

Summer 2018

ATYPICAL MORNING

5:10 A.M. MY hands along the wall feeling my way to the stairs. Like a burglar, always creeping around in my own house. First stair. Careful. Second stair. Don't breathe. Reach the fourth stair, stretch leg down to the sixth. The fifth stair creaks. The fifth stair is the devil. The fifth stair can change the entire course of a day.

Slowly open the metal baby gate at the bottom of the stairs. Gingerly ease it shut. It makes a tiny *creak*.

I cringe.

"AH AH AH!" from upstairs. She's heard it. Drag myself back up the stairs that just took me five minutes to creep down. Big inhale as I push open her bedroom door to the static drone of the sound machine. *Haaaabbbbbb*. It sounds like a space station. Still smells like a baby's room. Doughy and sweet. It's the one thing about caring for her that I will never tire of.

Her bedroom is stark, functional. No trophies, no knickknacks. Just a dresser, a nightstand, and a zip-up, tentlike bed that looks like a futuristic sleep capsule. The sleep capsule keeps her safe. Keeps her contained. Keeps her from getting up and banging on the door at three in the morning. There are two soft, unbreakable canvas pictures stitched with baby birds and butterflies hanging on the wall. Still decorated for a two-year-old even though she's thirteen.

"Good morning, Ellie," I say.

"DUN!" she shouts.

She blows me a long, wet, squeaky kiss like someone releasing the air slowly out of a balloon.

She's sitting up with the side of her head smushed into the top of the mesh sleep capsule. She's too big for it. (Mental note: Add bigger

futuristic sleep capsule to long list of things that need solutions.) Pull back sound-blocking curtains. Lift room-darkening blinds. Take out sensory friendly clothes from her dresser.

“AH AH AH!” Ellie shouts.

“Quiet, Ellie. Dada is still sleeping.”

“KAY!” she shouts.

I brace myself as I unzip her mesh sleep capsule bed. Ellie emerges feetfirst while clutching her favorite blanket, like a child astronaut taking her first bold steps onto another planet.

“UH OH.” She says this with the correct inflection—the UH going up in pitch, the OH going down.

“That’s right, Ellie, you’re one big uh oh, aren’t you,” I say, smiling.

She gives me a big smile, her hair all tousled. It lights me up. I try to hold on to it. She will turn soon.

“Give me a kiss, Ellie.”

I approach her carefully, grip her head tightly with both of my hands so she won’t use it to hit me. I kiss her open mouth. Her breath smells stale, like mothballs. From all the meds.

“Love you, Ells.”

I try to put my arms around her, being careful to keep my head a safe distance from hers. She swats at me and pushes me away. I lead her down the stairs with me in front so that my body will break her fall, just in case. She’s always a bit unsteady on her feet when she wakes.

The metal baby gate at the bottom of the stairs becomes a starting gate. I unlatch it and she pushes past me, lands hard on the wood floor. *Thud.* The sound of the starting gun. And she’s off. Stomping. Running. StompRunning with all her weight. Zero to sixty, house of extremes with no in-between. I chase after her. The two of us running now. The whole house is shaking. *It’s too early for this.*

“Bathroom,” I say.

A demand.

“UHNNN!” An angry guttural groan forced from the back of her throat. She StompRuns toward the bathroom, takes a two-foot detour to hit me first, then turns to run in the other direction. I catch her by her anti-strip *teensie*¹ that zips up the back so she can’t take it off. I turn her body toward the bathroom.

1 *teensie*: a onesie, but for a teen

“Bathroom,” I say again. She twists her torso and swings her long, loose arms back and forth around herself to hit me. Like a Japanese den den drum from the dollar store that you twist between your palms. She StompRuns into the bathroom and whips the side of her head against the door as hard as she can.

Whack. Whack. Whack. Whack. Each hit sends shock waves through the house.

“Okay, Ellie, let’s go potty,” I say calmly. I stroll past her into the bathroom while she’s still smashing her head against the door. She’s looking for a payoff. A rise out of me. But I won’t give it to her.

I pull her away from the door and unzip her *teensie* while she twists her den den arms around herself to hit me again. She does this with the perfect amount of force. She knows right where the cusp is—exactly how hard she can hit me without fear of recourse.

I take off her diaper. The bitter smell of dark concentrated urine fills the room. Today I pulled in about a two-pounder. We haven’t worked on taking her to the bathroom at night yet. Not sure if we ever will. Not high enough on the list of things that need correction.

“Go potty,” I say.

Another demand. She drops herself down as hard as she can onto the toilet seat.

“UHNNN! UHNNN!” She starts bucking on the seat, smashing her entire body against the tank with unbelievable force.

I pretend not to notice. Like I’ve seen this every day of my life. A naked thirteen-year-old girl violently throwing her body against a toilet tank over and over.

She’s finally still for three seconds. Three seconds has become an eternity. She starts to go with her body slumped, her legs wide. Some urine sprays over the front of the seat and onto the floor. Like a little boy just learning. I let it spray. Learning to use the toilet trumps any mess that I have to deal with later. She jumps up before she’s finished. Some urine drips down from her onto the floor.

“Good girl, Ellie,” I say as I pat her dry.

Grab new diaper and kneel in front of her. Ache in my lower back from crouching.

I get the new diaper on in record time, touching her as little and as strategically as possible. I tap her leg for her to get back into her *teensie*.

“UHNNN!” She shoves her left leg in.

“UHNNN!” She shoves her right leg in.

Whiny angry grunts, like having clothes put on her is torture.

I pull the *teensie* up over her body, slip her arms through, and quickly zip it up the back. She throws her head back to try to hit me with it. I throw my own head back at the same time to avoid hers. Our well-rehearsed contemporary dance routine.

“Wash your hands,” I say.

“UHNNN!” She forces the faucet lever up as hard as she can.

The vanity rocks.

I help her wash her hands, being careful to stand next to her, not directly behind her. I’ve learned this the hard way, by nearly having my nose broken on several occasions. I dry her hands as she swats at me.

Suddenly, I grab her den den arms with all of my strength. “Stop hitting me,” I say through gritted teeth. My arms tremble as she fights to be released. She’s as tall as I am. We stare into each other’s eyes. A showdown. I show her I’m stronger. But not by much.

She breaks free from me and beats me to the kitchen.

When I get there she’s already taking a giant ziplock bag of frozen bananas that I use for my smoothies out of the freezer and grabbing the red wine vinegar out of the fridge.

“Ellie, those aren’t waffles and syrup,” I try to explain.

She ignores me and brings them over to the table, leaving the fridge and freezer doors wide open.

I snatch the bananas and vinegar from her and while I’m throwing them back into the fridge *<NeedOverlap>*² she’s already opened the cupboard I forgot to latch and is pulling out the bag of potato chips that I forgot to clip. I didn’t dot some *i*’s and now I’m paying the price tenfold. She turns the unclipped bag upside down and *shhhhhhhhhhh...* chips raining down all over the kitchen floor.

“Dammit, Ellie!”

With record speed I grab the bag of chips from her, clip it, toss it into the cupboard, and quickly pull out two boxes of cereal—Cap’n

2 *NeedOverlap*: while one is addressing, recovering from, or cleaning up after one need, another has already begun

Crunch's Peanut Butter Crunch and Golden Grahams. Gluten-laced breakfast of champions.

"Choose," I tell her.

Her head turns back and forth between the two boxes. Back and forth and back and forth.

"Ellie, chooooooos." My patience is disintegrating.

Her eyes gleam with concentration as I take in the few seconds of respite. Of silence. She softly taps the box of Peanut Butter Cap'n Crunch with two fingers.

"Excellent choice," I say.

She turns and StompRuns to her chair.

"AH AH AH!" She climbs onto the chair and stands up, looking down on me like a queen surveying her most loyal subject.

"Ellie, get down from there." I yank her down and push her body onto the chair.

I quickly pour a mountain of Peanut Butter Cap'n Crunch into a plastic Tupperware bowl. Before I can finish pouring, she grabs a huge fistful and is shoving as much as she possibly can into her mouth with the base of her palm. An occupational therapist's worst nightmare. I should sit down next to her and dole out each crunchy peanut buttery ball one at a time to help her work on her pincer grasp. I should at least give her our homemade modified spoon and help her learn how to scoop cereal into her mouth.

I should do a lot of things.

I walk across the room to make some coffee.

"AH AH AH!" Panic in her voice.

Two stray peanut butter balls have dropped and rolled a few feet away from the table. I scoop them up and drop them back into her bowl. Not worried about the five-second rule. I'd be fine with a five-hour rule. I've seen her eat mulch. She shoves another fistful of peanut butter balls into her mouth. Apart from the sound of her sloppy open-mouthed crunching, she's finally quiet. I enjoy the break from the sound of her voice. The sound of her angry guttural grunting. The *Sound of Need*.

I grab a broom and start sweeping up the potato chips.

"AH! UHNNN!" A garbled, goopy mouthful of peanut butter crunch all over her teeth.

"What now, Ellie?"

She gently touches her cereal-covered fingertips together. “More” she’s telling me. The bowl is still half full and she’s already asking for more. Never satisfied with what she has, just like the rest of us.

“Ellie, when you finish what you have you can have more.”

“UHNNN!” She smacks her fist down onto the bowl and flips it onto the floor. Peanut butter balls everywhere.

“All done, Ellie,” I say with every ounce of composure I have left. I drag her over to the sink as she whips her head against my shoulder over and over. I want to take the bowl and throw it against the wall. I want to take *her* and throw *her* against the wall. *Special needs special needs special needs*. My mantra. My reminder. Of why I can’t.

I turn on the water and wipe her mouth using my bionic special needs parent sleight of hand, quick, before she can bite me. I hold tightly to her hands to rinse them, fighting to keep them under the running water.

“Okay, dry your hands,” I say. She turns to run, and I stretch my leg out to block her. The next sequence of our contemporary dance routine.

“Ellie, I said dry your hands.”

“UHNNN!”

I dry them off for her with a kitchen towel. She swats at me with whichever hand is free at the moment.

“Okay, go play.”

She StompRuns into the living room to find her green bin full of foam alphabet blocks. As she carries the bin into the TV room, it tips and one of the blocks falls to the floor. She leans down to pick up the one that dropped and four more fall out. Like an old-timey comedy sketch.

“AH! AH!” Panic in her voice until she collects each precious block and gets it back in the green bin. Her universe is restored. She finishes her StompRun into the TV room with her bin and drops directly from standing onto her knees into a perfect W-sit, a physical therapist’s worst nightmare. I can’t remember exactly why we shouldn’t allow her to sit that way. Something about not good for the trunk muscles, something taking away from something else, blah blah blah, not high enough on the list of things that need correction. She positions the bin between her W-sit thighs and starts to flick the blocks around. They make a soft, familiar, muffled shuffle.

“TSTHSSSP.” She slurps some drool back into her mouth. She looks at me and swipes her palms together. *Swipe swipe*, she says with her hands. Her sign for “music.”

“Ellie, it’s too early.”

She swipes her palms again, this time harder, insisting. *SWIPE SWIPE*. My *Emotional Funding*³ is low. Extra low. I give in. Channel 852. Dance music. Terrible dance music. I know all the lyrics.

I open the kitchen cupboard to draw her meds. One, two, three syringes. I put the syringes in a plastic cup, hide the cup behind my back, and walk into the TV room. I discreetly grab a big throw pillow from the couch, drop it on the floor behind her and reposition it with my foot, trying to predict where her head will land in a few seconds. I say a quick prayer. *Please God, let this go well.*

“Okay, Ellie,” I say. “Medicine.”

“UHNNN!” She whips her entire body from her perfect W-sit straight back onto the floor. Her head lands squarely on the pillow and it helps cushion the blow. I exhale in relief. Her legs are still bent beneath her like a blond girl-frog. I expect her body to snap in half, but her low muscle tone has always made her very flexible. She releases one frog leg, then the other.

“I’m sorry, Ellie. I have to give you these. It’s for zappies.” Our word for seizures. Even though she probably doesn’t know what a zappie is. Or a seizure. I syringe the meds into her mouth, one after the other. I don’t have to sit on her chest while she bucks me to do her meds anymore. Progress.

“Good girl, Ellie.” I stroke back her bangs. She hits me and I let her.

“Okay, time for shower,” I say.

“UHNNN!” She jumps up and StompRuns to the bathroom. I chase behind her. The glass panels of the armoire rattle as we thunder across the wood floor. Jim is wearing earplugs, but I know he can feel it in the bed. As I unzip her *teensie*, she quickly slips out of it and starts pulling down her diaper.

“Ellie, wait!” She pushes the diaper down her legs in seconds then steps right onto it, into her own urine before I can pull it away.

3 *Emotional Funding*: the amount of fortitude, hope, faith, and courage needed to care for a special needs child. If overdrawn, a parent may resort to other forms of coping such as eating an entire pizza, screaming at one’s spouse, etc.

Could have been worse.

She stomps into the shower.

“Okay, look out, Ellie.”

I turn on the water.

“UHNNN!” She protests. It’s too cold.

When the temperature is just right, she’s finally quiet. She composes herself, stands fully upright, cups her hands in front of her chest and walks slowly underneath the warm shower water like she’s part of some sacred ceremony. Like she’s walking up to receive communion. Once beneath the water, she bends slowly at the waist until she’s completely hunched over. She catches the water in her cupped communion hands and tosses it up, over and over, like a stooped little old grandmother trying to make an important point.

I undress and step into the shower with her.

“Turn around, Ellie.”

She complies. The water distracts her. I wash her thirteen-year-old hair and body with baby wash. Forever tethered to the baby aisle. Backside first, washing, rinsing off all the urine she slept in, then front side. As I wash her, I think about how much you have to love someone to wash them like this. A strange, undesired intimacy.

“Okay, Ellie, we have to brush your teeth.”

I have the toothbrush with paste waiting. Deep inhale. I insert the brush carefully into her mouth like a real-stakes game of Operation. I quickly brush as much and as well as I can. She taps her shoulder over and over. Special needs charades. She wants me to sing “Head, Shoulders, Knees, and Toes” while I brush her teeth.

“Head, elbows, knees, and feet,” I sing, messing up the words on purpose. She smiles big. The dimple on her right cheek appears like a rare star. Her teeth are crooked, and they’ll stay that way. She’ll never be able to tolerate braces. Her glassy eyes sparkle through the droplets of water. Toothpaste all over her chin. My heart swells. I try to hold on to it. The sight of her smiling. A beacon of light in so much darkness.

“Okay, almost done, Ellie.” She hits me in the chest.

I’m brushing too long and now she’s angry. She bites down hard on the toothbrush and won’t release it.

“Come on, Ellie, stop it.” Tug-of-war between me and Ellie’s jaw until I rip the toothbrush out of her mouth like I’m starting a lawn mower.

She backs away from me and whacks her head as hard as she can against the tiled shower wall.

Thud. Thud. Thud. Thud.

I'm suddenly nauseous but I keep my face blank. I can't give her attention, especially for this.

"Okay, spit out the toothpaste," I say evenly.

"FTH FTH," she tries. A bit of toothpaste and saliva dribble out of her mouth. I swipe across her mouth and face to rinse the toothpaste, using my bionic special parent sleight of hand, quick, before she can bite me.

She's clean. I can finally wash myself. A solo shower is a long-lost luxury. I wash my hair and body as fast as I can, keeping one eye open in case she sucker-swats me.

I get out first, dry myself off with a scratchy towel, and pull on my robe. Then I grab the softest towel we have for her and brace myself. Deep breath.

"Okay, Ellie, all done with shower. Time to dry off."

Ellie stays bent over in her hunched grandmother stance, tossing the water up and down and up and down with her cupped communion hands.

"Okay, Ellie, time to get out," I say again, this time a bit louder.

"TSTHSSSP." Ellie stays put and slurps some shower water into her mouth.

I turn off the water. The spell is broken. Ellie slowly stands upright and stares up at the showerhead, the source of all life and goodness, hopeful that the gods will have a change of heart.

"Ellie, time to get out."

"UHNNN!" She stomps out of the shower and swats me in the chest.

Next round, here we come. I throw the towel over her head and do my best to dry her as she swats and bites from beneath the towel. The two of us fight and fumble across the bathroom floor—another contemporary dance routine.

I hear Jim slowly making his way down the stairs to take over.

"Good morning, gorgeous," Jim says when he sees her. He looks as tired as I feel.

I give him an update as I head up the stairs to get dressed.

"I already did her meds, her clothes on are the kitchen chair."

We're Ellie's caretaking pit crew. As I hand her off to Jim to do his piece, I feel guilty. Like I'm handing a pulled grenade to someone I love. I slowly climb the stairs, already worn out from the morning shift.

I take my special mom uniform out of the dresser: stretched-out leggings, pilled T-shirt, Gap hoodie. As I dress, I look at a black-and-white photo of Jim and me on the dresser. The two of us in a gazebo on the beach, my wedding veil blowing gently in the breeze. Two young, happy, relaxed newlyweds awaiting their future.

I stare at my younger self. The younger self who wanted to be a mother. The best mother she could be.

I want to warn her somehow.

"Run," I say to her. "Just run."

She stares back at me with her fresh, hopeful face.

"Fool," I hiss at her. "You don't know what's coming."

CAST, IN ALPHABETICAL ORDER

Advocate x 1
Aide x 30
Allergist x 1
Audiologist x 1
Anesthesiologist x 5
Behaviorist x 6
Cardiologist x 2
Case Manager x 6
Developmental Pediatrician x 1
Endocrinologist x 2
Epileptologist x 4
Gastroenterologist x 2
Geneticist x 2
Infectious Disease Specialist x 1
Medical Marijuanaologist x 2
Neurologist x 6
Occupational Therapist x 5
Oculoplastic Surgeon x 1
Ophthalmologist x 2
Orthopedist x 2
Otolaryngologist x 3

Pediatrician x 3

Pediatric Gynecologist x 1

Physical Therapist x 4

Plastic Surgeon x 1

Psychiatrist x 3

Speech Therapist x 4

Vision Therapist x 1

Plus one psychic medium who told us that Ellie functions on a higher plane where souls communicate telepathically and she doesn't speak because human speech is much too simple for her. (This evaluation will prove to be one of the most helpful.)