



Why Dizziness Is Still a Mystery

**Balance disorders like vertigo can be devastating for patients—
but they're often invisible to the doctors who treat them.**

BY SHAYLA LOVE | OCTOBER 10, 2023

One morning last August, while making my bed, my entire visual field shifted sharply to the left, as though I were watching a movie and someone had bumped into the projector. After half a second, my vision snapped back into position. I froze, pillow in hand, and carefully looked around. The furniture in my room was still, apparently innocent of whatever had just happened. But I felt a lingering unease that my surroundings were not bolted down.

I went for a jog along the East River, in Brooklyn. Everything seemed to be in the right place—clouds above me, wooden boardwalk below. Still, the 7 a.m. sunlight seemed brighter than usual, and the water rippled in a disjointed way, like a film reel missing a few frames. My head was heavy on my shoulders. Confusingly, it also felt as though it might float away.

Back in my apartment, I rolled out a yoga mat and stretched. When I tilted my head to touch my foot, the room began to rotate like a carousel. I'd had dizzy

episodes before, but never anything this intense. I lay down, but the spinning only sped up. I curled up and waited—prayed—for it to end. When it didn't, I reached for my phone and called a friend who lived nearby.

To let my friend in, I had to crawl the length of my apartment. “Something is wrong,” I told her softly.

At the emergency room, I was helped into a wheelchair because I could barely stand. During the next hour, the E.R. staff ruled out anything life-threatening, like a stroke, yet they couldn't say what was wrong. It was difficult to diagnose the cause of a dizzy spell, the doctors said, because dizziness is a sensation, not a disease. Many different conditions can produce it. One said that I probably had labyrinthitis, or inflammation of the inner ear, and typed it into my chart.

The swirling behind my forehead lasted all day and night. I couldn't look at computer screens, so after a week and a half I took sick leave from my writing job.

I scheduled appointments with virtually every relevant specialist. An audiologist checked my hearing and an ear, nose, and throat doctor shined a light into my ears. Neurologists inspected the movement of my eyes. A physical therapist who specializes in balance issues asked me to close my eyes and stand on one foot. Simply visiting all these doctors was dizzying. As I crisscrossed the city, I had to focus on every footstep to keep from toppling over. Through it all, my tests were coming back normal. My hearing and sight were fine; an MRI was clear.

During one appointment, my neurologist's questions began to veer off the medical path. Did I get car sick as a child? Did I enjoy roller coasters? What about boats? Had I made any big life changes recently? Finally, we seemed to be making progress: I hate roller coasters and have always been prone to car sickness, and my life had, in fact, changed dramatically of late. I had left a long-term relationship and, for the first time in ten years, was living alone, untethered. I was going on dates, and thinking about leaving my job for good.

My neurologist seemed to be suggesting that dizziness was more than a physical phenomenon. To understand it, I would need to think about what was going on in my head and my life. Based on my answers, as well as my sensitivity to light, he at last gave me a diagnosis: vestibular migraine.

The symptoms of vestibular migraine—the world spinning like a globe, days of painless dizziness—seemed to match. But the diagnosis also frustrated me.

Even as a health journalist, I had never heard of vestibular migraine. Its name suggested that an unwieldy neurological condition, migraines, could somehow get tangled up with the vestibular system, which helps shape our sense of balance.

The experience of dizziness has been documented for thousands of years, and it's one of the most common complaints that bring people to the doctor. Even children can readily identify it: if you are old enough to play Ring Around the Rosie, you know what it feels like. Yet dizziness, like pain, isn't something that can be seen directly in an X-ray or an MRI; it must be described by the person who feels it, and terms like "vertigo" and "light-headedness" never seem to capture the entire experience, or how profoundly it can unsettle us. Even doctors break down dizzy spells into a staggering number of mythic-sounding categories, many of which are poorly understood: labyrinthitis, mal de débarquement, benign paroxysmal positional vertigo, Ménière's disease, vestibular neuritis, vestibular migraine. I left the neurologist's office with new words for my symptoms, but they didn't adequately clear up what was happening inside my body, or why. I had a pamphlet about migraines in my bag, but I felt haunted by all the questions it didn't answer.

I experienced my first spell of dizziness about ten years ago, when I was a twentyone- year-old college student living on a farm in France. I went to a doctor in the Pyrenees, and because my vocabulary didn't include the words "dizzy" or "offbalance," I waved my hands a lot and repeated the phrase *mal à la tête*, or headache. I was confined to bed for a week. Two years later, during my senior year of college, a thin film of dizziness perturbed me for almost three months. Even in my native tongue, I could only explain with metaphors. My dizziness made me feel that my skull was a washing machine on a spin cycle, or that the ground was bulging upward under my feet. Sometimes I felt that my body was subject to a different gravitational force than those around me. For more than ten years, my medical tests were inconclusive. My condition was unfindable, invisible.

Many dizzy people struggle to describe their symptoms. "I hear 'light-headed' a lot," Sue Whitney, a professor of physical therapy at the University of Pittsburgh who helps people with vestibular rehabilitation, told me. Her patients often say that they feel like they're floating—"or, 'I'm off,' or 'my head feels funny.'" Soumit Dasgupta, an audiovestibular doctor from the U.K., added "fuzzy-headed" and "brain fog" to the list. A friend, who also received a vestibular-migraine diagnosis,

told me that his episodes begin when his eyes start to drift toward the left. Living with dizziness, he said, is like trying to walk on a rocking boat.

Biologically speaking, the vestibular system is located in the inner ear, next to the spiral-shaped cavity known as the cochlea. If the cochlea were a snail's shell, the vestibular organs—the saccule, the utricle, and three semicircular canals—would make up the snail's body. Together, they are known as the labyrinth because of their twisting shape. The canals are positioned at roughly right angles to one another, and as fluid moves through them, they can detect if the head is moving up and down, side to side, or left to right. The saccule and utricle detect acceleration and tilting.

Vestibular organs appeared early in evolutionary history—they are key for survival— and most terrestrial animals have them. One medical textbook describes how the vestibular system “plays a subtle, almost occult role” in our sensory experience. Michael Goldberg, a Columbia University neurologist, has said that the vestibular system helps our bodies answer “two questions basic to the human condition: Where am I going? Which way is up?” But there are many ways that the vestibular system can malfunction.

You can trigger a dizzy spell by standing up too fast, skipping lunch, spinning in a circle, or drinking too much alcohol. Dizziness can be linked to one's ears, brain, heart, or metabolic system. The treatments, likewise, are heterogeneous. In benign paroxysmal positional vertigo, crystals in the inner ear canals become loose; physical repositioning, known as maneuvers, can usually treat it. For conditions of chronic dizziness called persistent postural perceptual dizziness (P.P.P.D.), vestibular rehabilitation and S.S.R.I.s, which normally treat depression and anxiety, seem to work better. Vestibular migraine is treated through the use of migraine-specific supplements or medications—which wouldn't be advised for someone with the buildup of inner-ear fluid known as Ménière's disease.

The sensation we call dizziness is a sort of general alarm system for the body—but just as a fire alarm can't tell you where a fire is burning (or whether someone walked through the emergency exit by mistake), it doesn't necessarily tell you what's wrong. Dasgupta argued that diagnosing the causes of dizziness requires a lost clinical art known as anamnesis, or a holistic interview about the patient's symptoms and their surrounding context. “This is like detective work,” he said. Diego Kaski, who treats vestibular patients as a consulting neurologist at the U.K.'s National Hospital for Neurology and Neurosurgery, tries to understand his patient's symptoms by imagining that they are happening to him. He often relies

on gestures: if people have vertigo, which includes the illusion of movement, “they might spin their finger or their hand around,” Kaski told me. Others will hold onto their heads or rock their upper bodies from side to side. Patient accounts tend to be psychological as well as physical. “You lose control of what your body is doing, and that can be quite a fearful experience,” Kaski said. Many dizzy people wonder whether they are dying.

While visiting doctor after doctor, I learned from a Google search about what sounded like a dizziness utopia: the German Center for Vertigo and Balance Disorders, or D.S.G.Z., in Munich. It was originally funded by the German federal government and, since 2019, has operated as an interdisciplinary center of the University Hospital of Munich.

In February, I travelled to Munich and took a train to the hospital’s expansive medical campus, about half an hour from the city center. To find the D.S.G.Z., I followed an elaborate system of colored lines and numbers that were printed on the ground. They led me through a maze of hallways and stairwells until I arrived at a door, which was adorned with an image of a brain and the labyrinth of the inner ear. I found Andreas Zwergal, a neurologist and the director of the D.S.G.Z., in his office. He wore a white doctor’s coat and had a thick head of brown hair, which bounced when he got animated.

Zwergal did not set out to become a dizziness doctor, but he has had a personal connection to the condition for much of his life. His father had a dizziness episode in his late fifties and had to retire early from his high-school teaching position. More recently, Zwergal’s wife woke up dizzy one morning; he was the first doctor to examine her. He concluded that she was experiencing a vestibular migraine, like me.

I pulled out my notebook to show Zwergal a list of the dozen conditions that my dizziness has been attributed to over the years, from labyrinthitis to low blood pressure. He seemed unsurprised. “People do have these long trajectories and patient histories,” he said, leaning back in his chair. With a gentle tone that softened his German lilt, he added, “Hopefully, you’ve survived that psychologically normal, but many patients get depressed or frustrated.”

To explain the differences between diagnoses, Zwergal imitated their manifestations. Some vestibular disorders, like B.P.P.V., affect a person’s balance and walk; he staggered from foot to foot, swinging his arms and tilting to one side. For others, like P.P.P.D. or Ménière’s, the dizziness is constrained

to the head, and to one's perception; he demonstrated by grabbing one temple and swirling his eyes around in their sockets. He did all this without a trace of mocking or humor. Chronic dizziness is more serious than most people can imagine, he said. Half of patients have so much difficulty that they take part-time jobs or stop working altogether. "If people had to rate the severity of impairment of benign paroxysmal positional vertigo against a heart attack, most of them would say that vertigo was the worst feeling of their life," Zwergal said.

The D.S.G.Z. clinic is a circular loop of examination rooms, each containing different tools to measure aspects of dizziness. "We bring everything together in one place," Zwergal told me. The majority of patients come from more than two hundred miles away. On a tour, I saw an older woman looking at black and white lines on a screen as they moved horizontally. Another patient gazed at a spinning cylinder that a woman in scrubs was holding. These tests looked at the eyes, in hopes that their movements could be correlated with a particular disorder. Nearby, in the "gait room," a special carpet measured the precise weight, position, and speed of a person's steps. One of the D.S.G.Z.'s aims is to create a taxonomy of every kind of dizziness, which could bring about a new era of diagnosis for patients like me. In recent years, specialists have started using a standardized diagnostic process called TiTrATE, which focusses on "timing, triggers, and targeted bedside eye examinations." The D.S.G.Z. has asked doctors around the world to send videos of their dizzy patients to the center and has also created an online initiative, dizzynet, where clinicians and researchers can collaborate. One day, doctors will be able to compare a patient's eye movements, walking patterns, and visual or auditory disturbances with all the others in the database. A center scientist, Virginia Flanagan, is working with colleagues on a method for measuring and analyzing eye movements; others are studying posturography, or how people stand.

In the hallway, Zwergal pointed at a reproduction of "Senecio," a 1922 painting by Paul Klee. An abstracted face—a little goofy, but also haunting—loomed in front of an orange background. The figure's red pupils were not in line with each other. This is a common vestibular symptom known as skewed deviation, Zwergal explained. "The eyes are the window to the brain," he said.

On my second day in Munich, down the hall from the clinic, I visited Doreen Huppert, one of the few researchers who studies the history of dizziness. She had the look of an art gallerist, with shoulder-length blond hair and blue eyeliner. She spread a stack of papers across her desk:

descriptions of dizziness she has found in ancient texts from around the world, from Rome to China. In “The Yellow Emperor’s Classic of Internal Medicine,” a Chinese text from around 300 B.C., a man named Huang Di asks a doctor about height-induced vertigo. “Everything spins around and I feel dizzy,” Huang Di says. “What kind of Qi causes this?”

The word vertigo comes from the Latin verb *vertere*, which means to turn; another word, *caligo*, described dizziness that came from feelings of exultation or losing one’s grip on reality. Dizziness was understood as an emotional state as well as a physical one: when Vespasian assumed the role of Roman emperor, after Nero’s suicide, he reportedly felt “an earthquake” in his body and was seized by “a curious dizziness.” Claudius Galenus, a doctor who treated Marcus Aurelius, named the labyrinth in the inner ear after the Cretan myth, of the maze with a minotaur at its center.

When I told Huppert that I have vestibular migraines, she shuffled through her papers to find a quotation from Aretaeus of Cappadocia, who described a headache paired with erratic eye movements in second-century Rome. “The face is distorted spasmodically, the eyes remain glassy and rigid like horns or move to and fro forcedly, and the patient is dizzy,” Aretaeus wrote. He noted that patients may be overcome with “taedium vitae,” or a weariness of life. I felt a pang of solidarity with the ancient Romans.

Medical anatomists studied semicircular canals in the sixteenth century by cutting open cadavers and drawing their insides, but doctors didn’t gain a deeper understanding of the vestibular system until the nineteenth century. When a French scientist, Jean Pierre Flourens, removed and destroyed the inner-ear canals of pigeons, he showed that their heads started to move and the birds lost their balance.

There is still much left to discover. Zwergal told me that the center was investigating a biological test for vestibular migraine. Patients with traditional migraines often have elevated levels of a protein called calcitonin-gene-related peptide, or C.G.R.P. Could the same protein serve as a biomarker for vestibular migraine? When Zwergal asked me whether I wanted to try the test, I readily agreed.

At the clinic, I asked Zwergal what he needed from me—blood, urine, saliva? Actually, he explained, the protein was found in one’s eyes. I sat in a hard chair and leaned my head back as a researcher placed a thin plastic pipette up

against my tear duct. I thought about how, this past summer, I woke up each morning hoping that the dizziness had faded, and often cried when I discovered that it had not.

“Look up to the sky,” the researcher said, and collected seven microlitres of my tears.

Six years ago, on his family’s land in Indiana, the author John Green cleared a trail straight through the woods near his house. He dug up honeysuckle and ivy, laid down a bed of wood chips, and lined the way with bricks. A week later, his balance failed. “The world began to roll and spin,” he wrote in an essay about the experience. “I was suddenly a very small boat in very high seas.” He was diagnosed with labyrinthitis and needed six weeks to recover.

According to a video that Green made, dizziness pushed him to reexamine his life. He decided to stop pursuing projects with only money in mind and focus on what he was passionate about. “It’s tempting to make labyrinthitis a metaphor,” Green wrote. “I spent a month drawing a straight line of a trail only to be told that life is never simple paths—only dizzying labyrinths folding in on themselves.”

For a while, I found comfort in a metaphor, too. When my dizziness began, my apartment was decorated with a blue-and-white poster of a square labyrinth, by a graphic designer named Utsav Verma. A caption explained the difference between a labyrinth, which follows a single continuous path, and a maze, which contains many forks and dead ends. In the E.R., when the doctor said “labyrinthitis,” Verma’s print flashed in my mind.

Labyrinths, for me, became a symbol of acceptance. I told myself that even when I felt lost in a dizzy spell, I was slowly moving toward the center of something. Like Green, I reflected on what mattered to me: I quit my job, moved into a new apartment, and tried to create a more balanced work life. I visited labyrinths in New York and built one out of bricks, at a community garden where I volunteer.

Then, in July, I visited a famous twelfth-century labyrinth at the Notre-Dame de Chartres, in France. For nearly an hour, I stood in line with tourists, who seemed less interested in walking the winding path than in stopping to pray. Jostled by the crowd, feeling anything but acceptance, I realized that I had reached the limits of my metaphor. If there was any meaning in my experience, I wasn’t going to find it here. And so I left.

Back in New York, I was walking through a subway station, on my way to meet a friend for breakfast, when I checked my phone and saw that Zwergal had e-mailed me. I opened his message while climbing stairs, two at a time—an activity that, less than a year before, I would not have dared to attempt. My tears, Zwergal wrote, contained unusually high levels of C.G.R.P. I stopped on the stairs, taking in the news, and noticed some tears forming in my eyes.

Once you've been dizzy for a while, it can be hard to tell when you're feeling better. As I got used to going about daily activities, I sometimes asked myself: am I still dizzy, or not? What does a non-dizzy state even feel like? Lately, I have come to think of dizziness itself as an absence, not a presence. It is the opposite of balance—the foil to knowing where your body is in space. Many things have to be working properly for you to feel balanced; only one needs to malfunction to send your world spinning. This is why I had so much trouble talking about my dizziness. It's like trying to describe a silence, or a shadow.

The discovery of a protein in my tears is not life-changing, and potential treatments are some ways off. Even so, Zwergal's e-mail gave me the first piece of physical evidence I had ever had for my dizziness. I started taking supplements that help with migraines. Slowly, I began to feel better.

Recently, I woke up early and wondered whether I was ready to go for a jog. I had been avoiding running since last summer; it was too tightly linked to the day my dizziness set in. I tightened my laces, walked outside, and, with trepidation, broke into a slow run. I looked for any sign that something might be wrong, but the ground stayed steady. I jogged my old route and caught my breath in a waterfront park. I looked out at the river and saw sunlight shimmering on the surface. The water was in motion, and I was still. I turned away from the shore and ran home. ◆