

RULES FOR 50/50 CHANCES



FALL

Rule #1: Don't make
plans you can't keep.

One

IF YOU HAD A CRYSTAL BALL, LIKE IN A FAIRY TALE—OR a magic mirror or one wish or whatever—would you want to know how you were going to die? Would you want to watch it happen, in slow motion, every day?

My mother is my crystal ball.

On Sunday I wake up to glass hitting the kitchen floor.

It's the Sunday before Labor Day, the last Sunday of my last summer vacation of high school. I have no ballet today, and what I'd really like to do is sleep late, then nothing in particular. No such luck.

It's a juice glass. I can tell because the sound is more like a tinkling-shatter than a heavy crash. My mother drops things with some regularity these days, so I've become aware of the particular cadences of different materials hitting the floor. This is a thin glass.

When I get down to the kitchen, my mother is standing barefoot by the sink. Her hands are shaking. And there's a glass, formerly used for holding juice, in shards on the floor.

“I’m sssuch an *idiot*,” she says. “Sssorry.” Her words slur gently, not a stutter but like her mouth is full of slick ice cubes, like they have more and more regularly over the last six months.

“It was an accident,” I say. “Careful. You’ll cut yourself.” I bend over and pile a few shards in my palm.

My father pounds down the stairs in his towel, dripping from the shower. “What happened?”

“Just this fffool,” Mom says. “Throwing gggllasses.”

“That’s my wife you’re talking about. Don’t call her a fool.” He leans over and kisses her. “I’ll get a broom.” As he crosses to the pantry, he calls over his shoulder to me. “Get a move on, kid! Places to go, people to see! It’s a beautiful day to walk for genetic research!”

Indeed. We’ve been walking for genetic research every Labor Day weekend since my mother’s diagnosis, when I was twelve, which makes this my sixth Walk for Rare Genes. The walk is sponsored by an organization that does advocacy for something like seven thousand genetic diseases, most of which are too rare for anyone to particularly care about on their own. Unless, of course, you find yourself in possession of one, like we do.

Ours is a mutated gene on chromosome 4. The gene’s called huntingtin, and if yours is messed up like my mother’s, you end up with Huntington’s disease. Don’t ask why the two huntingtons—the gene and the name—are spelled differently; I have no idea. What I do know is that if you’ve got that mistake on chromosome 4, like my mother does—the tiniest typo in a book with billions of words—then your huntingtin gene goes haywire and basically wreaks havoc in your brain. Things start

deteriorating in your mind and your body, until you're not the person you once were, and then they keep deteriorating until you die. Slowly, painfully, and without any chance of reversal.

Oh, and as far as my genes are concerned—it doesn't matter that my father doesn't carry the mutation on chromosome 4. I only need to inherit the mutated gene from my mother to be royally screwed. Which means that after watching my mother fall apart, I have a fifty-fifty chance of falling apart, too.

I shower quickly, and dig out a navy blue tank top to wear with jeans. Blue is the color of the day, because, you know, the whole genes/jeans thing. Even the rare genes ribbon is made of denim. I've gotta hand it to them, this organization may be representing diseases that affect only tiny groups of people around the world, but their marketing people know what they're doing.

Just as I'm rubbing down my wet hair with a towel, Dad pokes his head into my bedroom, knocking once as he opens the door. He's dressed head to toe in blue, too—blue T-shirt, blue jeans; even his Nikes have blue trim, but I think that's an accident.

"All set?" he says.

"Bells on, I assure you," I say.

"Look, I know you're not that psyched about this." He taps his fist against the door frame a couple times. "But it's important to your mother."

"Is it?" I'm pretty sure that at this point, Mom doesn't even care that we do this every year. Maybe she'd prefer to just sit in the backyard all afternoon and enjoy the nice weather without

the fuss. Every time there's a beautiful day now, I wonder when it'll be the last day that Mom registers as beautiful.

The look on Dad's face makes me regret saying anything, though. A few years ago, I thought this walk was fun—joining all the other families in a sea of blue shirts and balloons, eating caramel popcorn and cheering all the way along the ten-mile route. Your feet hurt at the end, and that meant you'd done something worthwhile. There was a feeling of solidarity with all those other people whose lives had also been turned upside down by their own invisible bad luck.

But now, the sight of all those kids in wheelchairs and their parents plastering smiles across their faces like *they're actually okay with this* makes me feel kind of nauseous. Plus, Mom can't walk the whole way by herself anymore, so she uses her own wheelchair, and walking alongside her makes me feel like I'm supposed to be one of those smile-plasterers, too. It's all, "Hey, world, I'm so strong!" I'm not.

Still, I don't feel like bumming Dad out. "I'll be right down," I say, trying to soften my tone. He winks at me and disappears down the stairs.

When I find my family in the living room a few minutes later, Dad is loading bottles of water into a backpack and my grandmother is putting sunscreen on every visible inch of my mother and herself.

"Rose," Mom says, smiling at me, her mood already having shifted from our juice glass morning. "Ready?"

For the walk, maybe, Mom. Not for anything else.

* * *

When we get to the Boston Common, the registration area is already buzzing with blue-clad families. The organizers, recognizable by their enormous, spongy foam hats shaped like blue DNA double helixes, are chanting into megaphones: “Care about rare! Care about rare!” Across the grass, the starting line is marked by a huge, double-helix archway formed from blue balloons. There’s a steel drum band playing some cheery Caribbean tune, and circus performers (in blue, obviously) walking on stilts and carrying signage advertising a free performance by Blue Man Group at the end of the day.

Even the sky is appropriately clad for the walk—bright blue, of course, tempered only by an occasional wispy cloud. The whole Eastern Seaboard is supposed to get slammed with a hurricane tomorrow, but today is beautiful. The air is unusually crisp for so early in September—there’s no humidity, and it smells of freshly cut grass plus something like pipe tobacco. (I’m not sure it’s really the smell of pipe tobacco—I don’t smoke a pipe, obviously—but my dad used to when I was little, just every now and then on a nice fall evening, so that’s what fall smells like to me.) It’s hard to maintain an oppositional stance to this outing when the weather is so unrelentingly gorgeous.

Dad registers us, while Gram, Mom, and I stand around, taking in the scene. Or Gram and I do, anyway. Mom sits in her chair, looking mildly irritated every time one of us tries to fuss with something on her—her floppy sun hat, the pillow behind her back, the settings on her chair. Dad emerges from the crowd and passes around our T-shirts—all extra large, of course. Why do they only seem to order XLs and XXLs for these things? When I pull the T-shirt on over my clothes, it reaches

my mid-thighs. My best friend, Lena, could probably find a way to belt this and make it look trendy.

“Right, so, we’re in the ten a.m. kickoff group, so we’ve got thirty minutes until we need to head to the starting line. Anyone need a port-a-potty?” Dad asks. Gram, who’s helping Mom into her blue T-shirt, waves him off.

I shake my head. “I’m going to find some orange juice. Want anything?”

Dad checks his watch again. “No thanks. Meet us back here in fifteen?”

I flash him a grim thumbs-up and wander off, trying to find a way through the crowd. By the registration tables, my eyes land on a young couple with two kids, one on foot and the other in a wheelchair, carrying a placard with a third little girl’s picture on it. Blond curls frame a cherubic little face that looks almost perfect except that her features are slightly distorted—her forehead bulges out too much, her eyes protrude, her cheeks are distended. I look away.

The registration tables form a long border along one side of the park, and beyond them, there’s just empty green space, where a few normal people are out for a nice Sunday morning walk (no doubt wondering how they ended up in this mess). I make a bee-line for the normality.

“Hey there!” A guy a little older than me touches my arm as I try to get past the registration area. “Care about rare?” He grins at me. He’s wearing a collared shirt under his blue T-shirt and one of those double-helix hats. I force a smile.

“I see you’re here for the walk. Starting line’s that way.” He points, helpfully, in case I hadn’t noted the giant balloon arch and multiple signs pointing in the opposite direction from where I’m headed.

“Right, I’m just—I was just getting some air.”

He tucks his clipboard under his arm and takes me in for a moment, concerned. “The crowd’s a little overwhelming,” he says with an earnest nod.

“I guess, yeah.”

“It’s great to have so many people come out for this, though. Did you know that taken together, rare genetic disorders are one of the leading causes of childhood deaths in the world?” I didn’t know that. “I’m Levi, by the way.” He reaches out and practically grabs my hand to shake it.

“Can I ask you a favor?” he says, not waiting for me to introduce myself in return. “I’m short on volunteers handing out the ribbons over there.” He gestures toward one of the tables. “Mind giving us a hand?”

I squirm. “Oh, I . . . My family’s waiting, you know? I’m supposed to be walking with them.”

Levi nods. “Sure, sure, I understand. I just thought, you know, if you’re not feeling the crowd . . . I could use some help. No worries. Enjoy the day! Care about rare!” He gives me a little salute, and then saunters off into the crowd.

I stare out across the sea of blue, and for a second, I let myself wonder about all those people, about how their lives are like mine or not, and how much their genes dictate their every moment. Maybe it wouldn’t be so bad to try something different for this year’s walk.

“Hey, Levi!” I call after him. “Where are those ribbons?”

Levi gives me a big smile like he knew I’d come around, and introduces me to the lead volunteer at the ribbon table—a woman named Margaret—who explains that I’ll need to pin the ribbons directly onto most of the children because they won’t be able to manage the safety pins. I briefly wonder if we couldn’t speed things up by handing the ribbons to the parents and letting them deal with the safety pin issue, but I don’t say anything. Instead, I watch Margaret for a minute, grinning and calling out, “Care about rare!” as she waves ribbons at passersby. Then I plaster a smile on my face and follow her lead.

“Special delivery! Where do you want these, *Marg-oh?*” booms a male voice, coming up behind us. I turn, assuming it’s Levi, but it isn’t. It’s a guy, my age-ish, carrying what I assume is another box of ribbons for the masses.

“Just put ’em back here for now,” Margaret says, nodding toward our table. “Try not to leave the boxes someplace I’ll trip over them, please, Caleb!”

The guy tucks the box of ribbons under the table and dusts off his hands. “All set.” He notices me standing there and offers me his hand. “I’m Caleb, by the way.”

“So I hear. Rose.” His handshake is so firm that it’s almost painful.

For a split second, I register that I’m surprised to see a black guy here, and then scold myself for it. There are plenty of hereditary conditions that are common in black families, I know, but I guess most of the people I’ve encountered so far through the Rare Genes Project have been white. I’m not sure what that

says about the organization itself, but the realization makes my stomach twist a little bit with embarrassment.

Caleb is probably a foot taller than me, with a wiry build, an almost-shaved head, and thick, black plastic glasses—cute, in a skinny, nerdy kind of way. And the way he keeps his eyes on me, like we’re going to exchange more than just our names, is disarming.

A kid tugs at my arm. “Hey! Can I have a ribbon, lady?”

“Lady! Who you callin’ ‘lady,’ kid?” I tease, as I lean down to pin the ribbon on the little boy’s shirt. He’s probably six years old, pudgy-cheeked, and lacking in any discernible neck between the orb that is his midsection and the orb that is his head.

“*You’re* a lady!” says Chubs, sticking his tongue out at me.

“Well, you’re not much of a gentleman, are you?” I say, sticking out my tongue in return. Chubs lumbers off. When I straighten back up, Caleb’s watching me and chuckling.

“What?” I ask, squinting at him.

Caleb shrugs, in a kind of casual-cool-attractive way. “Nothing, nothing. You have little siblings?”

“Negative. I just like kids.” When I was in middle school I did the Reading Buddies program with the kindergartners. All I had to do was read Arthur books to a little girl named Annabelle for an hour every week, and she more or less thought I was the coolest person in the world. That’s why I like little kids: they’re uncomplicated.

Caleb leans against the ribbon table, his arms crossed. “Well, you can have my little sisters if you want them.”

I laugh. “Uh, no thanks. My family is unwieldy enough as it is.”

“Fair enough,” says Caleb, taking a pile of ribbons from the table and coming around to stand next to me. “Mind if I join you for the ribbon-handing-out?”

“Are you trying to impinge on my ribbon territory, here?” I say.

“Clearly.” He rolls one of the ribbons over in his fingers and chuckles. “Blue jeans.”

“Get it?”

“Got it, thanks,” he says, grinning at me. “Not my first time at the rodeo, my friend.”

Standing so close, I notice the gap between Caleb’s front teeth. It’s probably big enough to slot a quarter in, but in a charming kind of way. It gives his smile character. Over his left eyebrow, there’s a small, wrinkled scar. Whatever his genetic oddity is, it isn’t readily on show.

“Where’d you get that scar from?”

He puts a hand automatically to his forehead and rubs his eyebrow. “This one? Kicked in the face, school playground, age seven.”

“Are there others?” I ask.

“Others?”

“You said, ‘This one?’ like there are others.”

“Oh, right. A few. I guess I played rough as a kid. Damaged goods.”

I start to try to say something clever, about how since he’s volunteering at the rare genes walk I already assumed he was damaged goods, but I can’t quite come up with the right words.

Levi reappears, carrying a megaphone in one hand and a walkie-talkie in the other. “Ribbon bearers, I beseech you to listen up!”

“Did he just say ‘beseech’?” Caleb whispers, leaning toward me so that his shoulder is almost touching mine. The sudden shift in proximity bumps my heart rate up a notch.

“I’m pretty sure he did.”

“I need to ask you a favor,” Levi continues. “I’ve been asked to send a couple volunteers over to get some fresh boxes of T-shirts and bring them back to registration. Can I send you two?” he says, pointing to me and Caleb.

“Excellente,” Levi goes on, without waiting for a response. “T-shirt boxes are in the main supply tent, which is thataway.” He points across the Common to a huge white tent that looks like it could be harboring a college graduation or a decadent outdoor wedding. “Just take whatever they give you.”

I check my phone and see that I have a text from Dad, wondering where I am. It’s already ten o’clock. I send him a quick reply. I suspect he’ll be fine with me volunteering instead of walking—that must count as showing my commitment to the cause—and sure enough, I get a text back right away: “Great! Love, Dad.” He still hasn’t learned that he doesn’t need to sign his text messages.

Caleb and I set off across the green, threading our way through the crowd. “So you’re not new to this either, I take it?” Caleb asks after a moment.

“No. We’ve come every year since my mom’s diagnosis. I tried to get out of it this year, actually.”

Caleb laughs. “I guess I can’t blame you. It’s a lot of . . . rare genes. In one place.” I can feel him looking at me, but I keep my eyes on the ground. “I like it, though. It’s nice to feel like part of a big thing. The cancer people get a walk so we should too, right?”

“Seriously. The cancer people get like ten walks.”

“At least.”

The truth is, the rare genes walk is a nice idea in theory, but in practice, most of the people here are dealing with different diseases and competing interests. We all want our disease to get the attention, because attention means funding and funding means research and research could mean a cure. I keep that uncharitable thought to myself, obviously.

“So, what’s your—you know . . .” He trails off. My disease, he means. I can tell.

“My mom has Huntington’s.”

I sense Caleb sort of tighten up next to me. That’s the Huntington’s effect. For people who know what it means, who can picture the total terribleness of what you’re talking about, it’s always a shocker.

“That sucks,” he says. I’m not sure I’ve ever gotten such a blunt reaction before, but he’s right. It does. His honesty makes me smile.

“Yeah. It sucks.” After a momentary awkward pause, I ask, “What about you?”

“Sickle cell. My mom and sisters have it.”

“That sucks,” I say. (Although frankly, sickle cell is basically a walk in the park compared to Huntington’s. It doesn’t even kill you anymore.)

At the supply tent, a double-helixed guy with a clipboard points us to the boxes we’ve been tasked with transporting, each marked in black Sharpie with their sizes. Caleb piles one on top of the other in my outstretched arms, and then hoists up a stack of three himself.

“Why do you think they have no small or medium T-shirts?” I ask over the top of my boxes. “Look, your boxes are all larges and extra larges. Mine too, right?” Caleb surveys my boxes and nods. “What about us small people? That’s what I’d like to know. This is discriminatory.”

“You could take a kiddie size,” Caleb says, laughing. “Look—there are the baby ones. Five-T might fit you, actually. You’re miniature.”

“It’s called ‘petite,’” I correct him. Five foot one, and it’s already a sore point. I’ve been the shortest girl in ballet since I was three years old. “And I don’t need a kiddie size, thank you very much.”

“Whatever you say, HD girl.”

I’m glad the boxes are masking most of my face so that Caleb can’t see me blush. “Okay, Sickle Cell boy.” Over his pile of boxes, Caleb flashes me a gap-toothed grin.

We make several more trips back and forth across the green with boxes of T-shirts. They’re not light, and even though it felt like a cool, fall day earlier, after all the schlepping, I’m sweating and exhausted.

“Snack break?” Caleb asks, when we drop off our third round of boxes. I nod, scraping the hair off my sticky neck and into a ponytail. We make our way to the refreshments area and grab a bag of caramel popcorn and two cups of a juice drink in an alarming shade of red.

“You’d think this kind of beverage could actually *give* a person a genetic mutation,” Caleb says.

“Agreed. Didn’t they outlaw this shade of food coloring in Massachusetts already?”

We find an unoccupied patch of grass and slump down on it. The crowd around the registration area has started to thin as more people have headed off on the walk, and I stretch my legs out on the grass and point and flex my toes a few times in my sneakers.

“So is your family here?” I ask, taking a handful of popcorn from the bag.

“They’re walking. I’ve been doing the volunteer thing for a couple of years, ever since Levi got to me. You know Levi?”

“I just met him today.”

Caleb crunches on some popcorn. “He’s a pretty cool dude. He’s Mennonite, from Pennsylvania.”

“Mennonite, like Amish?”

“They’re close, but not the same. Levi’s got like five brothers and sisters with something called maple syrup disease, and now he’s in med school up here.”

Maple syrup disease—there’s one I’ve never heard of. I’ll have to Google it when I get home.

“Anyway, I met him at a fund-raiser my parents dragged me to, and he roped me in. He’s hard to say no to.”

“I noticed that,” I say.

“So, your mom has HD? Symptomatic?”

Caleb talks like me, like a person who knows something—maybe too much—about this stuff. I cast my eyes out over the Common for a moment, taking a sip of toxic red juice.

“Sick people are a pain in the ass, right?” he says.

I practically spit Kool-Aid all over myself. One of the unspoken rules of Having a Sick Loved One is that you don't talk smack about them. In other words, you don't ever say what you're really thinking, because people who don't Have a Sick Loved One will think you're being cruel. They don't get it.

"Yeah," I say. "Plus, then they die."

Caleb and I sit in silence for a moment, picking at the caramel popcorn, each in our own world. It's nice, in a weird way—knowing that the person in his own world next to me understands a little bit about what my world looks like.

"What about you? Have you been tested for it?"

I'm not surprised that Caleb knows that there is a predictive test for my mother's disease—that I'll be able to find out whether or not I'll get sick, before it happens. It's not something I'd normally discuss with a stranger, but there's something about Caleb that makes me feel like I can talk to him.

"No," I say, plucking at some grass at my feet. "It's really expensive, and insurance doesn't cover it. Like a couple thousand or something."

That's how Dad explained it to me, when they sat me down and told me I was at risk for Mom's disease, but that I had a lot of years left before I had to worry about it. It was a year after her diagnosis, and I guess they wanted to avoid my learning about the whole fifty-fifty chance thing via Google, which most definitely would have occurred. They thought if they told me the truth about my risk factor, they could keep me from worrying about it. But it turns out that it's not so easy to just *not worry*

about something like a fifty percent likelihood of death by drowning in your own brain.

“It’s that expensive? Really?” Caleb asks. “That surprises me. Sickle cell testing’s like a couple hundred bucks a pop. Why would the HD test be so different? It’s still just a blood test, right?”

I don’t know why it’s so expensive. That’s just what they told me. I never questioned the cost of it.

“Sorry,” Caleb says, practically interrupting himself. “I’ll shut up now.” He wipes his sticky hands over his jeans and stands up.

“No, it’s okay. Really,” I say, even though I’m feeling a bit queasy. I’m not sure whether it’s the conversation or the red juice that’s turned my stomach. Caleb offers me his hand and pulls me up to my feet. His hand grasping mine feels . . . warm. And strange.

The commotion at the registration area has thinned out significantly, and when we get back there, Levi comes bounding over like an enthusiastic puppy. “Sorry to break up this excellent team,” he says, “but I need to recruit Caleb for some heavy lifting. If that’s all right by you?” he asks Caleb, who shrugs.

“Whatever you need.”

“Excellent. Do me a favor and head back to the supply tent, and tell Bill that I sent you. He’ll fill you in.”

Caleb turns to me, almost apologetically, I think. “Nice meeting you, HD girl. See you later?”

“Sure,” I say, swallowing the lump in my throat. “Good luck with that heavy lifting.” I don’t think I’m imagining that Caleb

lingers there for just a moment, before he heads off toward the supply tent.

I stick around the registration tables, handing out ribbons to the last of the new registrants and, if I'm totally honest, waiting to see if Caleb's going to come back. But after an hour or so, I'm antsy and ready to go. I can't get our conversation out of my head. The truth is, I haven't looked into the cost of the Huntington's test because I've never really considered it an option. From the beginning, my parents always said it would be a choice I could make when I was much older, like getting ready to have a kid. They said children weren't allowed to get tested, and I believed them. I *was* a child, at the time. But now? I'm seventeen, about to head off to college. I'm old enough now to know what's really going on.

Charging across the Common toward the port-a-potties, my whole body feels like it's vibrating with nervous energy.

"Hey, HD!" I turn 360 degrees before I spot Caleb, jogging over to me. "I was looking for you. Look what I found!" He takes his hand out from behind his back and unfurls a blue T-shirt. Adult small. He's beaming.

"No way!" I exclaim. "What'd you have to do to score this?"

"Nothing . . . just tackled a woman with a tracheostomy, that's all. NBD."

"Thanks, Sickle Cell."

"My pleasure, HD. I'll see you around." Caleb gives me a light shove on my bicep, I presume by way of saying goodbye,

and then turns to go. “Oh, hey,” he says, turning back. “Do you have a last name, HD girl?”

“Who wants to know?”

“I do.”

“You planning to stalk me on the interwebs?”

He makes a face like he’s considering it. “We’ll see. I’d like to keep my options open.”

“Levenson,” I tell him. “What about yours, in case I want to do some stalking of my own?”

“Franklin,” he says. And then with a wink, which he manages to make kind of cool and not that cheesy, Caleb Franklin disappears into the crowd.

Right away, I peel off my giant blue T-shirt and replace it with the smaller one. On top of the tank top I’m wearing underneath, the small fits perfectly. I text Dad to tell him I’m leaving and cross Boylston Street to the subway, without waiting for a response.

At home, I unlock the front door and step into the quiet of our empty house. A draft is sneaking in through cracks in the floorboards and window frames, and the foyer feels almost too chilly for the first time in months. As if on autopilot, I go upstairs and wake up my computer. I’ve been thinking about this all the way home, and I don’t really have a choice anymore. Now that Caleb’s put the idea of getting tested in my head, I have to find out how hard it would really be.

Standing over my laptop, my pulse is racing and my mouth feels cottony-weird. I pull up Google and type, “Testing for Huntington’s disease.” Six hundred seventy-five thousand

results come up in 0.32 seconds. How is it possible, Rose Smart-Ass Levenson, that you have never typed those words into a search engine before?

The very first result is a guide to HD testing from an insurance company. Sure enough, it explains that coverage of such tests varies between plans, but that the cost tends to run about three hundred dollars. Three hundred dollars. Less than I have in my savings account from birthday checks over the years. Less than a month of my mother's drug cocktail, the cost of a handful of college applications.

Another result, from a foundation that does Huntington's research (I recognize the logo; my parents are on their mailing list) says that minors are only tested in rare circumstances. But I'll be eighteen in a few months, and as far as I can tell, there are no other age restrictions.

Two hours later, I hear a key in the lock downstairs.

"Child! We're home!" Dad calls as my family tromps in the front door. "Where'd you disappear to?" I hear him flick the television on immediately, turning it to the Red Sox game.

Taking a deep breath, I gather the various pages I've printed and pad down the stairs. My family is in the living room, collapsed on the couches. I drop the printouts on the coffee table in front of my parents, just as Dad's leaning over to untie both of their shoes.

"So, you lied to me, is basically what this is."

"Sorry, what?" It takes Dad a moment to register that I'm talking about something serious. I hear the crack of bat meeting

ball and the swell of the crowd—and then Dad mutes the television and looks at me.

“What is this?” He flips through the pages, squinting to read them without his glasses. Mom takes them out of his hands to look herself. “What are you talking about, ‘we lied’? Do you want to explain this to me like a rational human being or are you going to act like an adolescent?”

I know I’m being petulant, standing here with my arms crossed over my chest, waiting for them to get the picture without me having to spell it out for them, but I can’t help it. Gram gets up and sneaks out of the room, giving me a sideways glance as she leaves. I can tell she wants no part of this conversation, and I don’t blame her.

“First of all, you told me it cost thousands of dollars,” I say. “It costs three hundred dollars.”

“Thousands of—I don’t think I said that, did I? I have no idea how much the test costs.”

I stare at him, holding my ground. Could I really have made that up? Maybe he never said thousands. Maybe he just said expensive. Maybe I assumed. I can’t remember, to be honest.

Dad goes on. “We talked about this ages ago—they don’t do predictive testing on children, Rose. It’s a decision for adults to make when they’re ready.”

A conversation pops into my head out of nowhere, hazy, like I dreamed it: Dad leaning against the kitchen counter, Mom at the table, me hovering in the hallway where they can’t see me. Dad says something about health insurance. “Can you imagine the premiums they’d make her pay? Her whole life, she’d be

marked.” And then Mom’s voice, agreeing. “There’s no point, anyway. What good will it do her?”

“You told me I *couldn’t* take this test,” I say.

“I don’t think we ever said ‘couldn’t.’ I think we said ‘shouldn’t,’ not for a long time. Don’t be ridiculous.” Dad sighs. “Rose, we just got home from a long day. Do we need to talk about this now?”

“I’m almost eighteen. This is not ridiculous!” My voice catches in my throat.

“Rose, ssstop,” Mom interjects quietly. “Calm down.”

I turn from Dad to Mom and back again. “I’m sorry, but, Dad, you just don’t understand the position I’m in.”

“Excuse me?” my father says. “I don’t understand? We’re all living with this disease, Rose.” Dad puts his hand on Mom’s trembling knee. She holds the papers close to her face, scrutinizing them, her subtle tremors a reminder that none of this is hypothetical.

“You are not living with the possibility of getting it.” I force myself to breathe in and out three times before I go on. “You should’ve told me the truth about this test. Maybe you thought I was too young to understand, but I’m old enough now. Or maybe you’re just in denial about the truth, which is that I could end up like Mom.”

At that, Mom’s head jerks up. The look on her face, honestly, scares the crap out of me. It’s sadness mixed with fear mixed with shame or something, I don’t know. I don’t want to hurt Mom. Her illness, my risk—none of it is her fault. She didn’t choose this, and neither did my father. But I force myself to say

what I need to say anyway. “Now I have this information. And it’s going to be my choice if and when I get tested. End of discussion.”

I leave the room before they can respond. I know we’ll have to talk this through eventually. But for right now, I want to be alone with this new information, and the strange new possibility of doing something about it.

Two

THEY USED TO CALL MY MOTHER'S DISEASE HUNTINGTON'S chorea. "Chorea" because of the involuntary movements of any muscle group in the body that characterize Huntington's. It comes from the Greek word for dance. Which is kind of cruel/ironic, as far as I'm concerned, first because dance is what I *do*, and giving the same name to the thing that defines your life and the thing that swoops in to wreck it seems a little heavy-handed on the part of the universe, doesn't it? And second, because to dance one generally has to have control over one's body.

But as your chorea gets worse, you're losing control. I've seen videos on YouTube of patients with advanced Huntington's, and they look like they have no control at all: tongues sprawl out across their cheeks, feet jump, hands jerk this way and that way.

Among the other charming symptoms of our family heirloom: loss of impulse control; loss of motor skills; loss of the ability to walk, talk, and swallow properly; loss of empathy. Loss. It stops sounding like a word if you say it enough times.

Overnight, as predicted, a hurricane called Christine crept up the coast from the gulf. By nine on Labor Day morning, rain is already pelting my windows and a branch scratches anxiously at the side of the house. Outside, the trees lean hard with the wind.

I love storms, like my mother. We're New Englanders through and through, and I think there's something about being raised on the teetering edge of the mean Atlantic that makes you easily seduced by a weather forecast for big snow or thunder or gale-force winds. My father, on the other hand, sees only the inconveniences of weather: the snow he'll have to shovel, or the likelihood of a tree branch falling on the house.

When I was little and a big storm was heading for Boston, Mom and I would make a requisite Star Market run for Entenmann's doughnuts, the really bad-for-you kind with yellow cake inside and shiny chocolate coating outside. (It was the shininess that made them bad for you, that's what Mom always said.) We'd huddle in front of the television and compare the weather outside to the images from other parts of the Eastern Seaboard, checking to see if we were getting the good stuff or missing out. That was before our own storm hit.

I take the throw from the foot of my bed and wrap it around my shoulders, cozying up to the soft fleece as I tread down the creaky, uncarpeted stairs.

The living room, with big and not particularly well-insulated windows on two sides, sounds like it's in the middle of a car wash. Gram and Mom are already watching the news. I slouch

down on the couch next to my mother and wait for someone to say something—anything—about last night’s conversation. My words—*I could end up like Mom*—give me a sickening, guilty ache in my stomach every time I think about them. I hope Mom has let it go.

“Morning,” Gram says without looking up. There’s no hint in her voice of anything resembling a reference to last night.

I rest my head against the couch cushion and close my eyes, listening to Gram suck air through her teeth, like she has something stuck in them, while she works on her crossword. These days my grandmother makes a constant stream of soft, irritating noises: half-humming as she walks around the house, clucking her tongue as she reads the paper, this air sucking. It drives me nuts enough to not even want to look at her while she’s doing it. I’m afraid I’ll snap and say something mean, which I don’t want to do, because she really does mean well. Gram moved in with us last year to help her only son take care of his steadily falling-apart wife, so I can’t really blame her for being a little humorless about the turn her life has taken. Just as her friends in London were starting their “third acts,” going on cruises all over the world, or at least passing the days playing bridge and gossiping about the neighbors, she made a return to caretaking that is undoubtedly more demanding than raising her own three children was.

Gram glances up from her crossword book. “All right?” she says with an uptick at the end. She still has a thick English accent, even after spending half her life in the States. The way she says it, it almost sounds like one word—“aw-right?”

“Fine,” I say.

“Rose, this is a good storm, right?” Mom reaches over and squeezes my knee.

“Yeah, looks pretty good out there,” I say. I turn to Gram in an effort to be less irritable toward her. “What are they saying on the news?”

“Landfall in two hours or so. The brunt of the damage will be farther south but we could still see some flooding, evidently.”

On CNN, a British reporter named Alastair Dunsworth (which sounds more like a character out of *Harry Potter* than a real human) is currently standing in the middle of the street in Atlantic City, his feet planted wide apart so he doesn’t blow over and one hand holding the hood of his official CNN all-weather parka over his head.

“Can I change the channel for a bit?” I say.

No one responds one way or the other, so I switch over to HGTV, where there’s a repeat episode of *House Hunters* on.

“Oh, we’ve seen this one,” I tell Mom. “They pick the two-bedroom under budget. The brand-new cookie-cutter one.”

“Bad choice,” Mom says, her body whirring like a quiet refrigerator beside me—the motor inside her just humming and humming. Mom and I always agree that period features, crown molding, and subway tile trump most things. Who needs double sinks in the bathroom? You and your spouse can’t take turns spitting out toothpaste?

“Yowza,” Dad says, bursting through the front door with a sodden bag of groceries tucked under each arm. He’s got the thick, reusable shopping bags, but I can tell our food is still going to be damp.

“So it’s raining, I guess?” I say.

“You could say that. The supermarket was downright post-apocalyptic. I think I managed to score the last batteries in the city of Cambridge.”

Dad extricates himself from his soaked rain jacket and boots and drips his way to the kitchen.

“At least the power’s still on. For now,” he calls from the other room.

“Want to make your old mum a cup of tea while you’re in there, love?” Gram says. My grandmother would have tea fed to her intravenously if she could find a doctor who would do the procedure.

“Your wife wants tea too,” Mom shouts. She likes to assert that she still remembers she’s his wife. One of Huntington’s only kind features is that it tends to spare its victims’ recollections of close personal relationships. Of course, when you lose control of your impulses and start saying horrifically nasty things to the people you know you love, it doesn’t really help that you can remember their names.

“Oh, sure. No problem,” Dad says, poking his head back in the living room. “Don’t anybody worry about me, I’m only a little bit damp down to my bones. I’ll just fix the tea for the ladies. I suppose the child wants one too?”

“Yes please.” I shift myself off the couch and slink into the kitchen, where Dad’s puttering around putting groceries away.

“Chicken soup?” I ask, noting the celery, onions, and carrots on the counter next to the cutting board.

“May as well, right?”

I take a heavy blade from the knife block and start chopping the celery. Chicken soup is our family’s answer to all things

challenging. Bad cold? Chicken soup. Bad weather? Chicken soup. Bad news? Chicken soup. We've eaten a lot of chicken soup in the last several years.

The kettle whistles. Dad puts a steaming mug next to me on the counter, and then takes the tea bag out after just a few seconds—he knows I like my tea weak.

“Thanks, Dad.”

“Not a problem, my child.”

“Hey, Dad?” I rest the knife on the cutting board. “I’m sorry about last night. I was sort of a jerk.”

He stops puttering for a moment, holding Mom’s spill-proof travel mug in both hands. The steam floats off it and coats his stubbly chin in tiny beads of sweat.

“Okay,” he says. “And I’m sorry you felt blindsided. We were doing our best to protect you, and I still think it was the right call. But I can see why you would want to know all your options now. Okay?”

I nod. “Okay,” he repeats. Then he kisses the top of my head and returns to the living room with two teas. None of this is okay, in fact, but that’s all we can say about it right now, so I go back to chopping the vegetables for the soup.

I finish the celery and then start to quarter the onion. As soon as I cut into it, my eyes start to sting. Pretty soon, hot tears blur my vision enough that I can’t cut anymore without risking my fingertips. I retreat to the living room, squeezing a dish towel to my eyelids one at a time.

“This is bullshit,” Mom says, eyes still on *House Hunters*.

“Mom, I told you, they pick the wrong one.”

“I know you told me that. You don’t have to repeat yourself.”

I breathe and ignore her mood swing.

“Let’s see what’s happening with the storm,” Gram interjects, trying to distract Mom. The strangest things set Mom off these days, with more and more frequency—just another mystery of her deteriorating brain. She can be happy, almost her normal self, and then suddenly it’s like an invisible switch is flipped and we can’t reach it to flip it back.

It didn’t start like that. The lightning-quick changes in personality are a more recent development of the last six months or so. In the beginning it was more subtle.

The first sign that something was wrong was that she got into three fender benders in two months. The first time, she hesitated a moment too long at a left-hand turn and got clipped. Neither car had been going very fast and there wasn’t much damage. The airbag didn’t even deploy on the guy who bumped her. But he was still pissed—he said he’d looked right in Mom’s eyes as he’d first approached and he was sure she was going to wait. And then out of nowhere, she changed her mind, hit the accelerator, and burst out into the intersection.

The second time, she’d taken a wing mirror off a parked car while she was making a right-hand turn.

And the third time, she’d stopped short at a yellow light, and the woman behind her couldn’t stop fast enough. It was the other driver’s fault, obviously—it always is; they teach you that much in driver’s ed—but it was still weird behavior for Mom,

not taking the yellow light. Mom had always taken yellow lights.

Dad made her go to the emergency room that time, even though she wasn't really hurt—she'd strained her neck a little bit, that was all. But he joked to the doctor about prescribing a drug to improve her driving, because this was her third accident in a row. Three months of tests later, they named the thing that was changing Mom. Looking back, once she had the diagnosis, we saw that what all three accidents had in common was that she'd been unable to make the kind of quick decisions everyone makes behind the wheel—when to turn, when to stop. Decisiveness is one of the first things to go with Huntington's.

And no, we didn't see it coming. My mother's father died in his early fifties of some kind of crazy thing that no one talked about much—Mom always said he drank too much and lost his mind. Her mother had already been dead for years by that point. So Mom went out into her life unaware of the ticking time bomb she was carrying in her gene pool.

Gram switches the channel back to CNN, where Alastair Dunsworth is now clinging to a pathetic little tree that's swaying back and forth.

"This poor chap again," Gram says. "You know I think he used to be on BBC One back in the day. He's too old to be doing this nonsense."

Outside, the wind howls, and a sudden gust splatters fat raindrops against the window, making me jump.

I go to the window and look out at our near-deserted street. Leaves are plastered to the wet pavement, and no one's out except for one crazy neighbor jogging in shorts and a T-shirt, completely soaked through to the skin. I can sort of understand the attraction of going out there in the thick of it, just you and the rain and the big gusting winds. It must be kind of a rush.

I resist whatever impulse I have to run outside and tear my clothes off, however, and instead go back to the kitchen to brave the onion again. Once it's chopped, I scrape the chunks off the cutting board and into a pot of cool water, to get them out of the vicinity of my stinging eyes, then add extra garlic—two whole cloves. It's the garlic that seems to differentiate Jewish chicken soup from Asian chicken soup, I've noticed. When you get soup at a Thai restaurant, it's always nice and garlicky, but for whatever reason, us Jews haven't caught on. I'm personally changing that, one pot at a time.

I leave out the carrots. Mom would make me put them in, just for the color, but I hate carrots once they get soggy, and I figure no one will miss them once the soup is finished. Gram might, I guess—having grown up in London until she moved here with my grandfather a million years ago, it's sort of a point of pride for her that she loves vegetables with all the life boiled out of them. On second thought, I put a tiny saucepan of water to boil next to the big pot, and toss the carrots in. Carrots optional.

I dump the raw chicken in the pot with the vegetables and bring the whole thing to a boil, stirring it and watching the pieces swirl together as tiny bubbles rise to the surface. The

steam makes my cheeks clammy. When it's bubbling nicely, I set it to simmer.

Within an hour, the smell starts to creep into the living room. On CNN, they're looping through the same correspondents up and down the East Coast and saying the same things. Landfall's coming; power outages are expected throughout the region; if you haven't evacuated yet and you're in an evacuation zone, it's too late and you should've listened to your mayor or governor or whoever earlier. In Cambridge, we're far enough from the water that we never have to evacuate, but one time we were up in Maine during a hurricane, when I was about seven, and we had to spend a night in the local school, sleeping on the library floor. I worried because I'd left my favorite doll behind. In the end, she survived.

I put my feet up on the coffee table again. Gram's disappeared upstairs to take a nap, and Mom is reading the magazine section of Sunday's *Boston Globe* next to me, probably going over the same page three times. Huntington's makes it harder for things to stick in her brain. Just as I lean over Mom to grab the arts section, the lights flicker around us and then suddenly we're in darkness.

"Shhhhit," Mom says. "There it goes."

Dad appears in the living room, holding a flashlight under his chin and making what he thinks are spooky ghost noises. "Oh, laaaaaadies . . . mwa-ha-ha-ha."

Mom tosses the magazine at him, missing by a wide margin, but he stretches an arm out and grabs it midair. "What? Did I scaaaaaare you?" he says in ghost-speak.

“Dad, Casper, whoever you are,” I interrupt. “I’m hungry. Did you get anything good?” I’m hoping he came back from the grocery store with popcorn or M&M’s or something other than the bare necessities.

“Do I hear doubt in your voice, child?” he asks, shining the flashlight right in my eyes. “You think your old man doesn’t know how my women like to prepare for a good storm?” He goes into the kitchen.

“What about this!” he says triumphantly, emerging with a box of Entenmann’s chocolate doughnuts, the yellow cake kind with the shiny coating. “When was the last time you saw these babies?”

I can’t remember. It feels like another life.