Patients with narcolepsy face a dual nightmare of medication shortages and stigma

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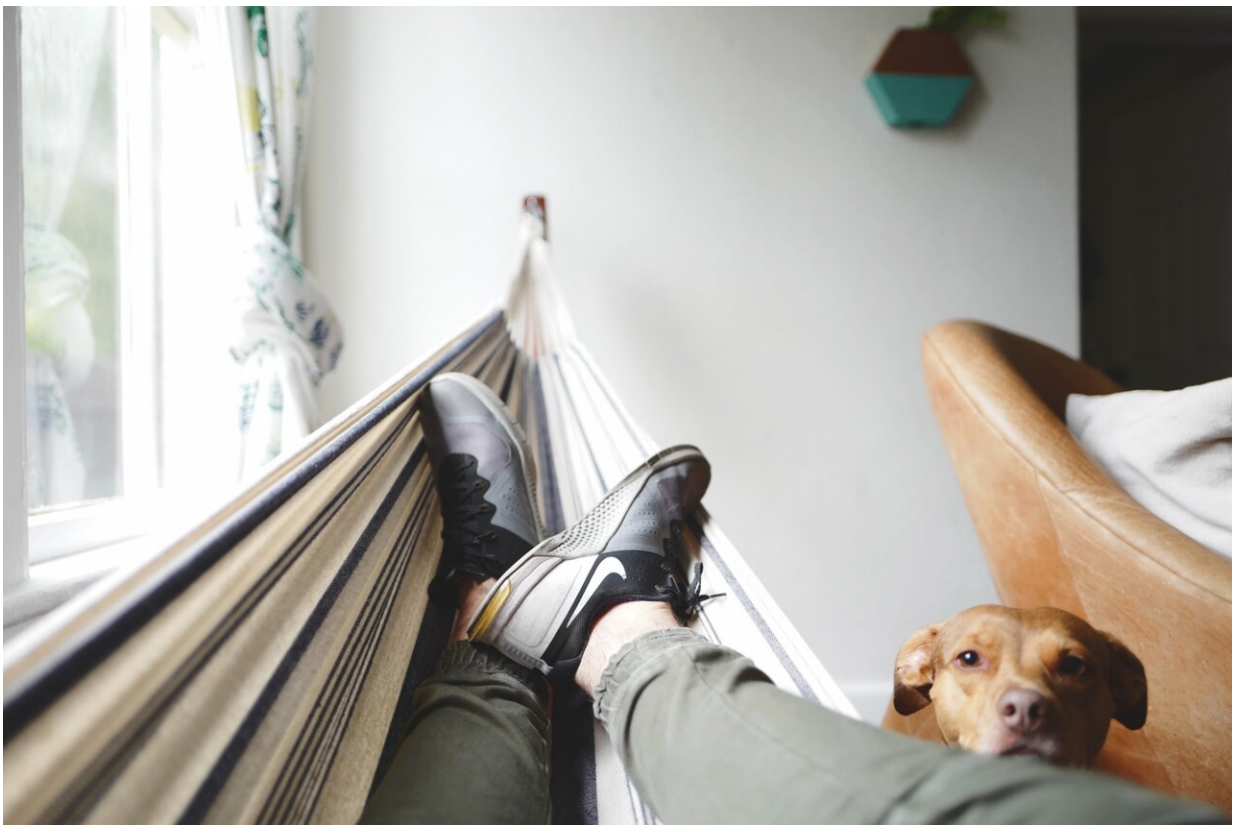

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Nina Shand couldn't stay awake. She had taken afternoon naps since she was a teenager to accommodate her "work hard, play hard" attitude, but

when she was in her mid-20s the sleepiness became more severe.

Menial computer tasks put her to sleep, and a 20-minute drive across her city, St. Petersburg, Florida, brought on a drowsiness so intense that her eyelids would flutter, forcing her to pull over. She knew something was really wrong when she no longer felt safe behind the wheel.

In 2021, she received a diagnosis: narcolepsy, a rare disorder that causes excessive daytime sleepiness.

Her doctor prescribed her Adderall, the brand-name version of the amphetamine-powered medication commonly known for treating attention-deficit/hyperactivity disorder.

It worked. For the first time in years, Shand, now 28, felt energized. She was no longer struggling at work, sneaking naps or downing coffees to trick her body into staying awake. She felt hope.

But by 2022, a national Adderall shortage meant pharmacies were no longer able to fill her prescription. Shand and countless others across the country were being turned away, left to piece together a new—and often less effective—treatment plan with doctors scrambling to meet their needs.

More than a year later, the shortage continues. In October, Democrats in the U.S. House of Representatives implored the FDA and Drug Enforcement Administration to work with drug manufacturers to ensure better supply.

"We cannot allow this to be the continuing reality for Americans," read their letter, led by Rep. Abigail Spanberger, D-Va.

But for now, it is.

Each month is accompanied by familiar anxieties as patients navigate a web of messy logistics and uncertainty while trying to get the medication they need to live normally.

Media coverage of the shortage—and even the House Democrats' letter—has focused primarily on the harms to people with ADHD. But for those with sleep disorders, like Shand, the effects may be even more consequential.

Basic tasks—like driving—become dangerous or impossible without medication. Job and school performances are threatened by the onset of sudden sleep and sometimes even paralysis. Hobbies and social lives can fall by the wayside, too.

"Adderall gave me my life back," said Shand. "Going from having a medication to not, it's like a roller coaster you desperately want to get off."

The resulting challenges, she said, have made particularly clear the loneliness of living with a rare and misunderstood disorder.

What is narcolepsy?

An estimated 1 in 2,000 people in the United States live with narcolepsy—more than 160,000 people nationwide. The disorder is part of a broader group known as hypersomnolence disorders, or conditions characterized by difficulty staying awake during the day.

There are two major types of narcolepsy.

Both types affect one's ability to stay awake, but type 2 is typically less severe. In addition to sleep disturbance, most people with type 1 narcolepsy experience sudden, temporary loss of muscle control or

paralysis, called cataplexy.

Cataplexy attacks are typically triggered by emotion—like laughter or surprise. For one person living with narcolepsy, an attack might look like a slack jaw or limp hand. For another, it could trigger full-body paralysis.

Causes of type 1 narcolepsy can include autoimmune disorders and brain injuries, but the underlying issue is believed to be low levels of hypocretin, a hormone that is thought to affect REM sleep—the dream state.

"Narcolepsy is due to a faulty switch in the brain for REM sleep," said Muhammad Ali Syed, a physician and the medical director of the University of Florida Health Sleep Center.

People with narcolepsy go into REM extremely quickly, Syed said. A person without a sleep disorder will enter REM around an hour or 90 minutes after falling asleep. But a person with narcolepsy may go into REM almost immediately and could have a fully fleshed-out dream in just minutes, Syed said.

In some circumstances, symptoms can also include sleep paralysis and hallucinations.

Increased demand

Every week since the Adderall shortage began, Fareeha Hussaini, a sleep medicine specialist at University of South Florida Health, has had calls to her office from patients struggling to access their medication.

College students are worried about plummeting grades and final exams. Patients in their 70s, who have managed symptoms with Adderall for

decades, are now forced to switch to other medications, like Ritalin.

Hussaini and her staff at USF Health have worked to help patients adjust treatment plans, but there's no denying the added stress. Some patients worry what a new plan may mean for their quality of life as shortages continue.

Drug shortages in the U.S. aren't new, but the past couple of years have brought an all-time high, said Michael Ganio, who directs pharmacy practice and quality for the American Society of Health-System Pharmacists, which represents pharmacists nationwide.

The Adderall shortage, Ganio said, is linked to increased demand.

The COVID-19 pandemic brought on a flood of new ADHD diagnoses. Studies have found absence of routine and increased screen time may have played a role. With those diagnoses came an increase in stimulant prescriptions, Ganio said—often via telehealth.

Adderall is a Schedule II controlled substance. It's highly regulated because of the potential for being diverted for recreational use. Prior to the pandemic, patients were required to have an in-person doctor appointment to get a prescription. But that requirement was waived during the public health emergency, and telehealth appointments were allowed. The telehealth allowance has since been extended.

"There's a broad group of patients who never had access, or suddenly have easier access, to providers who can make that diagnosis and prescribe," Ganio said.

Another reason for the shortage are production limitations put in place by the DEA. Each drug manufacturer is effectively given quotas of how much of the drug they can produce. But because manufacturers are

shielded by trade secret protections, it can be hard to know whether the DEA quotas are too low or if the manufacturers just aren't producing to full capacity.

In a joint letter in August, the leaders of the FDA and DEA called on manufacturers to work together to increase production and confirm they are working to produce up to their quotas.

A logistical nightmare

From the parking lot of a Pinellas County, Florida, Walgreens in November, Nadine Dixon, 50, waited anxiously to have her Adderall prescription filled. It was the third time she'd sat in a pharmacy parking lot that day.

For Dixon, who gets her prescription through monthly in-person visits with a neurologist, the past year has been a logistical nightmare. The effects of the shortage, she said, have been compounded by the layers of red tape around Schedule II drugs.

Unlike, say, blood pressure medication—which can be dispensed to patients in a 90-day supply—Dixon can get enough Adderall only for 30 days, and automatic refills are not allowed.

As the end of each month approaches and her pill bottle empties, her anxiety spikes.

At her doctor appointment, she picks up her prescription, commencing a cumbersome routine.

Some months, she has had to drive to upward of 10 pharmacies to find her medication. Sometimes she calls in advance to ask if they have it, but she rarely gets answers.

When she finds a pharmacy that has Adderall, a new challenge hits. Minuscule details—like a number written with numerals instead of being spelled out, or a doctor's signature that looks slightly different than it did the month before—can result in the pharmacy turning her away. Her only option then is to drive back to the doctor's office and ask for the paperwork to be adjusted.

Doctors can send electronic prescriptions to a pharmacy to avoid the issues with handwriting, but those pose their own complications: They can be sent to only one pharmacy at a time, and can't be transferred.

If the receiving pharmacy is out of medication, patients have to go back to their doctor to ask that they send the prescription elsewhere. And often only the doctor—not a nurse, nor a physician assistant, nor a staff member—is allowed to address that call for help.

Luis Enrique Ortiz, a sleep medicine specialist at Johns Hopkins All Children's Hospital, said that's put a strain on doctors, who are juggling efforts to rewrite prescriptions, guide patients, and handle appointments and research.

The result is often a delayed response.

"It can be really nerve-wracking," Ortiz said. "Their time is running out, and they need this medication to function normally. When they finally do get it, they don't know what the next month will hold. They have to go through it all again."

Dixon, who was diagnosed with narcolepsy with cataplexy in 2010, estimated she's spent up to eight hours a month trying to get her medication since the shortages began. In three of the past six months, her prescription hasn't been filled on time. She's experienced delays of four or five days.

The results are terrible migraines, mood swings, muscle weakness, and—of course—sudden sleep, she said.

"It feels like you've been awake for four days straight and are trying to keep your eyes open," Dixon said. "The second I sit down, I fall asleep."

Dixon described herself as an energetic person when she's on medication. She's a single mom and a caregiver for an older woman, and she works an online job for extra money. She has a full social life, too.

But without medication, she said, her life comes to a standstill. She can't go have drinks with friends. She can't go for walks. Simple conversations about stressful topics can trigger cataplexy attacks, which cause her limbs to go numb.

"It's really horrible," Dixon said. "Irregularities with the medication are hard on your body."

Almost an hour after she arrived at the pharmacy that November day, she got a phone call asking her to come in from where she'd been waiting in the parking lot. They couldn't fill her prescription, the pharmacist told her. The prescription had an error.

They sent her away with a sticky note spelling out the necessary adjustments.

She drove back to her doctor's office, but when she got there, she learned the doctor had left for the day.

She would have to try again the next day.

Stigma and hope

Adderall isn't the only treatment used for narcolepsy. Other stimulants, as well as newer drugs made specifically for treating sleep disorders, can help, but those can come with hefty price tags and insurance battles.

And when a patient finds a drug that works, any change can be scary, Shand said.

Since her diagnosis, Shand said, she's tried at least three other treatments.

"Adderall has been the only stimulant that really keeps me awake and feeling like I can go through my entire day without having to sleep," she said.

She's been able to get her prescription refilled since fall began, she said, but she's learned not to get comfortable. She never knows what the next month will hold—what stock local pharmacies will have available.

For Shand, who has narcolepsy with cataplexy, the years since her diagnosis have brought waves of frustration and grief but also a sense of loneliness.

In television and movies, narcoleptics are often the butt of a joke, she said. Most people, she's found, don't really know what narcolepsy is.

"It's not actually all that funny," Shand said. "It's genuinely debilitating. It's life-altering."