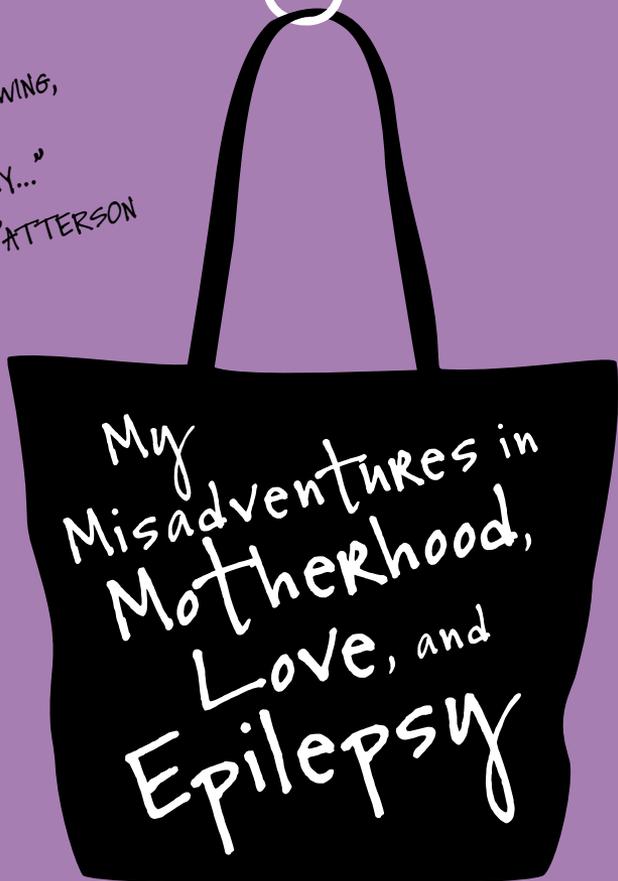


GOTHAM GIRL INTERRUPTED

"SMART, HARROWING,
HEART-WARMING,
AND VERY FUNNY..."
-JAMES PATTERSON



Alisa Kennedy Jones

GOTHAM GIRL INTERRUPTED

My Misadventures
in Motherhood, Love,
and Epilepsy

Alisa Kennedy Jones



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To my two, Olivia and Sophie,
and to Ed,
I made up this interpretive dance
with a stick and a ribbon
just for you.

I sing the body electric,
The armies of those I love engirth me and I engirth them,
They will not let me off till I go with them, respond to them,
And discorrupt them, and charge them full with the charge
of the soul.

—WALT WHITMAN

“Pull up your socks. Get over it.”

—NORA EPHRON

. . . And their hairs stand on end to a shimmer of leaves
or the movement of clouds, and the way that the tense
has been thrown like a switch, where the land turns
to dreams. . . .

—PAUL FARLEY, “Electricity,” a poem from
The Boy from the Chemist Is Here to See You

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Introduction

HELLO FRIEND! Thank you for picking up this book or for borrowing it from some well-intentioned acquaintance. And thank *you*, well-intentioned acquaintance, for foisting it upon some unsuspecting reader!

In 2010, at the age of forty, I was diagnosed with a severe form of epilepsy. The cause was a mystery. What is epilepsy, you ask? Simply put, it's an overabundance of electricity in the brain. Less simply put, it's a serious chronic neurological disorder characterized by sudden, recurrent episodes of sensory disturbance, loss of consciousness, or convulsions, associated with atypical electrical activity levels in the brain. With more than forty different types of seizures, epilepsy affects sixty-five million people worldwide. Because of the complex nature of the brain, epilepsy can strike at any age and manifest differently depending on a variety of factors.

My seizures are the kind most often portrayed in the media, meaning the afflicted person falls to the ground and thrashes around until some brave-hearted Samaritan comes to the rescue. They're dramatic. I look totally possessed when my eyes roll back into my head. If I'd been born during any other era, I'd

likely be institutionalized or burnt at the stake by some angry white guys. Over the years, I've had hundreds of seizures. They tend to involve four phases: the first is the *prodromal* phase, which means before the fever. This is the emotional or intuitive voice that whispers, "Some shit's about to go down." The second phase is the *aura*. Sometimes an aura can be as subtle as a shimmer of light at the edge of my field of vision. Other times, it's more hallucinogenic and has me asking, "Whoa, what kind of *Donnie Darko* movie is *this*?" Then, there's the third *ictal* phase—that's the seizure itself, the electrical storm in my brain where I'm usually on the ground in convulsions. To those around me, it may look agonizing but I'm actually not feeling any pain at this point—just a gorgeous black bliss. Lastly, comes the *post-ictal* phase where the convulsions have stopped and I'm out cold. In the moments when I'm regaining consciousness, I might be confused or frightened, but mostly I can really *only* focus on what's directly in front of me—often it's the smallest things.

Seizures tend to put one in a constant state of disaster preparedness. Picture a pilot fixing an airplane engine while it's flying or, in my case, as it's crashing. Some of the preparations I've made over the years might seem ridiculous, but then I've never claimed to be the most logical girl. Still, epilepsy is about having a plan, a "Here's what we're going to do . . ." and then improvising as things with the condition evolve.

People tend to think of epilepsy as something that primarily impacts children, but it can strike at any time, no matter how healthy you are. As with so many stigmatized chronic conditions, I tried to keep mine under the radar for years for fear that people might misjudge, mock, or withdraw. If I wasn't having seizures all the time, I reasoned, not everyone *had* to know.

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Then, in 2015, I had “the big one” that nearly destroyed me, laid me flat and left me the most vulnerable I’ve ever been. It was brutal. It changed almost every aspect of my life, forcing me to start completely over from zero—I couldn’t speak, eat, or work. I couldn’t go out in public without frightening people. The experience led me to believe that people *do* need to know more about this condition and that perhaps they also needed a different narrative approach. I know I certainly did.

For years, I’ve called myself a spaz. Why? Because when you are a nerdy, too-tall, introverted, single girl-mom with chunky glasses, who has epilepsy, anxiety, and depression, at a certain point you want to take the derogative term back from the historically mean asshats of the world—primarily people who say epileptics are spastic freaks who are addicts, junkies, drunks, crazy, dangerous, deranged, possessed, demonic, divine, incontinent, unreliable, unable to hold down a job, unable to care for children, and so on.

Whether you have epilepsy or not, chances are you know someone who is affected by it. I happen to think we are *all* a little neurodiverse—meaning we are all uniquely neurologically wired. Where one person is the quintessential extroverted life-of-the-party, another is an introvert completely overwhelmed by people, chatter, and music. Everyone experiences the world according to her/his/their neurological makeup, and we shouldn’t have to go around faking “normal” all the time.

Epilepsy is certainly not *all* that defines me, but it’s also a thing that’s not going away anytime soon. To go around hiding the fact is not only exhausting; it’s totally missing out on the richness and hilarity that comes when we are all put together, as people, side by side and forced to understand and deal with difference. And I’m with Carrie Fisher on this one; I am

constantly perplexed by the stigma attached to mental illness, the various chronic neurological conditions and the differently-abled. If you are walking (or rolling) around New York City or any town with epilepsy, living your life, connecting with people and able to feel compassion for friends, family, and your fellow humans, or to feel even slightly productive in your own right, you deserve a standing ovation—not a kick in the teeth.

We need to stop being such uptight weenies and admit that it's high time the world learns to adapt, make room for, and *embrace* all kinds of people along the spectrum of ability and neurodiversity instead of everyone always tiptoeing around topics of neurology, mental illness, autism, epilepsy, and so many other chronic conditions governed by our brains and genetics.

Over the years, people's questions about my conditions have ranged from "Do seizures hurt?" to "How come you're not completely developmentally delayed and/or traumatized?" More often than not, the questions are more a reflection of the person asking them than anything to do with me. My answers are typically, "No, my seizures don't hurt" and, "Actually, they can be quite beautiful." Indeed, some of the instances when I've felt most intellectually inspired, most human, and often most creative in my life happen when I fall, thrash around, and then get back up. For me, it's like the ultimate system reboot—a vibrant Technicolor awakening each time. I won't pretend that it isn't a doozy or not complicated, but my family (and Oprah) raised me to believe that my ideas, thoughts, and opinions mattered, that they were grounds for more inquiry, and that it's only when we are able to connect the dots between our deepest points of vulnerability and tell our stories that we can change things.

So, this is my story about *not* tiptoeing around the difficult dots. Little did I know (as I was writing this) how much the

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concept of neurodiversity would come to matter, the idea that whether you have anxiety, depression, addiction, bipolar disorder, autism, or epilepsy, the point is your own individual neural wiring might in fact be your magic rather than a tragedy, that it might allow for finding meaning in places you never expect it to and with people you'd never anticipate having in your life. Yes, you may be different; you may be in a chronic waltz to feel at home in your head or in your body. You may even feel trapped in there for a long stretch (as I was), but it doesn't make you less; it makes you magic.

That's what this book is about.

The one superpower epilepsy (or any chronic condition for that matter) *shouldn't* give you, however, is invisibility, so I wanted to write stories about loveable weirdos with all different types of wiring to ask, Why can't the awkward, spazzy nerd win after all? Why can't she/he/they end up with the good, funny, amazing person who is her/his/their own equal and opposite counterpart? What's to say they can't live out a truly great rom-com? Why can't they have a full tribe of kooky friends and family who have their back? Why can't they have a rich, rewarding career? Why, with technology, science, and modern medicine should there be any hindrance?

For my part, I have told these stories as I remember them, which means salted and peppered with truth and exaggeration, with names changed to protect the guilty and the innocent, starting with my parents. At times, it's more of a rescue-and-recovery operation than a memoir because I'm filling in certain blanks with reflections, bad ideas, and inappropriate metaphors. I wrote them in a kind of fever dream, my own series of seizures, a lightning-bolt flipbook of time-lapse photography on a hyper-loop. Factor in a few grim flashbacks, select absurd hypotheses,

and misunderstandings made funnier with prescription drugs, and there might be a book in it.

Epilepsy can lure you into powering down your whole self—especially your funny side—and I believe this is a mistake. Some things are out of my control. Others, well . . . let's just say are a self-made mess. Some are absurd. The breezy humor you find in this book may be a defense mechanism, but I believe it's a necessary one at times and an excellent self-care tool when you can tap into it. By taking a comedic approach to these stories, please know that there's never any intention to trivialize or diminish the suffering people experience as a result of epilepsy. It's a devastating condition, but we don't have to *stay* devastated.

Okay, time to get to your safe space, people. This is how it always begins. Here comes the shimmer . . .

1

"The Big One" (2015)

"DON'T SPEAK. It's going to be okay," he whispers.
Okay, sure. I don't have to talk at all. I'll do whatever you tell me because I am a really good student and . . . wait, where am I? I feel . . . wrung out like a dirty dishrag. And *who* is *this guy* standing over me? Well, hello, smoldering antihero! Mothertrucker, he's hot and his voice is so . . . swarthy?

"I want you to blink if you can understand me."

I close my eyes.

I open my eyes.

"Did you take something, Ms. Jones? Blink once for 'yes,' twice for 'no.'"

I try to shake my head "no" but I can't move. In fact, I can't feel anything. I think I'm strapped to one of those neck-spine boards they use to keep you from being paralyzed after an accident. For now, I can only look up at this man, whose hair is just stunning. So lustrous and thick, it's like a 1970s ultrashag carpet. You want to camp out on it and play Monopoly like a horny twelve-year-old at a slumber party.

Now, before we go any further, you should know it's practically a law in New York City and rom-coms everywhere, if at

any point in your beautiful life you ever pass out (for whatever reason—hold on, I am about to explain), you *will* invariably be woken up by a handsome, scruffy firefighter or paramedic type, someone authentically brave and badass, with a deep voice and great hair—like this guy over me. Whether you’ve gotten black-out drunk and inadvertently slept with him, or say your brain decided to spontaneously combust in the grocery store, it *will* happen at least once. In my case, it’s the latter scenario.

Still, the calculus of this exact moment, of waking up to an amazingly handsome man telling me to blink, isn’t quite computing. For God’s sake, I was just going for coffee. Wasn’t I? Not fancy coffee made for me by some well-intentioned barista with piercings and a soul patch. No, for once, I was actually buying coffee *in a can* to make at home because I was doing like Suze Orman told me and putting my latte money where it might count someday: drugs. Lots and lots of drugs.

As I made my way down Eighty-Sixth Street on the Upper West Side of Manhattan, I reveled in what felt like the first real day of spring. The air held a clean crispness. Think iceberg lettuce in a wedge salad. The kind they still serve at old-school steakhouses named Kevin’s or Ken’s. Where only a week ago the winter of 2015 had been as frigid and grim as in *The Shining*, now the glass and gunmetal buildings glowed sunstruck. Everyone was smile-squinting. Yes, even the most curmudgeonly of New Yorkers do this. That old guy on the stoop next door who always smokes a cigar in his purple bowtie, even *he* was smile-squinting. It’s like when the clouds part in Portland and everyone rushes outside for a fix of glorious vitamin D.

I slowed to bask in a warm, luxurious squint. I felt the muscles around my eyes scrunching up in the grin-worthy brightness. Shimmering fractals unfurled before me. To the west, a

double note of thunder over New Jersey. Or had I imagined it? I've always been oddly sensitive to storms, but I felt good. Maybe a slight itch of fatigue? I had been pulling long hours at work lately. I felt a subterranean murmur, like the thrumming of bees in the back corner of my mind. My epilepsy—or more specifically, my *seizures*—often begin this way. Well, most of the time. There's the shimmer at the edge of my vision, the thrum and the thrash. Should I turn back? No. I wasn't going to have one today, I told myself, pressing on. Not today. I feel fine. *Just breathe, girly.*

Mostly, I was feeling righteous. After a productive morning working on a new creative campaign for a live televised superhero takeover of the city, I'd survived hot yoga without being singled out by the teacher, Yogi Wallace, who somehow always managed to stupefy the class with his radiant smugness.

And yes, in that moment on the street, it might as well have been the opening credits to *Mary Tyler Moore* where she tosses her hat high up in the air just as you hear the theme song go, "You're gonna make it after all," because I *was* making it. After all.

I had gotten the best job in advertising a writer could get, making the most money of my entire adult life. Instead of navigating nomadically, job to job, from writing one bad TV crime pilot after another, I could finally afford to be alive without constant single-mother anxiety. The kind where you're always holding your breath at the checkout to see if the debit card clears. Finally, after years of scrambling, nose-to-stinky-grindstone, scraping to get by, sucking up to entertainment and tech-preneuer douchebags, who spoke almost exclusively in corporate synergism jargon interspersed with words like "hella" and "bro," I finally felt respected at my job.

I'd made the big move back to the East Coast for work, and so both my daughters could be nearer to their dad. The girls seemed happy. For the first time in years, they were finally going to have everything they needed. They weren't going to be the poor, broken-home kids that other parents pitied. They'd already been through too much in their short lives. Suffice it to say, I had made it through a feral divorce—a veritable blood sport of blame, self-recrimination, and dueling indictments. If you've ever been divorced, you'll immediately get this: it's the equivalent of waking up and being in a head-on car accident every day for about two years, complete with neck braces, scary forms, and even scarier attorneys. While I hadn't escaped completely unscathed, my hair still looked good, and my little blog, *Gotham Girl*, an ongoing love letter to New York City weirdos, was starting to find real traction. Plus, I hadn't had a seizure in almost a year. This was a big deal for me because as I mentioned earlier, my brain likes to blow a fuse (or all the fuses) now and then.

I'd spent five years trying to crack the code of epilepsy with different treatments, medications, diets, gurus, and whatnot. With each grand mal seizure, where I'd lose consciousness, drop to the ground, and convulse uncontrollably, my world became a near-constant obstacle course filled with sharp corners and hard edges. I'd awaken to crazy bumps, bruises, cuts, and concussions. Looming over me was an ever-changing cast of freaked-out strangers, prickly doctors, and loads of ambulances, bills, and consequences. But I'd solved it. The meds were finally working. *I was working.*

I was also in love. More love than I'd been in for what seemed like nine hundred thousand years, and I didn't want to jinx it. At this point, I'd probably qualified to have my virginity reinstated. His name was Loïc, short for Louis, and he was my

exact kind of crazy: a good-quirky-smart-silly Frenchy. We laughed nonstop—at my very broken French, at his even more broken English, with ridiculous conversations where he would implore me, “Mon amour, why not just to use zee sugar cubes if you always get zee wrong amount of sugar in zee café every morning? It’s plus exacte, non?”

Okay, yes, I was in love with Pepé Le Pew, but he was right; I *did* always grumble about putting the wrong amount of sugar in my coffee every morning, and these were *exactly* the kind of silly tête-à-têtes that I wanted to be having after all the years of struggle. Mostly, I could see us getting married one day in some handmade backyard ceremony in France—complete with Polaroids, ukulele music, and crafts that made the guests all feel mildly superior. I could feel a future weaving itself together like some richly patterned fabric.

I felt such long-legged joy as I walked into the grim little grocery store on the corner, only slightly bigger than a bodega. I was rocking my favorite jacket and my ever-present big bag, a Louis Vuitton Empreinte Citadine tote—a gift from an old squeeze—a terrible boyfriend but one with great taste in purses. To be clear, my big bag doesn’t look terribly fancy at first glance, but it is. For all you nerd ladies out there, it’s like Mary Pop-pins’s carpetbag when she meets the kiddies for the first time. It holds everything: computers, baby wipes, extra shoes, subway reading, a built-in pharmacy, too much lipstick, and even its own wallet on a leather string so you never lose it. How smart is that? I swear, if this bag had running water and electricity, I’d probably live in it.

Still, as I made my way down the coffee aisle, I was overcome with a sense of satisfaction that had nothing whatsoever to do with accessories. I felt I’d finally become the person I’d

always wanted to be: a solid person who wasn't totally failing at becoming a better person, who thought of others first, who paid all of her bills and all of her dues, who didn't let circumstance rule outcome *entirely*, who donated to public radio, who read *real* books, who showed up on time (more often than not), and one who'd let go of past gripes, grudges, and regrets.

Yes, I was finally figuring things out, and feeling pretty badass. Again, I shook off the hiss in my head, or was it the damn fluorescent tube lighting of the store? I couldn't tell, but just as I bent down for the can of Martinson Breakfast Blend coffee (smooth mild roast), the world fell away.

(My editor wants me to say here that *I* melted into the floor, but that's not actually how seizures work for me. There is no time and no feeling other than a buzzing in my head and sometimes maybe a tightening around my temples. But *I* don't melt into anything. Instead, it's the world that starts to shimmer, and *it* melts away in a swift vertical wash of slivering, slicing black cuts, like eyelashes blinking closed. Or *eyelashes*, as I call them. It's accompanied by a momentary feeling of exultation that, maybe, only I truly know, but still it's magnificent because it's a moment of pure, ecstatic joy.)

"Ms. Jones, *did* you take anything?"

Oh . . . you again. I tune back into the swarthy stranger above me now. If they were doling out middle school nicknames, his would simply be "The Hair." He reminds me of a pirate: a tidy, well-groomed pirate with perfect teeth, which now that I think about it, has to be spectacularly rare because everybody knows pirates never brush or floss. They're too busy looting. It's practically science.

I wish he would kiss me. For a second, he leans in closer and I think he might. Wait, no, I love someone. I love someone, don't

"THE BIG ONE" (2015)

I? Where am I? Things shift, and he looks so sorry and sad, as if someone has just spanked a puppy. I feel instantly terrible for him. In my head, I can hear myself: "What's wrong, *Mr. Hair?*" Still, there is a heaviness now bearing down on him, and on me, a kind of reverse gravity. He seems physically pained, like his chest is about to cave in. I take in his shirt: there was a medical snake-cross-thingy on the pocket, and he is covered in blood and bits of something pinkish-gray. Oh man, is that my brain?

Wait . . . did I just get brain on hot-hair-guy? And wow, that's *a whole lot* of blood. That's pretty much a *Walking Dead* amount of blood. And then I realize; it's happened again. I've had another one—another seizure. That was the shimmer I felt. The thrum. The hiss.

As I lay there wishing my brain bits were back inside my head where they belong, I think, *holy crapdazzle* . . . isn't this just the absolute, foundational analogy for life? The moment you think you're the person you've always wanted to be, suddenly you're *not*. The world rushes in to compel you to become something *more*, something different, something *else*, because nature abhors a vacuum. Where there's a void, nature always seeks to fill it with some kind of form. And that really *is* science.

You may be wondering, is this how this person really thinks all the time? Even after a seizure? Or is it creative reimagining? The short answer is, this is pretty much how I process the world. Even in the middle of a crisis, I live in a state of constant reimagining, creative commentary, and improvisation. Plus, again, I've had loads of these. I've never been a huge fan of the survivor narrative. Inspiration porn isn't really my jam as not all suffering is redemptive or transformative. Some of it is just *hard* and majorly sucky. To generalize wildly for a moment, I think you take certain risks; you make yourself vulnerable to go after the

thing you want. In the process, you fall, you thrash and flail around; maybe you get banged up, maybe even a little bloody, but then you get back up and press on. Just like a seizure. Fall, thrash around, get back up, and press on.

I can't really blink my answer to The Hair about having taken anything (mostly because I take *everything*), so I croak a whisper up to him as best I can, "I-nuh-staz . . ."

"A what?" he says, leaning down now as though I am whispering a code word for entry into a secret society.

I try again, "uh sppzzazzz . . ."

He cocks his head, looking quizzical. "A spaz?"

I close my eyes.

I open my eyes.

He suppresses a smile and says, "You've had a seizure." To his partner, a guy I can't quite see, he rattles off, "Status epilepticus . . . blah-blah-dee-blah-blah . . ." Everything sounds like molasses now. ". . . Dislocated jaw, compound facial, cranial, dental fractures and lacerations . . ."

Processing his words, all I can do is blink in a Morse code of my own making: *Good God, why couldn't I have fallen on my big bag instead of my face? What's the point of having a big bag if it doesn't at least function as a pillow or a helmet?*

Then he is back talking to me, trying to channel his most upbeat but sorry self: "There are things they can do . . . implants, prosthetics . . ."

Prosthetics? *Dear me, prosthetic what?* His words trail off again, and I can see him realizing that just before this moment, maybe only twenty minutes ago, I was probably a very different girl than I am now. And I just want to tell him, "Don't be sad, *hot-hair-ambulance guy*. This isn't my first brush with the electric."