

## AN AWAKING NIGHTMARE

Rachael Combe was coming apart under the burden of unrelenting insomnia. Nothing helped—until one day her dentist, of all people, told her she had the so-called “young, thin, beautiful women’s sleep disorder.” Flattered, she investigated

**I’d wake in the middle** of the night, gasping for breath as though surfacing from a near drowning. My heart would be racing, my skin clammy, my organs suffused with grief and fear, like I’d been pickled in some bitter brine while I slept, and now, at 2 or 3 A.M., I was fighting my way out of the jar. I’d then proceed to lie awake for hours, my life flashing before my eyes—but only the sad, bad, mad parts. Even the happy scenes curdled in this film—I was screwing up my children, ruining my marriage, wasting my life. And my life! Was I dying? This gasping and sweating in the night—*something was wrong with me.*

The episodes started in my early thirties

and went on for years, gradually progressing in severity and frequency until, according to my Fitbit, I was averaging only four hours of sleep a night. I’d always been an insomniac, but this was a new level of hell. In the past, I’d prided myself on being an efficient, hard worker. Now I could barely keep my mind on a task for 15 minutes. My body began to break down: My ankle gave out mysteriously, and I had to wear an orthopedic boot for months. I ached everywhere. I developed rosacea. It became hard to eat out because everything but the plainest food made me sick.

I am fortunate to have good health insurance, and I put it to use. I went to my gynecologist:

Was it perimenopause? No, she said, just stress and postpartum hormones. (I gave birth to my fourth child during this period—another red herring that threw everyone off: “Of course you’re tired! Of course you feel crazy! You *are* crazy.”) I went to my general practitioner: Was it cancer, Lyme disease, hyperthyroidism, early-onset Alzheimer’s? He tested me for all of them. Nope. I went to a gastroenterologist and a nutritionist, who failed to find anything wrong with my stomach or diet. I went to a psychiatrist, who diagnosed anxiety and prescribed sleeping pills, which did not help me get more sleep but did make me feel more





## It sounded too good to be true: Curing my sleep disorder would cure my anxiety, stomach problems, *everything*.

my problem when I went to get a new one. He peered down my throat and then motioned for his assistant to come over. “Look at that big tongue! No wonder!” he exclaimed. He turned to me. “This is easy. I know what you have. You’re waking up in a panic? In a cold sweat? Like someone just threw a rock through your window?” he asked. Yes, yes, yes, I told him. “You have low blood pressure? Cold feet?” Uh, yeah. “You have anxiety?” Yes.... “You had your wisdom teeth out? Were you ever told you needed a palate expander as a kid?” Umm...yes? “You have UARS. It’s the young, thin, beautiful women’s sleep disorder. You should write about it!”

In the 15 years I’ve known Dr. Gelb, he has never steered me wrong—an expert in jaw pain and snoring, he’s cured both my TMJ and my husband’s log-sawing. And yet, he’s such a smooth salesman, such an adept self-promoter, and so quick to diagnose problems that can only be resolved with \$4,000 retainers, I’m sometimes inclined to disbelieve him. I couldn’t hold my freakishly huge tongue in check: “Dr. Gelb, please. The ‘beautiful women’s sleep disorder?’” I laughed. “That’s not a thing.”

Gelb snap-snapped at his assistant, who printed out an inch-thick stack of research articles from reputable journals. Turns out, UARS is a thing. Upper airway resistance syndrome was identified in adults nearly 25 years ago by medical researchers at Stanford University. It’s a form of sleep-disordered breathing in which people get slightly less air than they should because some part of their airway is too narrow and—though they’re not actually in danger—their body perceives they’re suffocating and wakes them up.

The American Academy of Sleep Medicine categorizes UARS as a form of obstructive sleep apnea syndrome (OSA)—but UARS’s effects are subtler and its diagnosis trickier than the apnea most people are familiar with. Because the research on it is broad but rather shallow—and includes few randomized, controlled trials—sleep experts disagree about almost every aspect

of the disorder, from whether it’s distinct from OSA to the best therapies to ameliorate it. The exact prevalence of UARS isn’t known—in part because it’s thought to be so underdiagnosed—but the National Sleep Foundation estimates that 18 million Americans suffer from apnea overall, two or three men for every woman.

That said, there are some established facts about UARS: While OSA is associated with being older, heavier, and male, UARS sufferers are typically younger, leaner, and predominantly female, according to epidemiological data. A petite build may be a risk factor, because smaller bodies have smaller airways, which can be more easily crowded by adenoids, the tongue, and the uvula, as well as relaxation of the throat during sleep. (And while the literature is silent on the topic of beauty and UARS, one physician told me anecdotally that the facial structure that can put a woman at risk for UARS is sometimes linked with beauty in our culture: a small jaw and nose.) High blood pressure commonly occurs in tandem with OSA; the opposite is true for UARS, in which blood pressure can be so low that it leads to fainting and chronically cold extremities. UARS patients don’t always snore or stop breathing—symptoms a bed partner would likely notice—but they tend to complain of greater fatigue than people with standard apnea do.

The reason for the excess fatigue is the subject of debate. One theory is that people with UARS are more exhausted because they awaken at the first ragged breath, while the “classic” apnea sufferer may sleep through his funky breathing—unaware he’s snoring and even, at times, not breathing at all.

Undercutting that hypothesis, though, are sleep studies that show that tiredness isn’t necessarily related to the number of apneas or arousals patients experience—and some patients may have fairly normal-looking sleep studies but still suffer from brutal fatigue. These findings have prompted some scientists to bore in on the fact that UARS coexists with a host of other psychiatric and somatic disorders—anxiety, depression, posttraumatic stress, irritable

cotton-headed the day after I took them.

I followed all the “sleep hygiene” advice: no naps, getting out of bed at the same time every day, no caffeine, no screens an hour before bed. I exercised daily. I took lavender baths, hung blackout curtains, wore a sleep mask and earplugs. I took a seminar on stress reduction. I meditated. I tried sleeping in a different room from my husband. I tried giving up wheat, dairy, sugar, and—finally, painfully—wine. Nothing worked.

And then I crunched through the night guard I wore to stop me from grinding my teeth at night. Oddly enough, it was my dentist, Michael Gelb, who diagnosed





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bowel syndrome, ADHD, and fibromyalgia, among others. They've suggested that the exhaustion—and somatic disorders—aren't caused by a shortage of sleep but by the nervous system's overreaction to the disordered breathing. If that's true, treating the irregular breathing could mean the anxiety or fibromyalgia recedes without doing anything else.

It frankly sounded too good to be true: Not only did I have Gelb's "pretty girl's sleep disorder," but curing it would eliminate every ailment I've ever had. I felt like one of those parents who can't face that their child has a behavior problem and so, instead, blame gluten or vaccines or the kid being "too creative" for school. On the other hand, I had nothing to lose except debilitating insomnia, so I headed to the Stony Brook University Sleep Disorders Center in Smithtown, New York, where much of the research on UARS and somatic disorders has been done.

I walked in fully expecting to be told that my dentist was a quack and I was a head case. Instead, Susan Manganaro, MD, took one look at my history, peered into my mouth, and agreed with Gelb (although Stony Brook is abandoning the term UARS—they see it as a manifestation of OSA and think it's misleading to cordon off sufferers just because they're mostly thin women). Again, my tongue was of great interest. "See how it has ridges on the side?" Manganaro said. "That's called scalloping. It means your tongue is pressing against your teeth because there isn't enough room for it." (I swear, my tongue doesn't loll out of my mouth like on the Rolling Stones album cover.) She said I likely needed to use a continuous positive airway pressure machine (CPAP), which would blow air up my nose and keep my breathing even. To confirm the diagnosis and then titrate the machine to the right air pressure, I needed to do two overnight sleep studies in the hospital.

Those studies—sensors all over my head and body, a tube up my nose, a camera watching me while I slept in a Motel 6-ish room with pastel ocean scenes on the wall—showed 70 arousals in the 6.5 hours I spent in bed. I spent two of those hours lying awake, giving me a "sleep efficiency" rating of 69 percent (normal is anything over 85 percent). The diagnosis? Moderate sleep apnea with mild sleep fragmentation.

After some tussling with my health insurer (Manganaro says insurers seem to prefer to wait until people develop the calamitous downstream effects of untreated apnea—such as high blood pressure and stroke—

rather than pay for preventive measures), my CPAP machine finally arrived. It looked like a clock radio, connected by a long tube to a mask for your face. I had to try five masks before I found one that didn't give me claustrophobia or rub my nostrils so raw and pink that I looked like a coke-addicted rabbit when I awoke. Ultimately I settled on a snazzy ResMed AirFit P10 for Her, size extra-small, that goes just into the tips of my nostrils and gives me the appearance of having a dainty lilac-and-white elephant trunk dangling off my schnoz. It's the least sexy thing I've ever worn to bed, outside of the disposable panties filled with ice packs and Tucks hemorrhoid pads the hospital gives you after you have a baby.

I was told it would take a couple of weeks to get used to the machine, but it took me nearly two months. It was definitely a "nevertheless, she persisted" type of situation. At first, I had to use sleeping pills to be able to fall asleep with the mask, and I'd often rip it off in the wee hours. But then the turning point came: I woke up one morning and realized I'd slept straight through the night—CPAP success! But then my heart sank. Where was my mask? I didn't feel it on my face; I must have clawed it off without realizing it. I scanned my bedside table, looking for my little lilac elephant...before realizing it was, in fact, still on my face. I'd acclimated!

Once I was able to wear my CPAP through the night without sleeping meds, my fatigue and anxiety just...stopped. Another part of my brain—the part that had enthusiasm for work, playing with my kids, even getting errands done—turned on. It was like I'd been listening to a fire alarm for decade upon decade and then, finally, found the button to switch it off. At my follow-up visit with Manganaro, my resting heart rate had dropped from 79 to 60 beats per minute.

My sleep still isn't perfect, but now all the stress-reduction and sleep-hygiene tactics I'd tried in the past make a difference. Caffeine, wine, and PMS pretty reliably give me insomnia; exercising and setting my alarm for the same time every day improve my sleep. Now I'm no longer a black box, where nothing I do has the outcomes I expect. I'm more of a clockwork gumball machine: You put the quarter in and the happy rainbow gumballs roll out.

Four months into my treatment, I'm still stunned by the change. Who is this calm, elephant-masked woman? I called up Avram Gold, MD, director of the Stony Brook sleep center, Manganaro's boss, and among those

# Almost two-thirds of women experience insomnia at least a few nights a week, according to a National Sleep Foundation poll.

who believe that it may not be the extra sleep that makes people feel better rested—and just all-around better—but the reduction in activation of stress hormones. He blames the olfactory nerve for UARS. “For all mammals, the nasal passage is one of the fundamental ways we learn about opportunities and dangers,” he said. “Think of the rabbit on the lawn, sniffing to find something to eat but also sniffing to smell a coming dog.”

The olfactory nerve is directly connected to the limbic system—the emotional center of the brain—and senses not only smells but air pressure. Gold suspects that UARS patients’ limbic systems have come to associate a drop in air pressure during sleep with danger. For this connection to form, he postulates, there must be a stressful sensitizing event, whether the trauma of war or the strain of getting a divorce or becoming a parent. And perhaps, Gold argues, you need to be someone who’s more reactive to stress to begin with.

Manganaro points out that someone else, with a different nervous system, could have sleep-study results similar to mine yet feel completely fine. Though she has to grade apnea on a scale of mild to severe for health insurers, she is less interested in the number of arousals patients have at night than in the severity of their symptoms during the day. “If your brain is responding to the sleep-disordered breathing as a danger, and your fight-or-flight system turns on and the anxiety syndromes start up, it doesn’t matter how many times an hour you’re waking up,” she says.

Of course, not everyone is convinced by Gold and his colleagues. Scientists from Penn State’s sleep disorder center wrote an essay in a prominent sleep medicine journal a few years ago, complaining that his conjectures are based on small studies without control groups and that if physicians act on them without more proof, Gold “will have a negative impact on the health of our patients, on our economy, and, not least, on the credibility of our field.”

It is possible that all the benefits I’ve noticed are the result of a placebo effect. Placebos are considered particularly robust in

sleep medicine, accounting for perhaps 50 percent of the response to sleeping pills. One study found that just telling healthy subjects they slept well improved their performance on neurological tasks compared with subjects who’d been told they slept poorly.

Gold agrees that better studies are needed. “Sleep medicine is bullshit. We’ve built a branch of medicine on a very weak foundation,” he says, referring to the lack of investment in research. The result of the failure to fund double-blind, controlled studies, he contends, is that people whose sleep could be improved are instead dying of causes that range from suicide and substance abuse to cardiovascular disease.

Christian Guilleminault, MD, the Stanford researcher who identified the UARS population a quarter century ago, likewise lamented the dearth of research into milder forms of apnea. Women’s sleep-disordered breathing has been especially overlooked, he says, calling us “the forgotten gender.”

I’m almost embarrassed to admit how much I believe in Gold’s theories: My experiences are anecdotal, and I’ve been reporting on science and health long enough to know that medicine shouldn’t be a matter of faith but of data. Yet for the first time in my life, my symptoms make sense, and I’ve found a treatment that works. My husband used to gently tease me for being, as he put it, “highly calibrated,” as I tried in vain to come up with something that would relieve my unrelenting anxiety, insomnia, and irritable bowel (which, frankly, I believed were linked, well before I read dozens of papers on the topic). My husband was right: I was sensitive and remain so. But in the past, it was like I was trying to fine-tune an intricate machine that was on fire. You need to put out the blaze before you can experiment with the monkey wrench. I’ve come to think of the cool breeze from my CPAP machine as a little air conditioner for my brain. It turns down the temperature; it cools off my hot reactions. It gives me the time and peace to regard the beautiful machine of my body and mind with gratitude and kindness instead of fear and disgust.



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