

For hypersomniacs, no amount of sleep is enough

For most teenagers, getting out of bed in the morning is a drag. But when Lloyd Johnson was 13 years old, he suddenly found waking up not just irritating, but agonizing and confusing. Sometimes he would open his eyes and already be in the car on the way to school — with no memory of showering or getting dressed. Other days, his family would drag him outside and pour water over his head to stir him, but still he'd remain asleep. His toughest mornings began when he woke up in an empty house, realizing that his family had simply given up on waking him.

Things started not long after a failed surgery. He'd been having intense pains in his right leg for six months, which the doctors attributed to what they thought was a hip disorder. But the procedure was a flop. Lloyd, always a tall kid with a shock of blonde hair, left the hospital with the same old ache in his step — and this bizarre new sleeping habit.

What could make you sleep most of the day and still feel lethargic when awake? Lloyd consulted a sleep specialist who told him about hypersomnia, an umbrella category for excessive sleepiness. He began to search around on the internet and read up, but almost everything was about the most famous type of hypersomnia: narcolepsy.

Narcolepsy is characterized by sudden bouts of sleep, and caused by a lack of a brain hormone called hypocretin. Lloyd longed for this kind of clear explanation for his combination of ambiguous symptoms. But he knew he didn't have narcolepsy. Sleep didn't hit his brain like a bolt of lightning; it was more like a slow, thick fog.

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