recognize there's a river in the first place. The river goes up, the river goes down, and I'm present for all of it. When I'm ready for bed, I slide off the raft, run my hands along the rippled currents of my life, look downstream at what might be next, and—when I choose—let myself sink into slumber.

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