As we begin 2021, hoping for a brighter, less socially distant year and look forward still to a time when a virus no longer isolates us from each other, it is worth remembering how isolating migraine can be. Here is a fable, based on a real person, to put it in true focus.

**Sarah’s Spider Web of Pain and Isolation**

An aspiring actor and musician, Sarah toils by day behind the counter of a smoothie bar in the Hell’s Kitchen neighborhood of New York City. Some nights she comes alive, rehearsing until the wee hours in her third-floor walkup. In the morning, she’ll apologize to her neighbors, who tolerate—even enjoy, mostly—the multitude of cacophonous din and melodies wafting from her tiny studio apartment like the sweet scent of freshly baked bread. Those are the good nights, when Sarah is not struck down with her face in her pillow, pounding pain launching from the nape of her neck to explode into her right (why always the right?) eye, in a muddled state, thoughts turning sluggish, like cold maple syrup, withheld and slow to form. Even after the pain eventually slides away, as it always does, she is empty as a shell, achy and undone, possessed of a flu-like melancholy that stills her voice and curbs her creativity.

Sarah knows our vernacular. She is a *person with migraine*. A few years ago, she was a *migraineur*, a term she rather liked that has now fallen out of favor—like calling a person with seizures an epileptic, her neurologist told her. When Sarah’s migraines began, she was 11, and a host of other monikers and labels were applied. She was “anxious,” “sensitive,” or “dehydrated.” She needed glasses, more vitamins, less screen time, or maybe more sleep. The abdominal agony that rode alongside her head pain was ascribed to “nerves,” “an irritable bowel,” and “attention seeking.” A bow-tied pediatric gastroenterologist at Lenox Hill Hospital told Sarah’s mother that Sarah had “gluten and lactose sensitivity,” and prescribed a waxy diet that took alarming weight off Sarah’s already willowy frame. A heavy-set naturopath in Park Slope, whose home office smelled of clover and mint, certain the diagnosis was small intestine bacterial overgrowth, prescribed a complex regime of 13 daily supplements, which Sarah dutifully swallowed. There were 4 cobalt pills, 3 white, 2 each of lime green and orangey mauve, 1 ruby red and Sarah’s favorite, a football-shaped capsule the color of wet newspaper tasting of licorice that she always took last to enjoy the lingering tingle of anise on her tongue.

Sara’s pain continued and strikes her down 6 to 9 times every month now, according to her headache app. As a teenager she missed more and more school, acting classes, piano and voice lessons, social gatherings, sleepovers, and field trips. She felt she was the queen of missing things, because that’s what most of her life had been about. This distressing notion solidified when she heard a song from another Sarah—Sarah Barrielles—singing. “Who died, and made you king of anything?” It hit her then, “I am the Queen of Maybe, as in maybe I’ll feel well enough to do the things I want to do, but then again maybe I’ll be nothing more than a shadow in a darkened room, huddled over a garbage pail, puking my guts out.”

The disability of migraine visits itself on Sarah with a familiar, grinding monotony—an uninvited guest laying waste to outings with friends, ruining dinner parties, shortening work shifts—as much a part of her as breathing. Adding insult to injury, when Sarah bowed out of invitations, she learned the hard way not to tell anyone it was because of migraine, finding nobody thought a headache, migraine or not, was sufficient reason to warrant abandoning plans.

At times migraine paralyzed Sarah, constricting her world and leaving her feeling she was entombed in a spider’s web of pain and isolation. The Queen of Maybe—as in, maybe I can make dinner, maybe I can go to that concert, maybe I can get to know you—if only my disease were under any sort of decent control. Sarah gradually narrowed her life, coming to the grim conclusion that it was better not to make plans than to cancel at the last minute because of crushing head pain, nausea, dizziness, and the unraveled thoughts that lay waste at the base of her brain, unable to get up and out. She missed vacations with friends, trips upstate to see her parents, and so much more.

In a metropolis of 8 million, Sarah became an island unto herself. To combat her isolation, she bought a cat from a neighbor moving out of the city, like so many amidst the pandemic. The cat is half Siamese, half ragdoll ball of fluff—a companion to cuddle when the shades are down and the agony intensifies. The neighbor called the cat Gus, a name Sarah cannot stand to cuddle when the shades are down and the agony intensifies. The neighbor called the cat Gus, a name Sarah cannot stand and vows to change as soon as the perfect one strikes her.

**Sarah Meets Dev**

On a gray late-autumn evening, Sarah strode down Ninth Avenue, having finished her shift at the smoothie bar. She was distracted and upset, because her manager told her that she had been missing too may shifts, and her job was in jeopardy. “Why can’t you work with a headache?” he sneered...
at her as she closed out the register, his voice steeped in condenscension, like he was talking to child. “Me? I just take a handful of aspirin and tough it out.” “It’s not just a regular headache, Todd”, was all she could think of in response.

As light snow cascaded down, the flakes reminded Sarah of a million moths dancing around streetlights. An icy breeze stung her eyes. She was glad for her pale pink mask with the Hello Kitty logo, which at least kept her mouth and nose warm. As she turned onto her block, Sarah felt her neck shiver, the faintest of sensations, barely there, but clearing telling her what lay in waiting. That faint sensation would become a dull ache, the dull ache a throbbing misery, then her right eye would ignite, and she’d be done for. She quickened her pace. The Queen of Maybe needed to take her medicine, get out of the cold and slip into darkness. Head down, eyes tearing from the wind and preoccupied by work stress and the brewing commotion at the base of her skull, Sarah slipped on unseen black ice, sending her feet high up in front of her as her neck arched back. For a moment time stands still, and she recalls later, a single crystal-clear thought was there, “please, please don’t let me hit my head on the sidewalk.”

Before he could think, Dev dived toward Sarah, arriving just in time to cradle her head in the palms of both hands. His Chianti fared less well, shattering in its brown paper bag, red juice sluicing out, the sidewalk looking like a crime scene. On this snowy, slate colored, late-autumn evening, Dev had stopped into his favorite wine shop on Ninth Avenue, grateful for just in time to cradle her head in the palms of both hands.

Sarah was shaken up, to be sure, but the frightful spill, interrupted at the last moment by Dev’s gentle hands instead of unforgiving cement, seemed to have knocked the migraine back. In the cold, prone on Ninth Avenue, head cradled in the hands of a stranger with eyes the color of amber and long, wavy hair, Sarah feels. . . good. They duck into an enclosed outdoor café, among the many that have sprung up in the city like mushrooms after a spring rain as the pandemic raged on and indoor dining became too risky. Over a maccha latte with oat milk for Sarah and Dev’s chi tea, they talk and laugh, and as the night wears on and the café closes, they find each other, kindred spirits.

But the Queen of Maybe holds back, guarded, afraid to commit, knowing she will repeatedly cancel plans, postpone activities, and, seemingly as always, disappoint. Long before this pandemic, Sarah’s life knew about quarantine—not from a virus, but from pain, and society’s lack of understanding and empathy. She considered thanking Dev politely, grabbing her jacket, muttering a line about meeting a friend in Chelsea. But there was something about this guy sitting across from her, smiling as he blew on his tea, his face honest with an expression as accessible as a summer sky. Sarah took a chance.

“I have migraines, really bad ones,” she launches in, “and sometimes I’m totally out of commission.” She stirs her latte nervously, holds her breath and awaits his reply.

“Ha, coincidence, me too,” Dev replies matter-of-factly, sipping his hot tea. “Mostly gone now, but yeah, they’re awful. Totally get what you’re saying.” Sarah exhaled, her heart threatening to leap out of her chest. She stared at Dev, daring for just a moment to hope and to dream. To Sarah, finding someone who understands her disease, who really got it, who got he. That was everything.

Dev had lived with whopping migraines since before he could read. His immigrant parents, an engineer and a pediatrician, sought care for their only child at New York University, across the George Washington Bridge from their Fort Lee home. Fortunately, a daily tablet for a few years, some biofeedback, and puberty seemed to beat back the pain and now Dev has only a handful of attacks each year. An architect at a trendy firm in the West Village, Dev still remembers to stay on schedule, sleep 8 hours, and hydrate after workouts, because when he forgets, a gentle but firm notice, like the beginning of a not-so-bad hangover, reminds him of the right path.

Who Knows What the Spring Will Bring

So that’s how the Queen of Maybe met the King of Everything. Despite the pandemic raging through the winter, in that most trying of times, Sarah and Dev become a pair. They had each other now, which was all that mattered. On a sunlit winter morning they read in The New York Times that a vaccine would soon be available—mass inoculations were on the way. Winter would give way to spring, the snow would melt, masks would come off, restaurants would open, birds would return to the city and sing loudly of a new world without the killer virus, and hope would once again spring eternal. That thought, of a future brighter and more open than she could have imagined, will sustain Sarah through the end of the pandemic, the end of isolation, and the beginning of a new life—not a life without pain, but a life made more complete by an understanding partner. The Queen of Maybe will give up her throne. Then it comes to her—what to call that little half Siamese, half ragdoll that nuzzles up next to them every night. A name that was always there, off in the shadows just out of reach, now presents itself as the obvious and only choice: Hope.