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Have You Heard of MS?

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It begins with a tingle in your arm, sharp but gentle. It reminds you of what it feels like to stand outside when the rain is light and coming down fast. You look down near your radius and ulna and feel the tiny pops of electricity discharge down into your hand, until it stops—passing quickly enough that you think you must have pinched a nerve while sleeping. You don't worry about going to the doctor. There is nothing to be seen, nothing to be felt. Before you go to sleep, you massage your forearm and release the day's tension.

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You wake in the morning to the feeling of spiders crawling up your arm. An army of tiny recluses has come to eat your tissue. They inject their sphingomyelinase, burning holes in your flesh from the inside out. As you get out of bed, you wipe your face, pick the crust from the corner of your eye and flick it onto the ground. You think about calling the doctor, but instead you call your



mother. She offers validation that what you're experiencing is strange. "If it doesn't go away, you should make an appointment," she says. "It doesn't hurt to get it checked out." You agree that sometimes doctors are there to help. Eventually the pop-rock sensation fades, and you put off making an appointment until the feeling in your arm transitions into intermittent shocks throughout your body—a of couple of jolts in your leg, some on your back, a few on your scalp, every now and again on the tongue. You can't feel the right side of your face, but it never lasts long. It's only a few seconds before the Novocain feeling fades, too. You become frightened by the collection of daily disturbances that creep up on you while you're doing the dishes, taking a shower, driving in the car. You search your symptoms online and fall asleep at night, hoping that a mass of cells hasn't gathered on your parietal lobe.

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When you go to the doctor, you'll wait in the small, aseptic examination room for ten minutes before he walks through the door and shakes your hand. Following the routine, he will start by asking, "What brings you in today?" You will tell him about the tingling and the occasional facial numbness, the fatigue and, now, the sudden urge to urinate. Hesitating, you'll add, "And sometimes it feels like water is dripping down my leg." You will laugh at yourself, embarrassed by your body. After your grocery list of ailments, he will look at you

with confusion. You are young. You should be healthy. He will ask you to sit on the uncomfortable half-bed that's covered by a sheet of thin white paper. He will shine the flashlight in your eyes, checking to see if your pupils are reactive to the light. He will palpate your back, pressing his clammy fingers onto your L₄. He will look for tender spots and spasms and bone deformities. "Stand up," he will say. Now is when you will show him that you can walk heel-to-toe in a straight line. You can close your eyes with your arms stretched out like you're pretending to be an airplane or anything that works like it's supposed to. He will then sit with you under the fluorescent lights while silence fills the sterile, cold room, and he will ask you, "Have you heard of MS?"

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You will nod your head, thinking about the commercials you've seen in the living room of your childhood home—the ones with women (much older than you) in wheelchairs. He will explain that multiple sclerosis affects women your age, twenty-three. He will throw around words like "autoimmune disease" and "demyelination," and he will ask, "Does anyone in your family have MS?" Your thoughts will become harder to articulate and the room will shrink as you say, "Not that I know of." He will respond that it isn't entirely genetic, that even though you are young, this is the age that many women notice their first symptoms, have their first "attack." He will explain that the

tingling and numbness and fatigue and sensations are common in women with MS. Optimistically, he will tell you that there are many other causes of these symptoms, ones much less severe. He will order blood tests to check your vitamin D, your B12, your magnesium, your thyroid, your WBC, your bilirubin, and when all those tests come back normal, he will refer you to a neurologist.

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When you go to the neurologist, he will walk into the room with confidence, shake your hand, and spend a short amount of time asking you where you went to school and what you're doing with your life while he performs the routine vitals. He will have you repeat the tests that your primary doctor performed. You show him that you can walk heel-to-toe and that you can stand with your eyes closed, while he lightly pushes you back, without falling. He will speak into his microphone that transcribes his sentences onto his computer: "Patient can walk heel-to-toe. Patient passed Romberg Test." He will then have you sit on the examination table, and he will ask you to lift your thigh as he presses his hand down on each leg to test their strength. "Don't let me win," he will say. He will point out the left leg weakness that you've known about for months. You first noticed the weakness while you were going upstairs (you pictured yourself installing one of those motorized chairs that attach to the railing). The neurologist will then have you lie down on the table and run

the heel of your left foot down your right shin, and the heel of your right foot down your left shin. One leg can do it, the other can't. He will say it could be weak back muscles, but given the paresthesia he will ask, "Have you heard of MS? It can cause poor coordination if there's a cerebellar lesion."

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You won't need to ask what a lesion is. You already know. He will repeat the information you found online. He will tell you that MS is an autoimmune disease that is very hard to diagnose. "It can take years," he will say. He will explain that your nerves are covered by myelin sheaths and when the body attacks the myelin, it damages the nerve endings, exposing your electrical wiring. He will say that the demyelination creates scar tissue, or lesions. Looking at you with sorrowful eyes, he will tell you that MS typically comes in waves and leaves those affected with arbitrary but dreadful symptoms—ones that can be as debilitating as the inability to walk or as casually maddening as the feeling of fireworks down your spine when you touch your chin to your chest. You will leave with referrals for an EMG (electromyography) and an MRI (magnetic resonance imaging).

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First, you'll go for the EMG. It's an in-office procedure that you don't want to research beforehand. If you do, you'll find forums describing the needles

that the doctor will stick into your defective body to check the health of your muscles and motor neurons. Some people say it's worse than a tattoo. Having had both, I can tell you that is true. When the needles go in your arms and legs and hands and feet, they will touch parts of you that you didn't even know existed—deep muscles that feel private and intimate and so very close to you. You'll close your eyes and breathe deeply. The doctor will occasionally tell you that “you're doing a good job.” As you lie there, staring at the ceiling, your palms will sweat, and you might even think of the other men who have taken their hands instead of needles, and touched you, until it was finally over. When the doctor is finished, he will leave the room so you can change back into your clothes. There will be blood on your legs.

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When you go to the hospital for an MRI, you get a wristband that tells the world, “I might be sick.” A technician will walk with you through the hallways, guiding you to a small room. She will ask you how your day is going, and you will lie and say it's going well. When you get to the room, she will ask you to change into the oversized hospital gown that is made of cotton and ties in the back, and after you have changed out of your clothes, you will stare at yourself in the mirror hanging on the wall and wonder if plaque is adhering to your brain and if there are dark holes in your grey matter. You will sit down in a chair and look at the

covers of magazines on the table. The top one says, “Jack Osbourne told the world he has MS.” You wonder if Jack Osbourne is your omen.

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When the technician comes back to get you, she will bring you into a larger room where it's you versus the MRI machine. You will crawl into your radiological coffin and select classical music for your playlist. She will give you a shot of gadolinium and tell you that you need to remain completely still while she's taking the pictures. Putting the headphones on, you will lie down and the machine will push you further and further back until you are completely enclosed. While you are inside of the MRI machine, Mozart will penetrate your eardrums, but despite the music you will hear loud wind-like noises circle around you. A small mirror will hang directly above your eyes, allowing you to see into the imaging room. The technician is eating her lunch and there will come a time where she puts down her sandwich and looks intently at the screen as if she is watching your fate unfold. You will watch her wipe her eyes and you will wonder if she's crying or if she has a cold. You will become fearful and your hands will feel like melting ice cubes and you will close your eyes and imagine how you will tell your mom you have multiple sclerosis. When you leave the room, she will walk with you through the hallways back to the waiting room, where, without looking at you, she will say, “The doctor will be in touch.”

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When the results from your EMG and MRI come back normal, your primary doctor will tell you that it often takes multiple MRIs until lesions shows up, and even if you do have MS, there is nothing that can be done to cure it. He will flip through the results and shake his head. He will sympathize with you and remind you that these things take time. He will remind you that it could be something else. He will talk about Fibromyalgia, Lupus, and Lyme disease.

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Then, he will do what some doctors do when they don't have an answer and you're a woman. He will talk to you about anxiety and depression. He will tell you that women can get symptoms like yours just from being anxious or sad, worried or stressed. Still, you will plead. "I wasn't like this, I wasn't like this, I wasn't like *this*." you will insist, until you were told you might have MS. You will think to yourself, "*Even if I was depressed, even if I do suffer from anxiety, I know my body.*" Repeat it. "*You know your body, you know your body, you know your body.*"

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Your doctor will be understanding. He agrees that your symptoms are concerning— but remember, you are a woman. Give it a year or so before other

doctors refer you to a psychiatrist, before they tell you that your unilateral leg weakness is from your heels, before the very pills they prescribed to you to help you through your medical limbo (Alprazolam and Zoloft) are used against you as evidence that you, a woman, must be clinically depressed—that there must be trauma you haven't healed from that is now manifesting itself on your body. Your body, your body, your body is *their* proof. It rests at the intersection of sick and female.

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After leaving the doctor's office, you will call your mother and share the results—no cancer, no MS. She's overwhelmed with happiness, and you agree that this is good news. The best. You will drive back to your apartment feeling defeated and invalidated, confused and hopeless. You will wonder if you made this all up inside your head, your tormented, womanly head with all its wild and rampant thoughts. You rationalize your symptoms by recounting your stressful childhood and recently failed relationships. With tears behind your eyes, you will question your own body. It is now the "other." You will lose trust in its ability to function the way it is meant to, the way it has for the past twenty-three years. As time passes, you will give up on making doctors' appointments, but you will continue to take your SSRI and Benzodiazepine, and you will wait for the drugs to build up in your bloodstream until you barely recognize the woman in the mirror. You will lay awake at night in your

hot apartment and feel the spiders crawl from your feet all the way up to your abdomen, and you will acknowledge that this could be Uhthoff's Sign—a temporary flare of neurological symptoms caused by the heat.

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You will know that the symptoms of MS are different for each person, but for you it will look like this: left leg and hand weakness, pain on the inside of your left forearm when your sweater brushes up against it (allodynia), tingling (paresthesia) and burning sensations throughout your legs (dysesthesia). You will experience dizziness and fatigue in the middle of the day, electrical shocks down your spine and in your feet when you touch your chin to your chest (Lhermitte's Sign). You will notice urine in your underwear when you use the restroom at lunch (urinary incontinence), and an unwavering sense of subtle fear will eventually become something you carry inside of you. For a while, you will stop dating, because you won't know how to act or what to say on a dinner date. You will lose your sense of self. You will forget the woman you were and you will grieve that loss every day. You will look up ways to help those with invisible diseases. You will momentarily forget about what you're going through. You will think about becoming a doctor. You will read articles about anti-inflammatory diets, and your friends will tell you that you're okay. You'll scream into your pillow and hope your neighbors can't

hear you. You'll research every neurological disease that mimics MS, and you'll remind yourself you're not crazy. You'll pray for an answer, as you curse God. You'll wonder how many women are aching inside of bodies that have been discarded by the doctors that "treat" them, and you'll think, over and over again, about how we don't get to see *those* scars—the ones stuck to our brains and our hearts.

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