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Ashley's Sister

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Ashley's Sister

by

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ABSTRACT

This nonfiction project is a memoir, constructed in sections, about my relationship with my sister with an intellectual disability.

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The Follower

In the mornings during my senior year of high school, I took an advanced placement government class at the other public high school in town, called Nashua North, which was the sister school to mine, Nashua South. Ashley had been going to North instead of South, which was in our neighborhood, because the special education program was bigger and my mom knew several of the teachers. In the previous year Ashley had been at Nashua North, Mom would bring her to her classroom in the morning, but since I was going in the building anyway, I offered to take over the task.

Ashley was born less than two years after me, with an intellectual disability called Trisomy One. The disability impacts both her mental and physical capabilities. As a result, she needs near constant supervision, and assistance accomplishing basic tasks, like going to the bathroom, making her lunch, and walking up and down stairs. Every morning, she needed an escort to her classroom, where she would meet up with her one-on-one aid.

I only knew some people at North just because Nashua wasn't that big, and half of my middle school had split to go there. Most of the students I knew congregated in the wings reserved for seniors, while everyone else hung out in the main hallway that led from the front entrance to the back of the school, where the Special Education wing was located. On the first day of the year, I asked Mom from the backseat of the car, "Where do I need to take her? I haven't been in North before."

Ashley looked at me from the front seat.

“My school,” she said.

“Yeah, Ashley knows where she’s going. Just follow her.”

When we walked through the front entrance, Ashley, carrying her lunchbox while I wore my backpack and tugged her wheeling backpack that had lights on the wheels behind me, smiled and waved to the security guard at the door.

“Hi Ashley!” He waved back at her and gave her a high five. Once inside, my sister plowed through the throngs of students I would have weaved to avoid, walking through the middle of conversations and instructing people to “Move. Out my way,” when they were unlucky enough to not clear a path. I followed behind, dragged by Ashley’s grip on my hand. Every tenth person we saw seemed to know my sister, and she waved back and called out to them by name. When we reached the Special Education wing, Ashley dumped her coat in my hands while she opened her locker and stuffed her bag inside. She took the coat and, without glancing back at me, said “bye bye Christina” as she made her way to her classroom.

“Uh, okay. Bye Ash.”

One of the teachers popped her head out of a door as I turned to find my classroom and waved. “Thanks, Ashley’s sister!” I didn’t even bother telling her my name, just smiled and walked away.

HAPPY

I am in a constant state of reinforcing.

During a physical, I was asked to identify distinguishing marks on my body, such as scars and tattoos. If I had to use these physical markers as representations of myself, I have four. There is a scar stretching across my knee from where I split the skin on the sharp, unfinished edge of our porch that my father had yet to sand. There is another scar on the lower right side of my stomach that marks the missing appendix that almost killed me. There is a scar on my right hip, from where I fell while running on a hot afternoon when I should have taken a day off. I left the two-inch-long pavement scrape open and un-cleaned while I finished the last ten miles. Finally, there is a tattoo on my left forearm: a line drawing of an unsmiling face, with the word HAPPY written underneath in jagged capital letters: the deliberate and permanent choice I made to mark myself by my sister's hand, from a picture she drew in a diary that none of us can read. It is a reminder that happy and HAPPY are not the same things, and that the best things in your life are often the ones that cause you the most pain.

Before

Before Ashley, my father dropped out of high school at sixteen, got his GED and hitchhiked across Sweden. In the few photographs I have of him from his younger years, his white blonde hair reaches his waist. After returning from abroad, my father became a carpenter and woodworker. He moved to New Hampshire in his early thirties and enrolled at Daniel Webster College, an aviation school in Nashua. There, he met my mother.

Before Ashley, Mom got her pilot's license at sixteen, and worked her way through college by working three part-time jobs, one of which was at a small airport, filling gas tanks and cleaning airplanes. She moved to Nashua to teach at Daniel Webster, and was one of the first female flight instructors at the college. She met my father after he made an emergency landing in a field in one of the school planes, when the engine failed during his lesson a few miles from the school.

Before Ashley, my parents married and my mother took a job at a regional airline based out of Vermont, and my father decided to try his hand at flipping houses in Nashua. They bought a house in disrepair with my mother's good credit, and it sat largely untouched, plumbing shoddy and tile ripping up from the floor, until my mother got pregnant with me and a bigger conglomerate bought out her airline. My parents moved to Florida, where my father grew up, and then relocated to North Carolina in time for my birth.

Before Ashley was born, my mother, father, and I lived in a rented house on the edge of a farm in the mountains of North Carolina. Mom referred to it as “the gate house,” because it was near the handmade stone gate at the entrance to the farm.

Before Ashley, I developed an affinity for motion. Mom bought a baby swing that moved on its own, and I would lay in it, lulled by the rocking. I still have trouble sitting still, and fall asleep in cars and rocking chairs.

Before Ashley, I said my first word. “Dow!” I yelled, pointing out of the kitchen window at the cows wandering in the fields by the gatehouse.

I don’t remember any of this. The “before Ashley” part of my life is mapped out only by photographs and memories from my parents, and in the small remnants of habit that linger in me.

It is easy to divide life into segments of before and after those moments that fundamentally alter who we are. The problem is that a defining moment doesn’t erase what came before it. I remember Christina before the wooden paddle, before the jump roping team, Christina before the stolen hearing aids and the divorce. I remember the way to become suddenly aware of my own ignorance, like the first time I learned that just because you tell the truth, you don’t have to be believed, and that many adults choose to lie to themselves. I don’t remember who I was before my sister, and for that reason, she is more fundamentally a part of me than anything else.

A Line of Code

“Your sister had a bit of trouble finding her way out,” my mother once told me. “She was pushing in the wrong direction, trying to go sideways instead of down.”

When Ashley was born, I was twenty-one months old. Ashley was two weeks late. The doctors had to perform an emergency cesarean section because she was perpendicular to the birth canal. Mom said she could feel Ashley pressing her head against my mother’s stomach, trying to find a way out of a dead end.

Ashley was born with a clubfoot on her left leg. Her foot was turned inward at a forty-five degree angle, so for the first couple of months of her life, she had a tiny cast to straighten it out. Twenty percent of the time, a clubfoot is a red flag for a genetic abnormality. For example, it is seen in infants with spinal bifida, a disability where the spine doesn’t fuse correctly, or the membranes around the spinal chord aren’t fully formed. Clubfoot is a hallmark sign of neurological problems during fetal growth. In fact, it was probably the first indication that something was abnormal about my sister.

Even before Ashley was born, Mom told me she felt like something was off. Compared to me, kicking and rolling and pounding on our mother’s bladder, Ashley didn’t move much in the womb. While this might not be reason enough to suspect something was wrong, I wouldn’t go above saying my mother had some intuition during her pregnancy. I don’t doubt her body was picking up signals from my sister that things were not proceeding as they should.

In one of my science classes in college, I learned that the wrinkled indentations on the palms (the ones palm readers study to predict a person's future) are indicative of how much that person moved while in the womb. As the hands form, the clenching and unclenching of the fingers creates lines that become permanent. This can be an indicator after birth of how healthy an infant was during development.

When I told Mom about the hand wrinkle fact, she interrupted Ashley from where she was cutting up pictures from magazines at the kitchen table, to look at her palms.

"Mom....?" Ashley turned to look at me, as if to confirm that our mother had lost her mind.

"Wow, that's interesting. Look at her hands."

My sister's hands were still like those of a child, even though she was eighteen at the time. Her fingers were tiny, with fingernails barely larger than the "O" key on a keyboard. The skin was soft and smooth, un-calloused, and her palms were unwrinkled. The "heart line," a palm reader's name for the darkest line that stretches from the index finger horizontally across the middle of the palm, was almost completely invisible, and lines at the joints of Ashley's fingers were nonexistent.

Mom and I looked at our own palms, which were deeply marked by motion.

Ashley went to Shriner's Hospital for the continued treatment of her clubfoot. A nurse who changed Ashley's casts asked Mom if she thought Ashley was developing at the same rate that I had, because I was always at the appointments, and was what my mother called "precocious," chatting with nurses and climbing all over things. When Mom explained that Ashley was not nearly as active or aware as I was, the nurse set up a

genetic test. Up until that point, the doctors and medical professionals who saw my sister hadn't said anything if they suspected my sister's development was off.

Later, we would learn that Ashley had a spontaneous mutation of the first chromosome, called Trisomy 1. It was a disability that none of her doctors had seen in real life before. They had only read about it in medical journals, in studies of stillborns. When I did research on the mosaic trisomy of chromosome 1q, which is the more specific nomenclature for Ashley's disability, I found a case study entitled "Mosaic Trisomy of 1q: The longest surviving case," through the National Center for Biotechnology Information. In the abstract, the authors say, "He died at age five months." The study was published in 2009, sixteen years after my sister was born.

Your chromosomes are like twenty-three long sets of instructions, simple codes that cue your cells to make and destroy the chemicals that keep your body moving, your lungs breathing, your blood circulating, your brain thinking; each chromosome contains thousands and thousands of orders. Every single cell in the human body possesses an identical chromosome guidebook, if you will, and depending on where the cell is, and what the cell is designed to do, it uses different parts of each chromosome for its instructions.

Chromosome one is the largest of the twenty-three. Because of this, it holds the most information. Bodily functions are not sorted concretely between chromosomes; for example, all instructions for muscle function are not on chromosome two, and instructions for processing of blood sugars on chromosome five. The directions are

mixed up with one another, tagged by proteins as though indexed in an encyclopedia, so each cell uses only certain codes from each chromosome in order to operate.

The term Trisomy One means that part of my sister's first chromosome has an extra part, as trisomy means "triple." In actuality, if you look at a photograph of a set of my sister's chromosomes under a microscope, you can see that the X-shaped first chromosome is a little lopsided. A small chunk at the end of her first chromosome, for some unknown and untraceable reason, broke off and reattached itself at the other end of the chromosome during her development, leading to the "triple" terminology. Every single cell in her body has this lopsided copy of her first chromosome.

Once, when Ashley was a toddler, my mother brought her to the hospital for some infection, and was greeted by a young, and clearly nervous, resident.

"So can you tell me what your daughter's disability is?" he had asked, as he scanned the chart with furrowed brows.

"Trisomy One. A partial relocation in the first chromosome," my mother said. For some people, she found it was easier to barrage them with medical lingo right away, as if to establish the credibility that was sure to be questioned. This, she hoped, would keep them from insisting she was wrong.

"Trisomy *One*?" he repeated. "Um. Okay. Excuse me."

He turned and practically fled the room, clutching the chart. When he returned a few minutes later, my mother said he looked bemused, as though discovering a secret that nobody else knew.

“I apologize,” he started. “I just wanted to check my notes. In one of my classes a few weeks ago, we learned about first chromosome disorders. And my professor said they were ‘incompatible with life.’”

So, he seemed to be saying, when he saw Ashley, it was like he was discovering a make-believe creature. Or a miracle.

I think my mother looks back on this story with a great deal of fondness. For the first six months of Ashley’s life, she carted my sister from one doctor to another, insisting that something was wrong, no, something was different, about her daughter, only to be turned away or told to wait and see. I was too young to remember. I do know I spent hours in those hospitals as Ashley got sick over and over, from illnesses we couldn’t prevent, because nobody could tell us what about Ashley’s body made her so susceptible. Finally, when Ashley was hospitalized for yet another bout of pneumonia, this time so serious my religious aunt on my father’s side prayed she would “let go,” the nurse at Shriner’s insisted on the genetic testing. They completed a full spectrum genetic study, and that was when they discovered her first chromosome mutation, one of the only ones medical history ever recorded on a living child. Even with a diagnosis, no one knew anything about Ashley’s prognosis. My family went from specialist to specialist, trying to find out why her disability was making her constantly ill.

Though the interior of a hospital was familiar to me since I was two, from the time I’m old enough to remember understanding Ashley’s disability, at least on a basic level, it was just that: Ashley’s disability. Clearly defined, with photographic evidence.

When people questioned me, I knew how to answer. On a cellular level, the way Ashley was different was never uncertain to me.

I try to imagine what it must have been like for my mother during those early years, when Ashley got pneumonia over and over because her weakened smooth muscle meant she couldn't separate swallowing from breathing, and kept inhaling her food by mistake. When Ashley was delayed in milestone after milestone: sitting, grabbing, crawling, walking, talking. When she remained, as in so many pictures from my childhood, reclined in a carrier seat, eyes bright and curious, but muscles small, head limp, fingers unclenched. And how, when a resident asked the same question so many doctors asked before, and Mom had an answer, he did not discredit her, did not try to fix Ashley's chart as though there was a grammatical mistake. Instead, he went and looked up the very condition she described, and came back excited, pleased to have learned about a medical phenomenon he could bring back to class, and show the professor that he was wrong.

Beacon

If you looked at Ashley in those early days, you wouldn't have known she was intellectually disabled. She just looked unusual.

Ashley was small, even though she was more than full term, and her head was oddly large and square. She also had a bright red birthmark that stretched across the middle of her forehead. For the first few years of her life, it was a deep pink that turned a dark angry red whenever she was sick or upset. As she got older, Ashley's birthmark faded until it was barely noticeable, but it never failed to flare when Ashley was running a fever. It is sort of a beacon for Ashley's health.

Kids with Down syndrome are typically identifiable by looks immediately after they are born. They have a distinct nose, chin, and forehead shape that is caused by the malformation of the twenty-first chromosome. My sister's appearance: the broad forehead, wide-set eyes, large nose bridge, and small mouth, would be recognizable as traits of her disability, if it were as common as Down syndrome. We didn't realize this until she was two, and my mother sent a letter to a magazine for parents with special needs children called *Exceptional Parent*, to see if any readers or contributors knew anyone with Ashley's specific disability. A family in Tennessee reached out, and Ashley met another boy, around her age, with a similar "extra" on his first chromosome. In the few photographs my mother has of the two of them together, they looked like twins.

Nonetheless, Ashley is the only person my family knows of whose Trisomy comes from another part of her first chromosome. That other boy, and all other recorded cases, involves a piece of another chromosome breaking off and attaching itself to the first. The implications of my sister's specific case are still something we are trying to understand.

Say Goodbye to These Things

There are two types of mourning for those who have a child with special needs. The parents mourn for the child, and they mourn for themselves.

Once Ashley was diagnosed, my parents mourned. Mom had to accept that she would raise a child who would never have it easy, because everything she had to do would be harder for her. She had to accept that Ashley would not get the normal experiences that I, her older sister, would have. And of course, Mom had to mourn the fact that things would change for her too. She told me she once went to a conference for parents with special needs kids on Ashley's first birthday. One panelist wrote things on balloons like "license," and "college," and "marriage" on the board, and popped them one by one.

"You need to say goodbye to these things. Because your child will not have them," the panelist said. Mom broke down in the middle of the conference, sobbing with the realization of all the things Ashley, and by turn, she, would lose. She realized at that moment she might spend the rest of her life taking care of Ashley, and she would never be able to watch Ashley grow into a fully independent adult.

The difference between my mother's mourning and my father's mourning is in how they handled it. I am sure my mother must have thought "why me?" and was mad at how her life had changed. But she counteracted that feeling by becoming consumed by helping Ashley, and didn't allow herself to slow down long enough to fully process how vastly her life had changed.

For my father, I think the grieving manifested itself differently. He was frustrated at how things weren't going how he expected. I imagine he probably also felt a little lost: my mother always had the capability to make getting shit done seem effortless. In the same way that she took charge, he stepped back. He put distance between himself and the rest of us, and instead devoted himself to other things, like work. For a man who had always had the freedom to travel, change jobs, and make decisions on a whim, dealing with the permanence and all-consuming nature of a child with special needs was probably paralyzing.

The Man on the Couch

The first time I met Ashley, I gave Mom the silent treatment.

“It was horrible!” Mom exclaimed when I asked her about it. “Every time I came into the room, you turned your little nose up and walked right out. The first pictures of you with Ashley all show the back of your head because you wouldn’t look at me behind the camera.”

Since this event seemed to have so traumatized my poor, post-cesarean section mother with a newborn that had a clubfoot and angry red birthmark on her forehead, I assumed I must have ignored her for months, more than a week at least.

“No, it lasted a day. You just sat next to your father on the couch and refused to have anything to do with me and Ashley for hours.”

This was the first and last time my father and I would stand on a united front. For six or seven hours, on a Saturday in early May of 1993, we shared the solitude of the couch with one another, rebelling against the screeching infant and weeping mother at our backs.

I remember my father as a man perpetually covered in sawdust and paint. He liked to tell stories about skipping high school to go surfing while he was growing up in Naples, Florida, and about the horse named Chief that his father owned, and that was so wild nobody but Dad could get close enough to ride him.

Dad was the kind of guy who had four shirts, two of which had little holes from wear, the other two of which were faded denim. He always kept his haircut the same, and drove a pickup truck full of tools and scrap wood. He smoked cigarettes in the detached garage of our rented house and told me not to tell Mom about it. The first time I walked on the sticky floor of a frat house in college, I recognized the cheap beer I always used to smell on his breath. He bought me the *Harry Potter* books and waited patiently until I finished them so he could read them next. He pretended to hate *Spongebob Squarepants*, but I would always catch him laughing when I watched it. He tried to get me into *Lord of the Rings*, and if we still spoke, we probably would have talked at length about *Star Wars*, and watched all of the movies together. I think my father would have really liked having a son.

My mother is the type of person who doesn't understand what it means to be lazy. When she was getting her doctorate in physical therapy while I was in high school, and she used to spend an entire day at work, come home, help get Ashley ready for bed, and then stay up for several hours afterwards to complete her coursework.

I didn't realize how much work it takes to keep a house clean until I moved into my own apartment while getting my MFA in Creative Nonfiction in South Carolina, and discovered that floors get dirty really quickly if you don't sweep them, and it only takes about a week for a fine layer of dust to accumulate on the blinds and countertops. The next time I visited home, I watched my mother sweep the floors every evening, usually between giving Ashley her shower and loading the dishwasher with all of the dirty dishes my sister accumulated. Then, she wiped the counters and bagged up the trash to take out in the morning. Finally, she started a load of laundry and cleaned out the litter box. In the

same amount of time, I checked Facebook, fought with Ashley over whether we would watch a Hallmark Channel movie or another airing of the third *Lord of the Rings*, and answered a few text messages. When I came in to say goodnight a few hours later, my mother was reading a book about writing, for fun. The very same book, in fact, that I had bought for my graduate writing class and stowed under a stack of ungraded papers from the freshman English seminar I had taught the previous semester.

In the same way that I assumed my father wasn't available, I assumed my mother always was. Whether this is because he became more absent or she just took over, I can't say for certain. More likely, it was a combination of both. In the same way that my mother paid for college by working full time at the airport after she got her pilot's license, she dove into caring for my sister, reading every book and talking to every doctor available about what needed to be done. She applied to graduate school for physical therapy shortly after my fifth birthday, and within a year, we had relocated to Chapel Hill, North Carolina, so she could study early intervention physical therapy, which focuses on infants and toddlers. She worked full-time while also taking prerequisites, and then went to school full time, and as a six-year-old, I don't remember noticing a difference in our household. She was still there to make sure we had dinner and our showers every night, she took me to my doctor's appointments and came to school meetings. If she slept at all, it wasn't for very long.

Meanwhile, my father floated in and out of the house at odd hours. I sometimes wouldn't even realize he was home because he would come in the door and sit down at the couch without greeting anyone. In the evenings, we used to eat dinner together. It was often canned vegetables, canned beans, and some kind of meat. After dinner, Dad rarely

did anything with Ashley or me before bed, and I don't recall him ever coming into my room to say goodnight. I remember being puzzled when both of my friend's parents, or just their dads, even, showed up to parent-teacher conferences in my elementary school. That was Mom's job, in my head. Nothing ever got done without Mom's okay.

I knew Ashley felt this way too. Whenever she was sick, Mom was the one who brought her to the doctor's or the hospital. When Mom was doing homework or cleaning around the house, Ashley was always in the same room. She would sit in a rocking car seat or on a mat on the floor and play while Mom paid bills and typed up lab reports. Then, Mom would give her a bath and get her ready for bed. If we ever fought, Ashley and me, it was Mom we deferred to.

First Words

My first word was “cow,” but my first phrase was “I didn’t do it.” Mom found me up to my elbows in trash, playing with eggshells, when I looked her right in the eye and lied. I don’t know what it means that my first sentence was an attempt at deception, especially since it was abundantly clear that I had, in fact, done it.

Mom doesn’t remember Ashley’s first spoken word, because her first words were signed. After meeting the boy from Tennessee who also had Trisomy One, and learning that he was hearing impaired, Mom brought Ashley back to the audiologists who had said she was failing the tests because she was disabled and didn’t understand that she needed to raise a hand when she heard a beep in the headphones. Mom and an audiologist sat down, and taught Ashley to drop a toy block in a bucket whenever she heard a beep, and at no other time. Ashley dropped the blocks in the bucket with the beeps, until they became too quiet for her to hear, and then she waited patiently, looking through the window of the testing room at my mother, as the beeps continued to play unheard in her ears.

Ashley was fitted for her hearing aids when she was in preschool, and a sign language instructor taught her how to sign “eat,” “bathroom,” and things like “Mom” and “Dad.” Ashley’s first consistent word was “eat,” which doesn’t surprise me at all.

Pavor Nocturnis

The houses we lived in were mishmashes of unfinished things. Enough clean bowls, but never enough cleaned spoons. A package of lunchmeat with three slices missing, and the rest starting to stink up the yogurt and cheese. A desk fully constructed except for the protective stain and a functioning middle drawer. A garage or basement covered with stray pieces of wood and sawdust and file cabinets with empty sections. Later in life, this incompleteness would follow me and I would litter my own house with it. I have a hard time finishing all of my laundry, or vacuuming and mopping the floors on the same day. I end conversations in the middle of sentences and abandon projects after a few weeks. The incompleteness feels like a hole, but one I am not strong enough to fill.

My father built me a bed when I was two that was about three feet off the floor, and underneath the mattress, there were a series of drawers designed for storage of clothes and toys. He painted the doors of the drawers white, and stenciled a pink flower pattern on top. But the drawers only faced one way, and they were the only things that were painted. The bed needed to rest against the wall at its head and on the left side, in order to hide un-sanded wood and the skeleton of the frame. On the bottom right side of the foot of the bed, there was a little door, about one foot high and one foot wide. It too was painted white, like it belonged there, but it opened up to a tunnel that stretched the length of the bed, in the twelve-inch by twelve-inch space the drawers didn't reach. It

was sealed in by a rough piece of plywood that rested against the wall. It looked and felt like a coffin. Structurally, the bed was like a bunch of mismatched Lego pieces stuck together to form the right shape.

Several years ago, I purchased a bed from a discount furniture store that needed to be assembled. When I opened the boxes containing the pieces, I was overwhelmed by the smell of treated pine and fresh, cheap paint. It was like I was back in that trundle bed, tucked inside the back coffin space, my nose pressed against the inside of the un-sanded door as I felt the floor vibrate with the force of footsteps.

I don't think my father and I ever spent more time together than in the first year of Ashley's life. As my mother shuttled my sister from hospital to hospital, specialist to specialist, my father and I attempted to carry out our lives in the empty house. I don't remember these years, except for the smell of the new bed and its hideaway and mistrustful images of dark shadows and loud yelling.

My grandfather on my father's side, a man who married into our family when my paternal grandfather died of a heart attack before I was born, took a special liking to me. There are dozens of pictures of us together when I was still young enough to wear diapers, sitting on the swing in his backyard or sprawled out on the porch of his house, chatting with each other with my rudimentary vocabulary.

"She's got spunk," he told my mother.

Perhaps this was why it was easy to notice when things started changing. When Mom was home, she would find me in the middle of the night, running around my room

and screaming, still asleep, and the only thing she could do was wrap me in a blanket and hold me until I calmed down.

After a few episodes, my mother reached out to my sister's new case manager, who was in charge of helping my family find services for Ashley and manage her care. The case manager offered to sit down with me privately and see if she could figure out what I wasn't able to communicate in words.

Night terrors are essentially nightmares from which a person cannot wake up. They are most common in children, but still only around three to six percent of children experience them. A night terror is classified by sitting up or running around during sleep, thrashing and heavy breathing, agitation and violence, and difficulty waking during the episode. Night terrors are caused by several different things in children: stress, sudden changes in environment or sleeping arrangement, and new medications. Often, it is nearly impossible to rouse someone from a night terror without causing the person to be confused or to lash out.

My father always had scrap wood that he left around the house or in his truck. It wasn't uncommon for there to be a half-finished project of his stored in the corner of the living room or on the porch.

The case manager had me draw a picture of my family. I drew my sister, my mother, and myself in stick figures on one side of a house. On the far corner of the paper,

as far away from the other figures as I could manage, I had drawn another stick figure. When the case manager asked me who that figure was, I told her, “That is Dad.”

“Why is he all the way over there?”

“He’s in time out. He was bad.”

When the case manager asked me what my father was doing that put him in time-out, I grabbed a doll from the collection of toys nearby, and started spanking it as I yelled at it.

A piece of scrap wood makes a good paddle. A piece of pine, perhaps, sanded or not, that can be used in a pinch for discipline.

My mother confronted my father about the spanking, and threatened to kick him out if he didn’t stop. She also insisted he go to counseling, which he did for a short time.

Eventually, my night terrors stopped, but I still cannot walk into a Home Depot or Lowes without feeling sick at the smell of wood.

Children find a way to communicate even when they don’t have the words to be understood. The need for self-preservation overcomes the inability to speak, though it may take years.

Blood Thicker Than Bone

I always had a work-study in college. My first year, I worked in a psychology lab as an “animal care technician.” Essentially, I was one of three people who changed and cleaned the several hundred mouse cages that held mice for various neurological experiments. We had to change all of the cages twice a week, but we could work on our own time to get it done. I often went in super late at night, when I was finished studying, and I knew I didn’t need to go anywhere else afterwards, because the smell of mouse tends to stick to the skin and hair. As a tech, I was also in charge of making sure the new litters of mice were weaned from their mothers soon enough after they were born that she didn’t eat them, but long enough after that they could nurse. I made a point of starting with the rooms of mice furthest away from the “birthing room” as I called it, so that when my coworkers came in, the only things they needed to worry about were the females. This was because during one late March night, I happened upon a new litter that was so small the babies were little blobs the size of the tip of my finger, their eyes still closed. I had to count and move the newborns, and their mother, into a new cage with fresh bedding and water.

When I went to set the clean cage on top of the table I was working on, I accidentally bumped the old cage, with all of the newborns, onto the floor. The mother mouse, too full of milk to go anywhere, just kind of stood up and walked slowly towards

the newly exposed floor, covered with bedding and her babies. I managed to snag her and put her in the new cage before turning to the others.

There were nine newborns. All nine lay still on the tile floor, thrown from the impact of the falling cage. Because I was the first one to witness the newborns, my boss never found out that there was a pregnant female that lost her entire litter. I just relabeled her cage as female, not pregnant, and put her back in the stacks. But picking up all of those tiny mice, so small I had to pinch their skin between my forefinger and thumb to lift them, just about did it for me. I managed to stick around for two more months without going near the mothers, but told my boss at the end of the semester that the bedding was making my asthma act up (partly true) and that I had gotten another offer at the school fitness center (not true, but I still managed to snag a work study there the next semester).

A few semesters later, my boss at the fitness center told me of a work study that was opening up at the staff gym at a charter school down the road, that paid a lot better, and had morning hours, so I wouldn't have to go straight from my long afternoon labs to evening work. In the mornings, I manned the front desk, checking in teachers as they shuffled to ellipticals and treadmills, trying to get their morning workout in before a day filled with screaming children. In the afternoons, when I finished my classes, I worked in the childcare center in a windowless room behind the cardio equipment. Most days, the childcare center was empty. Most of the teachers who had children got their workout done during lunch, or came on the weekends. It was empty of everyone except me, and my boss's infant daughter, Kamina.

Trina, my boss, was a trainer and the manager of the gym, and spent her afternoons teaching sagging and soft men and women to squat, do pushups, or run tempos

on the treadmill. She left her daughter, at the beginning of my time there only three months old, with me.

I don't understand how parents are so willing to let other people hold their children at parties, at weddings, in church. I see a picture of an eight-year-old kid holding his younger sister and grinning at the camera and cringe. Jesus, I think, aren't you a little bit worried he's going to drop her?

Though I was twenty-one, I understood even less how Trina trusted me with her infant in the afternoon. Like baby mice, human babies are tiny. Tiny and soft and unbalanced and wiggly and helpless, and I would sit in the rocking chair, holding Kamina up tight in my arms until my wrists went numb and cracked when I flexed them. I hated when I had to stand up and walk with her to change her diaper. I wanted to keep us as close to the ground as possible. When she slept, Kamina relaxed into my chest, completely beholden to my grip. Total and utter trust.

It scared the shit out of me.

When Ashley got big enough to graduate from a crib to a bed, my parents wanted to see if we could share a room. Ashley was two, but unlike myself at that age, she was still undersized, and needed help sitting up on her own. She wasn't walking, wasn't speaking, and still required the constant supervision of an infant. However, with a baby monitor and me for companionship, Ashley, my parents hoped, could learn to sleep on her own.

Ashley's new bed sat nearly on the floor. It was a toddler bed, with a small mattress and safety rails on either side, and there was almost no space between the bottom of the frame and the ground. Since Ashley wasn't walking, it probably made more sense to have a bed closer to the floor, so that if my sister did manage to wriggle herself out of bed, she wouldn't have far to go. They placed the bed on the opposite wall to the one where my bed rested, and from up on my mattress, I was about two and a half feet above and four feet away from my sister.

Once, Kamina was twisting in my lap while I tried to get her to take the bottle. She was more than a year old at that point, and robust for a baby, crawling and pushing herself up to stand. She put one hand up against my face, and her finger went in my nose. I remember wrapping my thumb and forefinger around her arm, and pulling it free. Even with those two fingers, it was more than enough force to tip her body back, her heavy head leading, so that if my other arm hadn't been there to catch her, she would have gone rolling off my lap and onto the floor. I was relieved I hadn't used more force. Even when she had a finger in my face and her other fist gripped my hair, she felt so tiny, so breakable.

The clavicle (also known as the collarbone) is the most commonly broken bone in the body. A thin, curved bone that stretches from the sternum to the shoulder joint, the collarbone holds the arm away from the chest. The collarbone is most commonly broken from a fall, when a person lands on the side and shoulder, putting pressure on the delicate parts of the bone that attach to the shoulder joint and sternum. Imagine dropping a full

glass bottle so it lands head first on the ground. Rather than shatter, the head of the glass cracks or breaks off as it absorbs the impact, or a thin crack stretches from one end of the bottle to the other.

I am afraid of strength. When I watch movies with people fighting each other, I try to diagnose the damage as it happens. Fractured rib. Punctured lung. Cracked cheekbone. Shattered toe. As a result, I am not much fun to watch action movies with. ‘No way would that guy be able to get up and run away!’ I say.

Ashley didn’t like her new bed. That first night, even though I was just feet away, she screamed. My parents came in, one after the other, taking turns. When I was able to sleep, I would always be woken up by my sister’s shouts, look over in the dark, and see one of their figures huddled over the bed, trying to calm her down.

Collarbone breaks do not typically cause bruising. There are less blood vessels around the ends of the bone, where the most common breaks occur, so typically, a break will have some minor swelling around the site of the injury. Bruising does occur if the bone is broken at its center, where the chest and back have a dense supply of blood vessels for nearby muscles and organs. These types of breaks are caused by force directly on the bone itself, such as a head on collision by a vehicle, or a crush under a heavy load.

It must have been early morning. It was still dark, and the crying hadn’t let up. Dad’s figure, looming, five-foot nine with broad shoulders from hours hammering and

sawing wood, thick forearms, often covered in paint, a tight back, muscles rigid through the thin t-shirt, was bent over Ashley, yelling maybe, I don't remember. Talking softly, even. I don't know. Because all I heard was the transition from angry wailing to ear-splitting *scream* from my sister's lungs. The kind of scream that takes the breathe out of anyone nearby. A scream, I would later understand, of absolute agony.

A badly broken bone can cause shock. The break sets the body's survival mechanisms into overdrive, slowing down the heart rate, reducing blood pressure, conserving energy in order to deal with the crisis. It is easy to tell when a person is beginning to go into shock, because it's like all the energy is sapped from their body. They don't really feel the pain, and don't much care. They become confused, sometimes combative, but usually, they just seem out of it.

In the morning, Ashley was glassy eyed and barely moving. Cringing away from touch. In the hospital, the unmistakable x-ray of a collarbone, snapped in two at the center.

"She must have gotten out of bed and hit her collarbone on the bureau," my father said. My mother didn't want to believe he could hurt Ashley that way. She trusted that if the doctors thought something else had happened, they would ask. And she was afraid, when she brought Ashley to the hospital alone, with me in the backseat, that we might get taken away from her.

The bruises were large, the size of coasters, or of hands, on Ashley's chest and on her back, in mirror positions. Purpling as the days went on, fading to green, then to yellow.

I don't know how anyone lets someone hold his or her small child. I don't know how anyone trusts another person to keep his or her kid safe.

I am skinny, like my mother, and when I hunch my shoulders, I can trace the groove between my collarbone and my neck. It's a pocket I could fit a small ball in, or a few of my fingers. I could fill it with water.

My mom wouldn't find out until years later that the doctors who treated my sister suspected excessive force, the kind consistent with child abuse, which they noted in their report, but dismissed because my sister was disabled and therefore, they couldn't confirm what happened. Or something. Really, I suspect abuse of a disabled child was less easy to investigate than a non-disabled one. Because these are the kinds of decisions that save time and effort. Mom moved Ashley back into my parent's bedroom, and put Ashley's crib on her side of the bed. She told Dad never to touch Ashley or me when he was angry again. My father backed off parenting pretty much entirely.

A two year old learns before she remembers how to sense anger. A two year old carries that knowledge and fear with her, whether or not she understands why.

Placement

When you are the oldest child, and the only sibling of someone with special needs, you quickly learn how to stay out of the way. I don't mean this as a necessarily negative thing. But I do know for certain that without Ashley, I would have an entirely different understanding of myself.

Mom likes to joke that the most important year of my life was when I was three. This is because my favorite stories from my childhood, the ones I always tell other people, the ones I always remind her of, I am convinced happened when I was three years old. More likely, I was four or five, or the memory is actually something my mother told me herself, or that I filled in with photographs and vague images. I like to think I learned who I was when I was three, because those younger years, three, four, even up to six, were the years when I realized, on some level, that I may be the center of my world, but I was not the center of anyone else's world.

Barney and an 80s Leotard

When I took the three and four-year old ballet and tap class at our local dance studio, I had this idea that I was a star. I thought my recital was a showcase of my unbelievable talent that had the entire audience enraptured.

On more than one occasion, I was dropped off at dance class by one parent and picked up by another. After preschool, I learned to look for either of their cars lined up outside, my mother if Ashley wasn't sick, my father if she was. Ashley was continuously sick when we were toddlers. She ran fevers from crying too hard, choked on liquids and food without provocation, and seemed to catch every bug going around, and develop complications from it. If I had a cold, Ashley would catch my cold, which then turned into bronchitis, and then pneumonia, and within a week she would be in the hospital, needing help breathing. Once, in Ashley's infancy, Mom laid down for a nap and asked Dad to watch over my sister and me. When she woke up, less than an hour later, he was gone and Ashley was laying on her back, choking to death in the same gruesome way college students who drink too much and vomit in their sleep do. She was utterly helpless to roll herself over, trapped by her own weakened body and an hour of negligence in her crib.

It took several years for Ashley's doctors to figure out she was not swallowing things like food or saliva properly, but instead inhaling them, and then drowning in the fluid in her lungs. My days and weeks were punctuated by trips to the doctor or to the

hospital, and I was as familiar with the beeping of a heart rate monitor as I was with the playground down the street from our house.

One evening, Dad and I drove to the hospital after my dance class, and I bounced into the pediatric ward undeterred by the change in events wearing an 80's inspired galaxy-print leotard and pink tights. And I came face to face with Barney. *Barney*. My idol, my best friend, my afternoon confidant. And rapidly forgotten was the little sister in the room down the hall, the fact that I was hungry and was actually missing an episode of *Barney and Friends* because there he was in the flesh.

I proceeded to follow Barney around the pediatric ward, demanding hugs, asking questions, touching his tail, and generally distracting him from the children he was meant to be visiting. When I asked Barney to say hi, he would wave his mitt and wiggle his head in a way that was supposed to articulate more happiness than the permanent smile spread across his face. When I asked Barney if he wanted to come over, he held up his hands and patted my head. When, finally, I lost my patience and demanded to know why Barney wasn't speaking to me, my mother appeared and said, "Honey, it's time to let Barney meet the other kids."

"But why won't he *talk* to me?"

"Maybe Barney has a sore throat. Let's say goodbye to Barney."

"But I want Barney to talk to me!"

That poor Barney impersonator was probably part of an organization that helped with programs in the pediatric ward at the hospital, and wanted to spend an afternoon cheering up kids with IVs and breathing machines. Instead, he was accosted by a tiny blonde terror in a leotard and snow boots.

Petty Larceny

Less than a year later, I robbed a convenience store down the street from our house. We were living at the top of a hill off the main road through the small town of Hendersonville, North Carolina. The turn onto our street was marked by a plant nursery on one side, and a gas station/convenience store on the other.

On the day of my petty larceny, it was the middle of winter, the kind of day when the color seemed leached out of everything. The night before, we had gotten a few inches of fresh snow.

It was the weekend, so the whole family was scattered around the house. Mom and Ashley were in bed, Ashley with her third bout of pneumonia that year, and Mom with a wicked head cold. Dad was in the living room, where he had been since early that morning, watching television. He shaped a dent in our worn couch, the back of his head over the top the only part of him I could see.

On the weekends, I was used to being on my own, occupying myself in my bedroom by playing pretend with my stuffed animals, or running around in our backyard, making leaf piles or eating snow and pretending it was ice cream. I spent most of that morning shuttling from room to room, my Barney doll in a red wagon in tow.

When I peaked into my parent's bedroom, on my way from one end of the house to the other, Mom's head popped up above the blankets.

"Christina?" she asked, "Would you get me some orange juice, please?"

I trotted back across the house, the wagon bumping on the uneven wood floor. When I opened the refrigerator, the dull echo of the television in the living room behind me, I found the carton almost empty. There was just enough to cover the bottom of a cup. I poured out what was left, threw the carton away, and shuffled into the living room.

“Dad?” I said to the back of his head. “We’re out of orange juice.”

A sigh. “Well then, why don’t you go get some?” He didn’t look away from the television, instead lifting a can to his lips before setting it down with a clink on the coffee table next to an empty bowl of cereal. The milk was yellow from Honey Nut Cheerios and starting to harden in the bowl. This was one of my father’s rituals. When he wasn’t tinkering around in the garage or at work, he was on the couch, drinking beer and eating cereal.

I went to the hall closet, pulled out my puffy pink winter coat and a pair of gloves, slid on my fuzzy boots and pulled up my hood, and walked out of the front door.

“Don’t walk on people’s lawns,” Mom always told me when we went for walks around the neighborhood, she pushing Ashley in the stroller and me shuffling behind, or running before. As I made my way down to the gas station at the bottom of the hill, along a busy downtown road, I purposely stomped on our neighbors’ yards, making little boot footprints in the snow that followed behind me like breadcrumbs. Of course in this situation, my mother would have preferred I walked on lawns instead of the street, which didn’t have sidewalks, considering I wasn’t tall enough to be seen over the hood of a car.

At the gas station, I had to wait for someone else to open the door, because the suction from the heat inside made it too heavy. I slipped in, and dodged people paying for gas or picking up gum and soda. From my height, the shelves were huge and sprawling,

and when I reached the back refrigerator, I had to wrestle a half-gallon of orange juice from a low shelf. I then turned around and marched to the front of the store and attempted to pass a woman who was coming inside. She might have been normal sized, but to me, she looked giant, inflated by huge boots and a heavy winter coat and a booming voice.

“Wait honey, you can’t just—” she reached down for me.

“No! This is for Mom!” I wrenched out of her grasp, stomped on her foot, waddled outside with my prize, and started back up the hill towards our house. Nobody stopped me, even though the pumps were crowded with cars and a four year old carrying a carton of juice the size of her torso in a bright pink jacket shouldn’t have been able to get very far.

On the way back, my trespassing on lawns was slower, weighed down as I was with my prize. By the time I passed our neighbor’s house, the sun had started to go down and my nose was red and arms and chest frozen from holding the cold juice. When I crested the hill, I saw my father, headed toward his truck, keys in hand. My mother stood on the porch, in pajamas, my sister tucked to her chest.

“Look, there she is.” Dad spun the keys in a circle.

“Christina!” Mom hurried towards me in the snow. “Don’t ever leave like that again!”

Her anger and fear frightened me. I started to cry, still holding the freezing orange juice. “I went to get you orange juice. You wanted orange juice!”

This story is still a hoot to me, if I look at it just as a story of a four year old who robbed a gas station and kicked a stranger doing it. But Mom never laughs at it. Not even

years later, when the statute of limitations for finding this type of story hilarious should have set in.

“I was worried sick. You could have been hit by a car. You could have been picked up by someone.”

“Yeah, Mom, but I didn’t. I was fine,” I’ll insist. She just glares, probably thinking about the quiet house, too quiet when I stepped out the front door. Asking my father where I went, only to get, “I thought she was with you.”

“Well, what’s the last thing you said to her?”

“I don’t know. She said something about needing orange juice, so I told her to just go get some herself.”

“Scott. That’s where she is. She went to get orange juice.”

“No, she wouldn’t have taken that seriously.”

“Yes, she would. She absolutely would. I need you to go find her.”

“Why can’t you look for her?”

“Because I have to take care of my other child, the one who is sick.”

My father, grumbling, climbing to his feet for the first time in hours. Walking out the front door, only to see me coming back again, from exactly where my mother thought I would be, carting a jug of orange juice, triumphant.

Forgotten Subject

When Ashley was three, and I was five, Mom signed us both up for horseback riding lessons. Ashley, because Mom had just discovered a new type of physical therapy called “hippotherapy” that used horses to encourage confidence and movement in special needs kids. Me, because Ashley couldn’t do anything at that age without me also wanting to try it. It was sort of like how a younger sibling always wants to do what the older sibling does, but in reverse.

The barn where Ashley did hippotherapy was run by a kind, elderly woman, who offered to give me lessons even though she didn’t usually teach kids who weren’t special needs. I had my class after Ashley’s on the weekends, and spent my time before my lesson rummaging around the grounds, gathering up quartz and zircon. I decided at that age that I wanted to be a paleontologist, and was on the hunt for fossils. The owner of the barn left a giant Tupperware bin in the tack room that used to hold cheese doodles for me to store my rapidly growing collection of rocks.

One time, Mom brought her video camera. I sat next to her while she taped Ashley during her lesson. She was applying for school for physical therapy at the University of North Carolina then, and I think she wanted to use the video for a project she was working on.

“Mom, are you going to tape me, too?” I asked.

“Yeah, of course, honey,” she said.

Later that week, I found the camera, with the tape still inside, in the living room, and rewound it to where my lesson started. You can see me about twenty feet away, inside the fence of the ring, setting up cones to weave in and out of on the old bay I rode. I set the cones in the straightest, neatest line I could, about three inches apart from each other. The entire time, my mother talked in the background to the woman next to her, whose daughter was finishing up her own hippotherapy session. I was nearly done setting up the seventh cone when Mom paused her conversation as she apparently saw what I was doing.

“Christina!” she called out, and my white-blonde head popped up from where I was bent over, hauling the cone into position. Mom and the other mother laughed.

“I think you need to put them a little further apart,” Mom explained when I put my hands on my hips in indignation of her laughter.

“What?”

“You need to move the cones further away.” Here, the camera shook as she adjusted her position. “Can you fit a horse between those?”

“Oh.” I looked around me at the cones, before I walked back to the first one, grabbed it by the base, and started dragging it backwards. Mom resumed chatting with the other mother about my sister.

In our living room I crouched on my knees in front of the television and watched the video in its entirety, staring at myself on the screen as I rode around in circles in the ring, my head high and my hair poking out of my helmet in all different directions. When I weaved the cones, I looked over at Mom and the camera, fleeting glances, and I can tell from the way I held my hands that I wanted to look elegant, like a warrior on her steed.

But none of that mattered. Because throughout the entire video, all I could hear was Mom talking to the woman next to her about Ashley, about Ashley's treatment at Shriners, about her genetic testing, about the new speech therapy she was attending, about how she was learning to walk with a walker. The video showed me, but only in fragments, when I happened to pass in front of the lens of the camera on my way around the ring, since my mother didn't bother to track my movements. It's like looking at a computer screen background with those moving lines of color that flicker on and off the screen every few seconds, the ones that appear when a person is lecturing using a computer and the screen goes to sleep, because they've spent so much time talking that they've forgotten what's right beside them.

The Butt-scoot

My legs are one of the strongest parts of me. I can squat and deadlift more than most women I know, and also a lot of men. I can't wear non-stretch jeans, and in tights, the bulge of my quad is noticeable above my knee. "Legs like tree trunks," a well-intentioned, but utterly idiotic boy once told me.

If you stuck my legs next to my sister's, they would look like sequoias to her pine saplings. Ashley doesn't have the strength to jump, balance on one foot, or squat. I've never seen her run.

During college, one of my favorite machines at the gym was the Stairmaster. I was not alone. At my school, we had two large Stairmasters, which are those machines that are about seven feet tall and have actual stairs that rotate on a belt so it feels like climbing a fast mini-escalator. Given how often the machines broke down during my four years of college, I was not the only one who loved them.

There is this sort of unwritten rule of etiquette at the gym: it's rude to wait behind someone while they are on a machine so you can snag it when they finish. However, it is perfectly acceptable to get on the nearest elliptical and glare passive aggressively at the girl texting while climbing the Stairmaster at about ten steps per minute until she gets off.

Another thing about the Stairmaster: it requires an incredible amount of coordination if you get it going fast enough. The higher the level, the faster the stair belt moves, and once the machine reaches level twenty or so, the only way to stay on the machine is to run up the steps like there is a coach with a really loud whistle chasing you. More than once, I've missed a step and gone sliding off the side with a lot of banging and grunting. It takes a lot of work to climb the stairs, which is why I'm not surprised ten minutes on a Stairmaster is enough to leave a person drenched in sweat and bent over, panting for air. It was the machine of choice for many of my college friends, from the wrestlers trying to make weight to the girls prepping for a night of heavy drinking.

On more than one occasion, Ashley has created traffic in a stairwell. The longer the flight of stairs, the more of a backup she causes. Once, when we were at the mall during the busy holiday season, trying to find my sister a dress she could wear to a Christmas party, we were forced to take the stairs because the elevator was broken down. My sister looked at the large flight of slick, white steps, and I could see her exhale, before she grabbed the railing on one side, and my arm on the other, and began to climb. As we reached the fifth stair, there were already several people queued up behind us, and one woman, apparently in a big fat hurry, passed us on the right side and bumped Ashley with her shopping bags, nearly sending my sister toppling over.

While I swore at the woman under my breath and told her exactly where she could stuff her giant shopping bags, my sister leaned against the railing, panting, and looked down at her feet. Once I had calmed down, she looked behind her, where people

were doing their best to look patient in order to avoid my wrath, or maybe because they were actually good, kind people, and resumed her climb.

We weren't sure if Ashley would ever walk. My sister's disability impairs her muscle growth to such a degree that supporting her own weight is a feat. Even after her clubfoot healed, her legs were always spindly and thin, and bowed outward at the knees. As an adult, her feet are tiny, and have always been several sizes smaller than they should be. She has never worn larger than a size four shoe. Before shoes were even necessary, Ashley developed her own method for getting around. Not quite strong enough to support her weight over her hands and knees in a normal baby crawl, she adopted a different technique.

My family calls it the butt-scoot, and if there were ever a sporting event devoted to moving yourself from place to place without your butt leaving the floor, Ashley would be a professional. Once she learned to sit up, which in itself took about twice as long as it should have, Ashley figured out how to propel forward by putting her feet out in front of her, knees bent, heels resting on the floor. She would lean back on her palms, straighten her legs, and use her heels to drag her lower body across the floor as she bent her knees back up to her chest. At the same time, she would lift her palms, bring her arms to her sides and forward, grabbing the ground in front of her with her hands. It looked kind of like a forward crab walk, but if the crab couldn't be bothered to lift its shell off the sand. By using her trunk as her center of gravity, Ashley was a butt-scooting monster.

We always lived in places with carpets, mostly because apartments generally have carpets, and we mostly lived in apartments when I was a kid. Ashley would never

become fully potty-trained because her incontinence and smooth muscle weakness would ultimately prevent that sort of motor control, but my parents, when we were kids, just assumed that, like with so many other things, Ashley would learn eventually. So long before Ashley could walk, years in fact, she butt-scoted everywhere, her diaper-clad bum sliding across the carpet. She left lines like vacuum cleaners leave and you could hear her coming by the shh-shh shh-shh of cloth across carpet.

When Ashley did learn to walk, I was seven, and she was five. By some miracle, all her butt scooting made her build up enough muscle to stand on her two skinny legs. Balance would come years later, but there were solutions for problems like that: walkers.

I like to think that my ability to withstand foot pain when I run long distance races comes from the sheer number of times I had my toes run over by Ashley's damn walkers. Because once she figured out how to use those suckers, it was like butt-scooting only with a lot more scratches on the wall, a lot more trampled food dug into the carpet, and instead of butt-carpet lines, there were little wheel lines all over the house. So at least there was that.

Walkers are most commonly used by the elderly, and usually are pushed in front, for balance and support. But walkers for kids who might learn to walk on their own are pulled, the frame behind the legs like some sort of snail shell being dragged along behind. Well, not exactly, because that implies there is some sort of speed control with a walker. There is not.

Ashley's walker was silver and had red handle grips, and was small enough that she rested her hands on the handles at hip level, about two feet off the ground. When she walked, she pulled the walker behind her on little scooter wheels, which made rattling

sounds on hard surfaces. Because the walker was behind her, Ashley stood upright when she used it, and it almost looked like she was walking normally, except with cargo. This made it so her abdominal and back muscles got stronger, without her having to bear her full weight.

Once, when we were at the store shortly after Ashley got her walker, I saw an elderly woman pushing a walker in front of her, one of those white ones with shelves for purses.

“Mom,” I whisper-shouted. “Mom, she’s doing it wrong. Mom, tell her she’s doing it wrong,” I insisted, pointing at the woman.

It was the same sort of self-righteous conviction that would follow me later in life: I can’t help myself if I see someone walking with a cane and holding the cane on the same side as the favored leg; I have to stop and explain to them the mechanics of properly walking with a cane on the opposite side of the weak leg to encourage strengthening and good posture. That’s mostly the reason I can’t watch *House*, actually. I don’t care what silly excuse those writers made up for why House can’t seem to use his cane properly. If any doctor of mine shuffled into my hospital room using his cane wrong, grouchy face and prodigy intelligence or not, I would not trust him.

“No, Christina, that’s a different kind of walker.”

“But why is she pushing it? Shouldn’t she be pulling it, like Ashley?”

Considering I was six, Mom probably told me something to the effect of, “She probably has to push it because she isn’t as good at walking as Ashley.”

A couple of months after Ashley got her walker, she went to a track and field event for the Special Olympics. I remember very little about that day except that it was hot and boring and the attention wasn't on me. The next day, the local paper covered the event. On the front page was a huge photograph of Ashley, hair flying, legs cranking, a massive grin on her face as she charged across thirty yards of a field, towing her walker.

In the background, you can see other athletes in walkers, nowhere near Ashley, who is barreling ahead at full tilt. She's wearing a Special Olympic t-shirt that looks long-sleeved on her for how far the short sleeves go down her arms, and the hem is below her knees, so the only part of her legs visible are her shins, which have large leg braces stretching up to the knee. It's an adorable picture, for sure. It's enough to make even the most pessimistic person feel some of her joy at being able to almost run. In her face, I can see her own realization that she can do something that probably seemed impossible before. She looks like a kid who knows what it feels like to work so hard to move at all, to be carried and pushed in strollers and lifted onto counters and chairs far longer than she expected.

Mom saved the article, and the photograph, had them both laminated. It was one of hundreds of pieces of evidence of my sister proving people wrong, and having a hell of a good time doing it.

Bah Bah Bah

When I was six, our family moved to Chapel Hill so that Mom could attend the University of North Carolina for her physical therapy degree. We lived in a large apartment complex called Southern Village, which, by the time we moved away, nearly required its own zip code. In addition to apartments, there were San Francisco-style condos, Charleston-style houses with doors on the porches, and three pools that all went up in a year. Someone built a church, then a bank, then a movie theater at the back of the neighborhood. The Methodist church was huge, with cathedral ceilings and fragrant wood, and stood near the bank and the movie theater and the pool with the fifteen-foot deep end.

I don't remember going to church when I was younger than six, but Mom seemed to take a special interest in church during our last year in North Carolina. The church had a playground and several rooms for Sunday school and devotions, as well as a kitchen and the kind of risers behind the pulpit that could fit a full choir. Since the church was new, I don't think I ever saw it more than a third full on the busiest Sundays, but that also meant that after a month or so, we knew pretty much everyone in the congregation, especially because many of us all lived in Southern Village as neighbors.

Ashley, we discovered during one of our first services, loved to sing hymns. I was a fan of mouthing the words and not letting a sound escape my mouth, but Ashley, who couldn't read and couldn't really care less, would sing in high, often flat pitches that

drowned out most of the people around her. For one month, I was a candle-bearer, which meant I got to wear a fancy white robe and light one of the candles at the pulpit before service, and snuff it out with a little bell stopped at the end of the service, and then sit at the front for the whole sermon. The job was short-lived, because I was too short to light or put out the candles, and I had several close calls almost lighting other people's robes on fire or knocking over a lit candle podium. In those few weeks, I could clearly hear my sister from my spot at the front of the church, even when my family was sitting ten or eleven rows back. From my vantage point, I could see the people in front and around my sister smiling as they heard her, but it just made me embarrassed. Perhaps because I was too embarrassed to try out for solos in the children's choir.

After a few Sundays with Ashley soloing from the audience, she was moved to the children's choir, and sang right in the center of the group, a huge grin on her face, loud and off-pitch. Ashley's songs featured things she was thinking about at the time. For example, she had a song for years that we called "The Everybody Song," because she would just sing, "everybody, everyboooooodyyy, Christina, everybody, Momma, everybody, Ashley, everybodyyy, *everybodyyyy*" and on and on. "The Everybody Song" could last anywhere from a couple of minutes to a solid half hour, until she would either get distracted or hungry.

The church took things a step further, however, when they cast their Christmas Eve play about the birth of Jesus. Most everyone in the congregation, including the kids, were used to Ashley leading our singing on Sundays, and so I suppose it made sense that Ashley would get a part in the play, just like all of the other children. I tried out for the part of Mary, of course, and I even plucked up the courage to sing for the choir teacher in

one of the classrooms, trying my best to show I was brave enough to solo on stage. The part of Mary went to a girl a few years older to me, and while most of the children my age were cast either as shepherds or angels, I was relegated to sheep, along with the youngest kids, including my sister.

I understood this move for what it was. If Ashley was going to be in the play, she needed someone to supervise her on stage, and since all of the people in the play were other children, it made sense to make me a sheep with the kids in her age group so that I would be able to make sure she walked in at the right time, sat in the right place, and left the stage when she was supposed to. I watched the girl who was to play Mary twirl around backstage in a long white dress, holding a fake baby, and tried not to be bitter about my sheep costume, which was basically a white shirt covered with synthetic cotton. While the girls and boys my age got to wear shepherds' robes and angel wings, I was gluing bits of fluff to a pair of sheep ears and trying to make them fit on Ashley's head behind her ears.

We sheep had one line. When the Shepard announced his job caring for the flock, we were to all sing, "Bah, bah, bahhhh." It was like sheep that harmonized their bleating. Because this was a big production, Mom and I took special care to make sure Ashley understood she couldn't sing when Mary had her solo, or when the angels performed their trio, or any other time except for when we were supposed to bleat in synchrony from our seated position at the back corner of the stage. "Bah, bah, bahhhh," I repeated to her until she was doing it back to me, and then she started singing it in the shower and while she was playing and during regular choir on Sundays leading up to the performance, and

everyone in the house alternated between humming the three-note tune under our breaths and rolling our eyes when someone else did it.

Ashley did not disappoint on Christmas Eve. From her spot in the middle of the group of sheep, she sat patiently and bobbed her head along when Mary sang, when the shepherds sang, when the angels sang, but she didn't make a sound. And then, when it was our turn, I touched her arm and nodded at her, to signal her it was time, and in synchrony, we sang, "Bah, bah, bahhhh." I was nestled in the corner of the group, practically off stage, and so I don't remember much else about the play. I spent my time systematically pulling pieces of cotton off my costume and rolling them into perfect balls on the floor.

Double Under

“If you can do fifty double unders in a row, I’ll let you teach me how to jump rope,” Dad said from the driver’s seat of his pickup truck, as we headed home in the dark on a Wednesday afternoon from the local high school. I was sweaty, and in my lap was a black duffel that held my collection of jump ropes. My speed rope, trick rope, and a punishment rope were all tangled together, smelling like gym floor and mildew. My arms and legs were covered in welts from when I had missed steps during a routine, and the rope slapped against my skin, and my upper lip was hot and swollen from an incident involving double Dutch and a girl who wasn’t paying attention while she was swinging.

Ashley went to a special preschool that attached to my elementary school designed for special needs kids, and they had a built-in after school program. To avoid having me hang around the neighborhood by myself for hours after school, our parents signed me up for a jump roping class that took place in the afternoons at our gymnasium. The instructor was the head coach of the local jump roping competitive team, the Bouncing Bulldogs, which was for kids from ages six to eighteen, and pretty soon, I was going to practices on Wednesday nights and Saturday mornings.

Dad brought me to my practices because it was probably a better alternative to feeding, bathing, and tucking in my sister. He could sit in the auditorium and watch us jump rope, which he sometimes did, but mostly, he had an excuse to hang out in his truck by himself for an hour and a half.

There were three main parts to a jump roping competitive team. Speed jumping looked a lot like running in place with a rope passing under your feet with each step. Freestyle tricks used a longer rope, and were my favorite types of moves, because they involved doing handstands and jump tucks and twists in the air to music. I liked group double Dutch less, I think because it involved teamwork and I felt guilty if I messed up because it messed up the rope spinners and anyone else in the routine as well. Usually we practiced with thin, stretchy plastic ropes that didn't hurt too badly when we tripped and were lightweight. But occasionally, we used thicker ropes that had plastic beads of alternating red and white that made a loud smack against the wooden floor and left bruises. These were the punishment ropes.

I discovered the Jackson Five, "Cotton-eyed Joe," and "Rockin Robin" from the jump rope team. We did cartwheels, handstands, flips, splits, and, most impressively, the double under.

During my sophomore year of college, I went to a friend's cross fit gym to do a couple of workouts, and discovered that cross fit had adopted jump rope as their own, much like boxing had in the eighties. Part of the workout involved doing twenty-five double unders, where you let the jump rope pass under your feet twice between each jump. When I reached that part, I picked up the nearest rope, and, having not jumped roped in over two years, completed the twenty-five without stopping or messing up. Beside me, a tan guy with absurdly large triceps and a thick neck struggled to do three or four in a row before he bent over panting, the rope tangled in his legs.

On the jump-roping team, we learned to do double unders in sequences of five or six for our routines, but after I struck the deal with Dad, I became obsessive. I would

spend hours after practice in the parking lot of our apartment complex, doing set after set of double unders until my shoulders burned and I was wheezing for breath. At a school field trip to a local pool before summer in first grade, my friends marveled over my six-year-old six-pack and muscular legs. In high school, a wrestling coach spotted me doing a speed ladder during track practice, and dragged me over to his assistant coach and captain to watch. Even though I was fourteen, almost a decade removed from my jump roping heyday, I had the foot speed to move through the speed ladder faster than they had ever seen someone do it before. I pounded out repeats of steps before them, the soles of my shoes leaving black marks on the floor, my hands at my sides, fingers curled as if holding handles, bouncing imperceptibly like they were swinging a rope.

I treated my father's challenge like it was essential to securing our relationship. Since moving to Chapel Hill, my parents had started fighting more, usually after Ashley and I were in bed. While Mom spent hours at night in class or at the lab, Dad needed to pick up the slack around the house while also working full time. He didn't care for Chapel Hill the way the rest of the family did. Mom met her best friend, Lisa, while we lived in Southern Village. They would sit on the playground picnic tables for hours talking while I played with Parker, Lisa's son who was Ashley's age, and other kids who lived nearby. When my father was at home, he wasn't outside. He left before dawn, and when he returned for dinner, he let me go play without his supervision. Often, I would spend my evening at Lisa's apartment before I was sent home to go to bed.

Ashley loved Chapel Hill too. The kids in the neighborhood got to know her well enough that they would sometimes play with her in the sandbox on the playground, and she and I would go for long walks around the neighborhood with our mom, admiring the

new construction. Once, after some heavy snowfall, Mom, Ashley, and I went out in the early morning, and while Mom dragged Ashley along on a sled, I rolled a huge snowball along the untouched street until it was almost as tall as my hips, and sent it careening down a hill. Dad was still asleep when we got back, and we stayed in the living room, drinking hot chocolate and whispering while we decorated the Christmas tree without him.

I hit forty double unders when Mom graduated from PT school and announced we were moving to Arizona. Her twin sister lived in Phoenix, and there was a lot of work in physical therapy in the city, and if that didn't work, there was a large commercial airline. At the airport, Mom, Ashley, and I each had four bags of luggage, and we spent the better part of two days making connections from Chapel Hill to Phoenix. When we landed, Dad was already in the city, partially moved into our new apartment. When we joined him, it felt like we were intruding on his privacy. I was about to turn eight. Ashley had just turned six.

In Arizona, Ashley got a wheelchair, and I left my jump ropes tucked in a closet. Our new school, the first one we had ever gone to together, was humungous, and even with a walker, Ashley had a hard time walking from class to the gym to lunch. Eventually, though, she got lazy.

“Wheelchair?” she would ask whenever we went to the grocery store.
“Wheelchair?” when it seemed like she was going to have to do any standing.
“Wheelchair?” when Mom pulled out a specially designed tricycle with straps and a

handle on the back, designed for kids with special needs so that their parents could hold onto them.

“No, Ashley, this is a bike.”

“Wheelchair.”

Even if Mom could convince Ashley to get on the bike, my sister quickly discovered that if she didn't want to pedal, Mom could push the back of the bike and it would roll forward, the pedals moving with Ashley's feet strapped to them, no effort expended on her part at all.

I don't remember if my parents looked into jump roping programs when we moved to Phoenix. I assume they did, but it didn't hold the same charm. I hardly saw Dad at all, and started horse-back riding on the weekends instead, at a large horse farm with a bunch of other kids my age. I stopped caring so much about reaching my goal of fifty double unders because I think I was afraid I would accomplish my goal, and Dad would have changed his mind about his end of the deal.

“No! I'm mad!”

From the kitchen table, I watched my sister cross the living room toward the bathroom door with alarming speed. It was dinnertime, about the time of day when Ashley fell apart.

Ashley charged across the carpet, arms swinging, her short brown hair flapping atop her head. It looked like she was the one-man team of a marching band, feet high stepping with surprising speed.

Ashley does just about everything better when she's angry, or when she wants something. On this occasion, she and I had been sitting at the table, waiting for dinner, when Ashley decided she didn't like the selection (baked beans and meat loaf, probably). She had pushed her chair away and power-walked to the bathroom.

When Ashley walks, she looks a lot like a sailor recently returned to dry land. It's like she expects the ground to dip and sway underneath her, and when it doesn't, she becomes the thing fighting for balance. Ashley has two different length legs, and two different sized feet, which are drastically so to the point where she often owns two pairs of the same shoe. Her legs are scrawny in the way that an elderly, frail patient labeled "fall risk" in the hospital's legs are scrawny. They are wide set, the muscles of her calves indistinguishable from her ankles.

I watched Ashley stomp to the bathroom with Mom, and we both burst out laughing.

"Man, if only she walked like that all the time," she muttered, and got up to follow Ashley into the bathroom.

I decided I wanted to learn how to skateboard when I was nine. I got a skateboard for my birthday, but quickly discovered I had neither the balance, nor the patience, to learn how to ride. None of the kids in my neighborhood were skateboarding, so there was nobody to learn from. Instead, everyone was into Razor scooters, which had a short learning curve.

I must have seen a wheelchair race on television, because I cannot fathom how else I got the idea. But one sunny day, I borrowed Mom's biking gloves, the ones with

the fingers cut out of them, and crossed my legs on the top of my skateboard, leaning forward to pump my arms like wheelchair racers did. I went up and down the street, pretending I was a wheelchair racer at the end of a big race, pumping my arms as fast as I could. If my parents saw me, they didn't say anything about it. When, at Christmas, I got an off-brand scooter called a "Just Go," I was interested in it long enough to scrape up the bottom and loose one of the grips on the handlebars. The skateboard I kept until Dad ran over it with his truck on accident after I left it in the driveway.

Rotten Afternoon Sun

Before-school was the first place I saw someone cry so hard he threw up. He cried until bright pink liquid came spewing out of his mouth and nose and all over the table and floor in front of him and onto the woman who owned the before-school program, called Sunrise Academy, while she tried to calm him down. We had just moved to Arizona, and I was entering third grade, Ashley first.

It was our first day of before-school, Ashley and me. Mom dropped us off while the air was still cool and the stars still stretching out over the desert mountains in the distance, before heading off to work. She had a job as an early-intervention physical therapist, which meant she drove to underserved parts of Phoenix, and evaluated and treated kids under the age of five in their homes, often in unsubsidized housing or in areas known for violence and gang activity. Her hours were long, and Dad had to get up even earlier for his work in construction because the peak sun hours in Arizona kept carpenters inside for long stretches of the day. Sunrise Academy opened around six in the morning, and had a van that would transport us to our elementary school, five minutes away, in time for class to start. In the afternoon, we would meet the van outside by the buses, and get driven back to Sunrise Academy for after-school, until one of our parents could pick us up.

Ashley and I sat in silence and watched the other kid, clearly also at his first day of before-school, calm down and drink an orange juice while a janitor cleaned up his

vomit. By the time we got to Kyrene de la Esperanza, our elementary school, I had to wake Ashley up from where she had dozed on my shoulder.

I would learn quickly that vomiting five year olds were preferable to just about everything that happened in afterschool. It was like Sunrise Academy became a different place when the sun was up. While there were maybe five or six kids in the morning, the place was crawling with elementary schoolers after school, all loud and excited and full of pent up energy from a day spent in class.

My parents had chosen Sunrise Academy because there was one teacher there who knew how to use hearing aids. Ashley's hearing aids, which she had just gotten a couple of years before, were tiny and looked more complicated than they actually were, but most caretakers balked at the idea of having to manage Ashley's special requirements. I saw the teacher who understood the hearing aids only if I sought her out. The first time Ashley's hearing aid started squealing, which it tended to do if my sister scratched her ear, took off or put on shirts, or fiddled with the mold, I spent ten minutes tracking down the teacher so she could take the hearing aid out and put it back in properly.

I hadn't ever really taken care of Ashley up to that point in my life. Several times, I had helped her in the bathroom, wiping her and making sure she washed her hands, or putting on her shoes, but at eight, I had a pretty good idea of her needs if only because we had shared a bathroom for most of our lives. The after-school teachers either didn't have the time or didn't care enough to get to know my sister. In their defense, there were as many as thirty kids in one room, either making a mess with crafts or gathered around the small television, watching *Teenage Mutant Ninja Turtles*. When Ashley needed to go to

the bathroom, or wanted a drink, she automatically asked me first. She knew, as well as I, that most people didn't understand her when she spoke, and were not likely to stop what they were doing to take care of just her needs.

So I brought Ashley to the bathroom, made sure she drank water before and after we had to go out into the sun for outdoor playtime, and stayed by my sister in a corner, avoiding the other kids while she colored or played with crafts and I did homework and read. One time, I forgot to apply sunscreen to our legs and faces, and we were scalded by the afternoon sun. We spent the rest of the day in one of the bathrooms, door locked, while I put cool, damp towels on our thighs and foreheads and refilled Ashley's Sippy cup with water. The next time we went outside, Ashley and I hung back from the other kids while I rubbed Banana Boat onto her skin in the shade of the back porch of the building.

I needed Ashley as much during that time as she needed me. As the new girl, I didn't know any of the other kids at the afterschool program, while they had been friends with each other for years. It was a relief to have some way to avoid them by hanging around my sister, and nobody gave me a hard time about it.

After an incident where Ashley was running a fever and I couldn't get a teacher to call my parents to let them know we needed to go home, Mom took us out of the afterschool program. She picked us up at the normal time, unaware that anything was wrong, only to see me practically carrying Ashley through the front lobby, my sweatshirt wrapped around her shoulders, and her face pale and clammy. The next week, a woman who had a yippy Chihuahua took over caring for us. She lived in a new housing development where all of the houses sat on sand because there had been no new plants set

down in the freshly razed ground. We would go to a park or the indoor pool or hang out in her air-conditioned house that smelled like fresh paint and was blissfully quiet until it was time to go home. I still can't handle *Teenage Mutant Ninja Turtles* whenever it comes on TV, because it reminds me of screaming children and sunburns.

Ashley's Sister

In Arizona, not only were Ashley and I spending our mornings and afternoons together, but we also shared the same school halls with one another for the first time. And the identity “Ashley's sister” began to follow me in way it would for the rest of my life.

Ashley may have been intellectually disabled, but she had no trouble making friends. She was in a normal first grade classroom with a one-on-one aid so she would be able to interact with other children and learn to socialize in a conventional school environment. My sister, despite having trouble keeping up with the other students when they walked to lunch or not being able to work with them on group reading projects, nonetheless gathered a circle of fans in about the same amount of time that my third grade teacher finally learned my name.

When I went to music class, my music teacher saw my last name and said, “Hey, you're Ashley's sister!” I must have looked creeped out, because she added, “My partner, Ms. Rogers, is your sister's teacher. I've heard so much about Ashley.”

After school, as I sat in the back seat of our babysitter's car, my sister and her aid were stopped by teachers and students alike for hugs and high fives. The PE teacher, art teacher, vice principal, and lunch monitor all recognized me through Ashley. The secondhand fame afforded me some privileges: I felt like I belonged at the school, even by proxy of my sister. But I also felt like I was slipping into her shadow, and, as the older sibling, I was not pleased by this.

“If anything, they should call her ‘Christina’s sister,’” I complained to my mother on the way home one afternoon. “I’m the bigger one.”

Not that I didn’t use Ashley to my advantage. I knew other kids in my class thought it was cool that my sister had a walker and that everyone seemed to love her, so I made sure to give Ashley a big hug whenever I saw her in the hallways. I waved at Ashley at recess, and sometimes pushed her on the swing, always thinking about the way I looked to the other kids. I felt like I was more grown up, and therefore worthy of their respect, because I had a sister with special needs. I have no idea if Ashley had any clue about how I used her for my own gain, but she definitely seemed a little baffled the first few times I went out of my way to say hi to her. She would look at me like, “is this a thing we do now? I just saw you an hour ago,” but hugged me nonetheless, and allowed me to heap my self-profiting affection upon her.

In fourth grade, we had the same post-lunch recess. During recess, students were supposed to leave their lunchboxes in a line next to the number that corresponded to their classroom. I was going through a big tetherball phase, and spent most of my time less than twenty feet away from the lines.

I happened to glance over at a boy who was in line near my sister’s classroom number. I saw him rummaging through Ashley’s lunchbox, which held not only her lunch, but also the batteries and case for her hearing aids. I watched the boy, who I didn’t know, pull out the hearing aid batteries, and stand up to throw them at the ground, like he expected them to explode.

Leaving in the middle of my ten game winning streak, I rushed over, and as the boy saw me barreling my way across the asphalt, he tossed down the batteries and took off running. I may not have recognized him, but clearly he knew who I was. My typical demeanor on the playground was aggressive: I liked to play soccer with the boys and was killer at dodge ball. I wasn't afraid to yell at someone for breaking the rules, or slam myself into a guy to get the ball from him. I probably should have known that early on that my aggressiveness in sports was a substitute for my lack of aggressiveness when I was at home. I let all of my emotions out on the playground. Later, when I was in high school, I would get a reputation for yelling at people on the field hockey field, mouthpiece in, spit flying everywhere, a fast blonde with a wicked temper.

By the time I reached the lunchbox, the boy was long gone, and the bell to go inside was ringing. I zipped up Ashley's lunchbox and looked to find her one-on-one aid, Mrs. Clausen, but they were on the other side of the playground, and my class was already lining up to go inside. I left the backpack, and went to line up without telling anyone.

On the way back to our classroom, I couldn't help but feel like I was choking. I was having trouble breathing, and my chest felt heavy, my mind racing. I walked up to my teacher.

"I don't feel well. My chest hurts," I told him. He wrote me a note for the nurse's office, and by the time I got there, my face was red and my lips were white. I could barely breathe enough to speak. The nurse, a woman who my mother would call grossly unqualified, put me on the phone with Mom.

“Mom, I can’t breathe. I can’t breathe.” Mom yelled at me over the phone to put the nurse back on. I was crying, gasping, and scared that I made her mad.

“If she isn’t breathing, then why aren’t you calling a God damned ambulance, instead of calling me?” I heard her yelling over the line.

As the paramedics arrived, my mother barreled in through the door in front of them. I was laying on a cot, curled up in a fetal position, my hands and feet contorted like claws from lack of oxygen. The paramedics put an oxygen mask on my face while my mother berated the nurse for waiting so long, and within about ten minutes, I was sitting up, trying to stretch out my raptor fingers, humiliated.

“Christina, what happened before you started having trouble breathing?” Mom sat on one side of me, and the paramedic was kneeling in front of me, still holding the oxygen mask in case I needed it. Through gasping tears, I told them about the hearing aids, about the boy, about not being able to tell anyone, and how mad I was that Ashley’s stuff wasn’t safe.

It would be the first panic attack I ever had. I wish I had just chased after that kid and punched him in the face instead. I would rather deal with those repercussions than have an entire squad of EMTs showing up to our school, and to watch Mom yell at a nurse in my defense.

For the next few days, I stayed close to Ashley’s lunchbox during recess, waiting for the boy to come back, hoping he would so that I could have an excuse to yell at him.

Kit the Cat

My sister's special education teacher found a tiny, starving tortoiseshell cat hiding in an unused hallway in our elementary school. She had no front claws, was missing hair, and cowered in front of men and shoes. When the teacher brought her to the animal hospital, they found a chip, but the phone number had been disconnected, and the house had new owners. Her family had taken out her claws, and then turned their defenseless cat out to the desert. They estimated, based on the when the house sold, that she had survived nearly two months in the wilderness, which was a feat in itself, considering she had no defenses and the days were hot, and the winter nights freezing.

When Mom and Dad brought me to meet her, the pet I hadn't asked for but that Mom knew I needed, she hid behind the couch, and trembled in her blanket when we brought her home. I wanted to name her Lightning because of the yellow flash of hair that split her forehead and nose, but when Ashley said "Lightning" it sounded like "nigh-ning" and at least "Kit" was close enough to "Tik," which is how she pronounced it, that the cat might know her own name.

That first night home, Christmas Eve, I spent on my stomach, one arm reaching toward Kit, who hid under my bed, letting her eat food off of my hand. When I eventually crawled into bed, I kept one hand stretched down between the mattress and the wall, so

that even if she didn't want to come near me, she knew I was there. I woke up to Kit perched on my stomach, her yellow eyes huge and alert. I laid completely still for the rest of the night, not even moving my arm to scratch an itch on my face, terrified that I would make her leave.

"I have good news and bad news about Kit. Which do you want first?" Dad unlocked the front seat of his pickup truck and I climbed in after school on a chilly January morning, less than a month after we brought Kit home, and three days after we learned that she was scared of newspaper and she started sleeping on my hip every night.

"Bad news," I said.

"We lost Kit." I didn't ask questions, just sat there silently as tears rolled down my cheeks, trying to understand how I could be so sad about the pet I was just getting to know. We were almost in the apartment complex, the car silent, when I said: "What's the good news."

Dad smiled, pulled into his parking spot, and said, "We found Kit." Years later, I still wonder how my father would have handled that question if I had said I wanted the good news first; would he have started with "We found Kit" and then waited for me to put the pieces together myself? I don't know how I feel about the fact that he assumed I would want the bad news first.

He was grinning, and I laughed, that sort of teary laugh that is jerked out of you when you're too angry to react properly. It turns out Kit had disappeared about two hours after I went to school that morning. Both my parents were home because Dad's brother Erik was visiting with their aging mother, and they all spent hours traipsing up and down the desert our apartment complex bordered on, calling her name and shaking a cup of

food. Mom told me later that my uncle kept stomping his feet every few steps, and when she asked him why, he said, “To let the rattle snakes know we’re coming,” and she had cried.

About fifteen minutes before I was supposed to be picked up, Kit wandered out from the nook in the back of my bed, the one I used to shimmy into when I was a toddler, yawning and looking around for food. When Dad and I got home, Mom and Uncle Erik sat at the dining room table under the air conditioning vent, their faces sweaty and sunburned from hours patrolling the desert. Whenever Kit went missing from then on, we always knew to look in that tiny nook under my bed. More often than not, I would open the little door and see the shadow of her shape, barely larger than a pair of shoes, tucked in the furthest back corner, her green eyes reflecting off the light from the room.

Kit, like most cats, was really sensitive to emotions. She wasn’t a huge fan of Ashley because my sister was loud and not very gentle, but whenever my sister was upset or not feeling well, Kit was right next to her, sitting just close enough that Ashley knew she was there. It wasn’t long after we got her that we started to suspect Kit might have been abused in her previous home. That our cat hadn’t had the nicest owners wasn’t particularly surprising, considering they had her declawed and then abandoned her. Kit never warmed up to my father. Whenever there were other men in the house, like relatives or even my friends, she would hide. She hated shoes, especially heavy ones like the construction boots my father wore. She was also terrified of newspapers. Dad had held one wrapped up in his hand one evening, and when he passed by Kit, she cowered into a ball and shook terribly, her face tucked into her paws.

When our parents would fight, or Dad would bang dishes and yell, I used to hide out in my bedroom. Soon after we got Kit, whenever I retreated to my haven, Kit was there. If she wasn't already there, she would be waiting outside of my closed door for me to let her in. We would sit together in the space between my bed and the wall, and I would throw a blanket over us to muffle the sound and Kit would curl up in my lap.

Ashley didn't join us. She liked to stay near Mom as often as possible, and I could usually hear her crying when they fought. Unlike me, she didn't have the option of retreat, unless I invited her. Which I didn't. I think I just didn't consider it. Probably, Ashley wanted to be right in the middle of the action, like she always does, but I don't know for certain if had I taken her into my blanket fort, she would have wanted to come. I know without a doubt that my sister was exposed to far more of the ugliness in our family.

Persistent Pain

Without my mother, I do not think Ashley would have lived past her first year of life. I say this not because I know first-hand the sort of shit my mother had to wade through in order to get Ashley diagnosed, and get the services my sister needed for her whole life. I know this because without my mother, I probably wouldn't have lived past nine. And I was the child in the family lucky enough to never have a medical crisis until I was in the fourth grade.

It was shortly after we had moved out of our apartment into a new house. I woke up sweating in the cool air conditioner at eleven at night, twisted on my side, a sharp, terrible pain in my lower right abdomen. First, it felt achy. I ran a mild fever, the pain came and gone, and Mom gave me some Motrin. Since it was October, it could have easily been the flu.

An hour later, I threw up. As a child who rarely ran a fever above 99, and who almost never, *never* threw up, I started to make Mom nervous. In the past, the few times I got food poisoning, I was more likely to stay in bed, fighting down nausea until my stomach revolted against my gag reflex, and I puked all over the wall and the door in my dash to the bathroom. Even then, I almost never ran a fever at the same time. My fever spiked to 102, and the pain in my stomach became sharp and stabbing. In my bedroom, curled up on the dark blue comforter, I cried in pain. I remember Mom leaning over me, and asking me to take a deep breath. She wanted to check something.

As I inhaled, she pressed her hand to the lower right quadrant of my abdomen. The searing pain that had been constant dissipated somewhat. Then, she let go. It felt like I had been stabbed. To this day, when a doctor asks me where I am on the pain scale, one to ten, I rank my ten as the pain I felt from that night.

Medical professionals call it rebounding pain. It is a classic sign of appendicitis. The appendix, a now useless organ that used to sort toxins from raw meat before people had refrigerators, can get infected and start leaking toxins into the abdominal cavity for absolutely no reason at all. It usually looks like flu symptoms that get progressively worse over hours or days, until the appendix completely ruptures. Usually, once this happens, the toxic cells the appendix holds infect the abdominal cavity, called the peritoneal cavity, so rapidly that it can kill you in a few hours. It infects the blood, is known as sepsis, and spreads to organs and causes widespread organ failure. The single best test for appendicitis is the rebounding pain test. Almost no other condition causes the sort of pain the appendix does when you press on it, and then let go.

“Christina, I think you have appendicitis. I’m actually almost positive. We are going to go to the hospital, okay?”

At the time, I remember feeling both justified and also sort of excited. Justified, because I wasn’t being a wimp about my pain. Excited because I had never needed to go to the hospital, and despite how awful I felt, there was a part of me that was excited about the prospect of having all of the attention on me. *You might need surgery*, she warned, and I pictured the scars. The popsicles I assumed I would be eating. The endless television I would watch.

At the hospital, my mother with my sister in tow, the nurses stuck me on a gurney in a room that had curtains between the beds. And we sat. And sat. At one point, a nurse asked me for a urine sample. My stomach was heaving and the pain stabbed every couple of seconds, and I was both cold and sweating, aching and dizzy.

“I don’t think I can,” I told Mom, as I lay curled up on my side, clutching the scratchy sheet to my cheek.

“Christina, I know it’s hard. But if you don’t, they’ll have to give you a catheter, and that is so much worse.”

And so, for the next ten minutes I sat hunched over one of the public emergency room toilets as my mother held the sample cup for me, rubbing my back and whispering in my ear, “Good job. You’ll feel better soon.”

Seven hours after we arrived at the hospital, after the third or fourth time the nurses had tried to send me home because I had “the flu,” my mother started to get ugly.

I say ugly because I imagine she was probably the worst nightmare of every ER doctor or nurse out there. She went into helicopter parent mode.

“She does not have the flu. She is too sick for the flu. I need you to check for appendicitis,” she said, over and over, to the several ER doctors who came in as their shifts changed.

It was all sort of foggy for me, probably because I was both seriously ill and because it was nearly time for me to be getting up for school the next day.

“Will I have to go to school?” I asked.

“No sweetheart,” Mom said, holding her hand over the receiver of the phone hooked to the wall, where she was talking to Dad. “No school for you today.”

After eight hours in the ER, my temperature had spiked to 104, and I was crying continuously from the unrelenting pain. It stabbed worse than before, so badly that the skin over my appendix felt like it was on fire every time someone touched it.

“If you do not call your on-call surgeon right now, I will call the hospital across town, have an ambulance take my daughter from your hospital to that hospital, and I will also call my brother-in-law, who works for the news station, and I will have reporters here to catch every moment of it. I know you don’t want that kind of press, *again*,” I remember my mother saying, quietly, but the thin curtain between me and the hallway did little to block the noise. Ashley sat on a chair next to my bed, holding my hand and dozing off.

Apparently, less than a month before, a girl around my age had come into the same emergency room complaining of the same symptoms, and was sent home because the doctors thought she had the flu. Her mother did not have a physical therapy license, probably didn’t understand how hospitals functioned from extensive experience with a special needs child, and did not question the doctors. Less than twenty-four hours later, the girl was dead from a ruptured appendix.

A doctor was called. He was in his sixties, with long white hair he kept slicked back. He drew a picture of the incision he would make on my mother’s arm, probably to keep me from being too scared, not that I really was. I was excited. After more than nine hours in the emergency room, I was wheeled into the operating room, my mother’s hand on my forehead the last thing I remembered.

My appendix had ruptured. I think the surgery took twice as long because the surgical team had to dig pieces of the exploded organ out of my peritoneal cavity. I

developed sepsis in my abdomen, called peritonitis. I woke up in a long-term hospital room, in more pain than when I had gone into surgery, and more needles and tubes and monitors hooked up to me than I had ever seen. For the next few nights, a nurse would come in every two hours to wake me up, turn me, and take blood from my arm.

I do not remember this, but my mother tells me when I came to, I was furious.

“You promised I would feel better after the surgery,” I spat from my bed in between doses of pain medication, when I was lucid enough to form a coherent thought. On that first night, a nurse pulled my mother aside and said, “She’s really mad at you. You shouldn’t have told her she would feel better when she was so sick.”

I cannot imagine what this must have been like for Mom. She was the one who brought me to the hospital the first time she suspected I was as sick as I was, and she was the one who threatened to sue and publically humiliate the hospital in order to have me treated. And now she was being punished, not only by me, but by the nurses who thought she had lied to me.

I was in the hospital for seven days. The first four days, I was too weak to get out of bed. I got a private room on the children’s floor, with a television and a big window. My mother slept on a pullout couch by my bed every night. I do not remember my father coming to the hospital once. I nearly died, my mother explained to me years later when I was old enough to understand. A few more hours, and my appendix would have killed me.

The entire time I was in the hospital, I remember feeling special. I liked that the attention was on me. I liked that I was the sick one, because it made me feel worthy of that attention. My friends in my fourth grade class all wrote me get-well notes, and when

I came back to school, I couldn't wait to show everyone the scar on my abdomen. I may have been mad at Mom and in a lot of pain, but that time in the hospital was a fond memory. I didn't even mind being woken up in the middle of the night for blood draws or having to use a special toilet so the doctors could monitor my pee to check my kidney function. I liked that the nurses thought I was brave. Residents were brought in to practice drawing blood on me because I was better behaved than other pediatric patients. I even tolerated that until I was stuck six or seven times in ten minutes and my mom came in and realized a bunch of med students were using me for practice, and she was furious and kicked them out.

Nine-Eleven

I was running around the basketball court at my elementary school in the morning before my fifth grade class started when a boy from my class ran up to me and said, “Did you hear about the bombs in New York? There are bombs coming from planes and knocking down buildings and all of New York is burned to the ground or something.”

“The world is ending! The world is ending!” We shouted as we ran in circles, our arms outstretched like the wings of a plane, until another teacher grabbed us and said, with the sort of fear I had never seen in an adult’s face before, “This is not funny. Do not laugh about this.”

“I’m not laughing. I’m sorry. Mom is a pilot,” I said, frightened by her fear, embarrassed for making her angry, and then, for the first time, aware that whatever was happening could actually affect my family. I remember looking to the sky, still slightly purple from the rising sun at around seven in the morning, less than an hour after the first and second Boeing aircraft flew into the North and South Towers of the World Trade Center.

Anyone born before the mid-nineties remembers where they were or what they were doing when they heard about the terrorist attacks on September 11, 2001. For my family, there were severe ramifications, but considering that both my mother and father were involved in aviation, or had been, in my father’s case, it could have been much worse.

During the school day, teachers routinely darted in and out of classrooms and gathered in the hallways to whisper back and forth. The phone in our class wouldn't stop ringing, and several students left throughout the day, picked up by their parents. By eight in the morning, my teacher decided that, as fifth graders, we were old enough to know what was going on, probably because she knew we weren't going to be doing any learning that day, and also because I'm sure she wanted to be glued to the news as much as everyone else in the United States that day. She told us that we had been attacked by terrorists, and then she had to define what terrorists were, and then she assured us that it was far away, on the East coast, that we weren't in danger. And then we did worksheets for the rest of the day, in silence.

That afternoon, Mom sat in the living room with me and we stared at the television agape until I saw the now infamous video of the plane crashing into the second tower, the loud bang and the utter finality of it. That, not the sight of the towers collapsing or the destruction of the Pentagon, made me start crying. And Mom turned the television off, hugged me, comforted me, even as she knew with absolute certainty that the life we had carved out for ourselves in Arizona was about to irrevocably change.

Mom was hired by America West Airlines, a commercial airline based in Phoenix not long after we moved to the city. The job as an early intervention PT had been too low paying, too high risk, and too demanding on her time. She had chosen physical therapy to understand Ashley, and help children like her, but Mom's heart was always in flying. The job at America West, a simulator instructor, was a much better one, with regular hours and flexibility and a higher salary, and Mom was the first female hired for the position within the airline. She trained commercial pilots to fly the huge jets with the newest and

most expensive technology in simulation. Before she got the job, we had lived in several apartments throughout Ahwatukee, the suburb we lived in that sat on the edge of a reservation. But now, we could afford a house, and my grandmother, my father's mother, was going to come live with us, ostensibly to help care for me and Ashley, and to help pay for our place.

We had been in the house for less than six months on September 11th. Within a year, my mother was laid off, as the last instructor hired, and therefore the first to go. She also discovered that my grandmother was not in fact fit to help take care of my sister and me. Rather, my father's sister had sent her to us under false promises in hopes that we could take care of her, because she was in the early stages of dementia. She never actually moved in to the house, that was how quickly we came and went, and the short time she lived in an apartment nearby, she got lost or forgot where she put her keys or got so agitated my father had to drive over to calm her down more than she was lucid.

I remember being excited to leave Arizona. But that might have been because I was sick of my parents fighting about my grandmother and money and the house. Mom found a new job in New Hampshire, at the same flight school and college where she had met Dad years before. I had never been to New Hampshire, but it sounded exotic in the way that places you have never really thought about before sound exotic. And there would be snow.

We sold the house and lost a lot of money on it, because the market tanked like so many other things after the terrorist attack. The people who bought it from us showed up one day while I was home alone after school, and let themselves in with a spare key they had gotten, illegally, from their realtor. They brought beer and were sitting down at the

dining room table when I came out of my room, only far enough to see them there, before I went back to call Mom.

“What do you mean, they’re in the house?” she asked, making me wince with the severity of her tone.

“I didn’t let them in, they just unlocked the door,” I said.

“Yeah, but they shouldn’t be there. I’ll be home in ten minutes, let me call the realtor.”

By the time she got home, the new owners had cleared out, leaving a couple of empty bottles in our trash. It felt like the house was never ours, even though we owned it for almost a year. Mom had wanted to paint, but Dad never found the time, and we didn’t have enough furniture to fill the square-footage, which was about double what we were used to, even at 1400 feet. I could do cartwheels in the living room, and the formal dining room had a beanbag chair right in the middle, where I would sit to do homework. We left the house in the same condition we came to it, with white walls and beige carpet. The only evidence that people had lived there were the bean plants infecting the back yard, which I had planted from beans I had taken from a crafting bag at school, not really believing they would grow into anything.

I said goodbye to the desert with the hope that starting middle school in a new place would mean I could branch out, forge a better identity than the quiet girl who had panic attacks at recess and had a sister with special needs.

A Different Perspective

Our new apartment in New Hampshire was half underground so that the windowsills were level with the mulch that faced the parking lot. Kit hid under my bed for almost a week, and paced irritably up and down my body in the middle of the night, hardly leaving my bedroom except to eat and use her litter box.

But before this, I went to a three-week summer camp run by family friends in North Carolina. Mom packed deodorant and sports bras into my trunk, and told me to make sure I washed my hair every day. Most of my clothes started feeling tighter, and I noticed the way they stretched across the skin on my chest and hips. I bought some new shorts and t-shirts to last me through infrequent laundry days, and purposely got them in sizes far larger than I needed so that the material hung off my body, and I could pretend it was because I was small.

Really, though, I was just getting wider, curvier, growing into that stupid “pear-shaped” label that women’s magazines would later tell me means I need to wear A-line dresses and do more cardio at the gym. My cabin mates, much like most of the girls in my sixth grade class in the fall that followed, had not started “blossoming”, and were still wearing the tiny shorts and tight tank tops I myself had worn just months earlier.

So there was this girl who I unfairly blame for the beginning of my self-consciousness about my body. I don’t know if this happens to everyone, or maybe I’m just more obsessive about things like body image to this day, but I very distinctly

remember the moment I looked in the mirror, and saw myself in parts: thighs, stomach, breasts, ass.

Henderson—that was her name— was still wearing girls’ clothes but had also brought mascara and eye shadow to camp. She apparently went into puberty in the right order: first equipped with the female products necessary to boost self-esteem, only then followed by the terrible body formations to match. I had not.

We were getting ready for some dance, the decades dance, from what I understand, because in the one photograph I managed to dig up from that night, one girl is wearing a poodle skirt and saddle shoes, and another has what looks like a skating costume, but is probably supposed to be a flapper dress. Because it was my first year at this camp (I would attend for five) I hadn’t known that costume clothing was as essential as clean socks and Sunday dresses, so I was forced to wander around the cabin, plucking discarded items from other girls’ costume bags to cobble together some sort of outfit that was, if nothing else, not something I would be caught wearing on a normal day.

In the bathroom, Henderson looked at me through the long mirror over the sinks with one plucked eyebrow raised.

“Well,” she said, taking in my athletic shorts, high yellow socks, tie-dye t-shirt, and one-sided ponytail, “maybe you can ask the counselor if she has anything you can borrow. You won’t fit into any of our stuff.”

This, of course, was not true, as at least three girls in my cabin were taller than me, and also in various stages of pubescence, but that did not stop Henderson from seeing me as something the other girls were not. I was a little on the pudgy side, I suppose, soft middle and big thighs. My hair was constantly greasy, like my face, as though my body

had decided we were living in the middle of an aerated desert and desperately needed moisture. Mostly, it was a compilation of these things plus my quiet personality. My changing body, and uncertain future, as my family picked up again to move somewhere else, had left me shy and intimidated by these girls with far more money, and savvy, than myself. I didn't feel good enough to be in their company. And Henderson had just, for all intents and purposes, confirmed my suspicion that I stuck out like a greasy, chunky thumb.

It was like a switch in my brain turned on. I noticed the way my stomach rolled when I sat down. I felt the sweat gathering between my thighs when I walked. The jiggle in my butt made me self-conscious in a bathing suit. 125 pounds, on a five-foot-two body seemed massive. Not to mention I still remember that I weighed 125 pounds and was five-foot-two.

Teen Spirit

“What wrong, Christina nose?” From where she was standing, in the doorway of the bathroom, Ashley pointed to the growing red mark on the tip of my nose that I hadn’t noticed yet.

Mom peaked her head into the bathroom, and looked like she was trying very hard not to crack up.

“What? What’s wrong with my nose?”

“Well,” Mom said, “I think you have your first pimple.”

In middle school, I was the girl who needed to start wearing bras before everyone else, and who had to learn the strategic method of hiding a tampon in my shirtsleeve when I went to the bathroom so I wouldn’t need to bring a purse and give myself away, because for some reason, these were things we were deeply ashamed of when we were younger. I was taller than most of the boys, even though I was only five-foot four then. While most of my friends were still parading around in tank tops with blissfully smooth underarms, I discovered that, despite having light blond hair on my head, I could scare off a person from ten feet away just by lifting up my arms.

I learned not to use gel deodorant after shaving, that toothpaste does not actually get rid of pimples, and that I did need to actually wash my hair every day if I didn’t want to look, and smell, like a heavily bearded man in an incense shop. I had the luxury of learning my mother did not know anything about makeup (“You taught me how

to braid your hair!” she reminded me), and that her experience with bras was mostly limited to the sport variety. Instead of pestering her for her makeup, I started pestering her for magazines and books about how to be a “woman.”

Because my mother was working full time, and also taking care of Ashley, as Dad was pretty much settled into the couch for the remainder of their marriage, I didn’t get to talk to her much about what it meant to grow up. Her twin sister and I had never gotten along, and were more likely to antagonize one another than have a civil conversation, so I didn’t reach out to her. I had cousins on Dad’s side, but they, with their closed off Amish-like community, did not keep in touch well either. And besides, I could only imagine my ultra-conservative, ultra-religious aunt’s stance on tampons.

At the same time that I went through puberty, I was in a new town, at a new school, with very few friends. I spent most of my time playing role-playing video games, and pretending my life was that of the fantastical stories I devoted hours to.

I started sixth grade at a local elementary school, because the school district was busy transitioning from a junior high (seventh through ninth grade) to a middle school (sixth through eighth grade) system. I only had to endure middle school for two years. But, at the same time, I am pretty sure schools go to a multi-class system right when kids hit puberty for a reason. There is nothing more isolating for a pimply, kind of heavy, period-paranoid eleven year old than being stuck in a classroom with the same twenty-four people who have known each other since diapers for eight hours a day.

On top of that, we were forced to participate in the sort of recreational elementary school activities that were about as useful to a bunch of pubescents as the posters of the alphabet and names of animals that were strung up in the halls.

Every Wednesday, we had PE class. In seventh grade, we would be awarded the privilege of changing into gym clothes for class. But since we were still in the elementary school, which didn't even have locker rooms, us sixth graders just wore our normal school day clothes for the hour we were forced to play freeze-tag and handball. Mom bought me a pair of those pants that zipped off into capris and shorts after I came home from the first day of PE crying because I had been forced to sit in my sweaty jeans for the rest of the day. I saved those pants for Wednesday, as well as a black t-shirt from a choir I had been in when I was in fourth grade. The pants could be made into shorts with a few quick zips, and the shirt hid any sweat that collected on my back and chest.

Nonetheless, after PE, which happened at ten in the morning, I would spend the next couple of hours in various contorted positions at my desk in our classroom. I wouldn't let my back touch the back of the chair, and I wouldn't sit fully on the seat, instead opting to tuck one leg under the other knee so I was only putting pressure on the outside of my thigh. This way, I wouldn't leave any butt-marks on the seat. I didn't let my arms rest at my sides, instead I kept them at an awkward forty five degree angle, so that I could air out my armpits, and I kept a deodorant hidden in the back of my desk, so that after PE, I could sneak into the bathroom and reapply.

Even worse than PE, though, was recess. Not only did I have to sit at lunch with my class and keep my mouth shut when the lunch monitor went around admonishing us like the seven-year-olds one table over, but I then had to go stand awkwardly, by myself, on the asphalt where a basketball court used to be, convinced, as everyone is at that age, that everyone else was looking at me and judging me.

Sometimes, I would play this game where I would weave through the different clumps of sixth graders, slowing down long enough next to one group that the other groups would think I was talking to them. Then, before the classmates I was hovering near would think it was weird that I had stopped a foot away from them and was just standing there looking at my shoes, I would move on to the next group. Twenty minutes is like a century when it comes to trying to blend in with strangers. And, anyway, I wasn't fooling anyone. Nobody ever offered to include me in the conversation in those few moments I hovered, and then, I was gone again, trudging through the snow-soaked ground to the next unsuspecting refuge.

A few times, Ashley's class had recess at the same time as we did. I would watch her throw a ball with her aide, or cheer on kids playing basketball from her class. Like me, she didn't have companions, but nobody really cared. It never occurred to me that nobody cared if I was by myself except for me, even though the only reason I was really upset to not be interacting with my classmates was because I was afraid of how it would make me look. I don't remember necessarily wanting to be a part of their conversations; most of my peers had so many inside jokes and built up history that I usually just got bored of their conversations. What I really wanted was to appear as though I was happy, and appear as though I belonged. It is not lost on me now that maybe if I had just not cared, like Ashley, or not noticed, I would both have been happier and also seemed less lame to my classmates.

Even though most of the people in my class paid very little attention to me, I was almost obsessively fixated on myself. It was like every sensation was heightened. Very few of my memories before I started menstruating and my hips got wider and my skin got

oiler involve any sense of bodily awareness. I know from photographs that I was lean and muscular from years of jump roping and running around with boys at recess in elementary school, but I have no recollection of what that feels like. I look at myself in fifth grade, even, the months before the summer my body started to change, and I wonder if I ever noticed my spindly legs and hard abdominals.

Just a Spot

Like almost everyone I knew in middle school, I had braces at age twelve. I was lucky in that my teeth were pretty straight, they were just all leaning backward in my mouth like they were afraid of touching my lips. When Ashley's permanent teeth started coming in, the pair of orthodontists, Doctor Deb and Doctor Diane, who I had been seeing for a year or so at that point, stood together in the office looking at the x-rays of Ashley's mouth and decided to take my sister on for a reduced price, partially because nobody else would, and partially because I'm sure my sister's mouth was the mouth that defined their careers. Not only did every single one of her bottom teeth seem to be facing a different direction, but she appeared to be missing one of her big front two teeth. Until, of course, it started growing from the middle of the roof of her mouth.

While I was fussing about the color of rubber bands I should have on my braces, my sister went down to Boston Children's Hospital for oral surgery to remove the small, jagged bits of tooth that were popping up around her gums, and make room for that missing front tooth, which Dr. Deb and Dr. Diane hoping to move into the front of her mouth by some oral engineering miracle.

The day Ashley came home from the hospital, her face was twice its normal size. Her upper lip was so swollen that it hung in front of her lower lip and pressed against her nose. Her eyes were puffy and the skin of her cheeks and jaw were turning green and blue. We had just moved into a new condominium, with several floors and mirrors hanging on the backs of the bedroom doors. Before Mom could stop her, my sister

walked up to one of the mirrors, and leaned in until her nose was almost pressed against the glass. We waited for her to start crying, to panic at the sight of her mangled face, but instead, Ashley reached up and scratched at a bit of blood that had dried on the corner of her lip. When it was gone, she leaned back and turned to Mom.

“All better!” she said.

The Summer of Shrinking

The summer before my freshman year of high school. I had signed up for the track team that spring, because my doctor noticed that my weight had continued to increase until I was one hundred and thirty five pounds at five foot five. I was not overweight, but my habit of hiding out in my room after dinner and eating a box of granola bars or a roll of cookies was starting to become noticeable.

At around six every night, I closed my bedroom door and put on a pair of headphones that did little to muffle the banging of dishes in the kitchen and Mom and Dad’s raised voices. My sister’s screams would come soon after that, and around that time, I started eating. Once, the school band had a candy-selling fundraiser, and each of us got a box of twenty packs of chocolate covered raisins, peanuts, and cashews. I sold six bars, and ate fourteen in the span of one week.

I started running on the weekends and my size twelve shorts began to hang off my hips.

I left for Greystone in late May. I almost hadn’t gone that summer, because every year, the bullying from other girls got worse. I had one or two friends, but mostly I spent time by myself, or desperately trying to keep up with the conversations of the girls in my cabin and spending the nights planning out how to act the next day in order to seem cool.

Despite my hesitation about going back, a bigger part of me wanted to get out of the house for a while. I was sick of ducking out of the front door and going on walks to avoid the fighting.

When I left, Ashley was almost intolerable. She screamed every time Dad got near her. When he had to give her a shower because Mom was at work, I could hear the muffled thumps as the two of them fought in the bathroom. Ashley was surly and tense, a lot like I was, and between the two of us, it was almost impossible to avoid fights on the stairwell or in front of the television or at the dinner table.

At Greystone, we had a schedule that alternated days. We could choose six different classes for Monday, Wednesday, and Friday, and then six classes for Tuesday, Thursday, and Saturday. I always took horseback riding, which took two class periods, and jump roping, because it reminded me of Dad. Usually, I filled the other slots with things like archery, ceramics, cooking, golf, and jewelry making. That summer, I signed up for track, an aerobics class, swimming, kayaking, hiking, and rowing. During our free period at the end of every day, instead of hanging out in my cabin with my cabin mates, I found myself going to the fitness center and reading my *Harry Potter* book on one of the ellipticals.

I didn't think about losing weight consciously. I liked running, because it made me feel calm, and I found that other sports that required all of my energy also soothed the constant circles of anxiety I had in my head. I liked that my shorts were looser, that I could see the curve of my quadriceps and feel the bone of my shin. I stopped eating bread in the dining hall, and didn't ask for seconds. That summer, I made more friends than I ever had before. I would go to extra track practices because the counselor and I got along

well. I woke up early in the morning and didn't fall asleep until long after lights out, and during the day, I was almost manic, jogging from class to class just because I had the energy to. I laughed loudly at meals. Henderson saw me in the dining hall, and a few days later, a mutual friend came up to tell me that Henderson had told her that, "You used to be kind of fat. But now you look good." During the fourth week of camp, I pulled on a pair of pants I hadn't worn since the first week, and they wouldn't stay up. At one point earlier that year, I hadn't been able to button them.

Greystone hired a few professional photographers every year to go around during the day and take photos of campers that they would post online, so our parents could see. Four days before the end of camp, a picture was taken of me at swimming class. I remember that when I put my hand on my hip to pose, I could feel my hipbone jutting out and my suit hanging off my chest. My mother told me she saw the picture and felt like she couldn't breathe. In other photos from camp, my clothes had hid my shrinking frame, but now, she could clearly see the way my bones looked like they were ready to poke out of my skin.

At the banquet at the end of camp, I won a bunch of awards. I got "MVP" in horseback riding, and "best attitude" in track. I had never won awards before, and now, I was the one in my cabin who had the most trophies and plaques at the end of the night.

When Mom and Lisa came to pick me up the next day, the first place they took me was a diner. Neither of them said anything about my appearance, but Mom watched me order a cheeseburger and kept staring at me until I finished all of my fries. We stayed with Lisa at her house in North Carolina for a few days, and she took me shopping for

new clothes for high school. My normal sizes were ginormous on me. I had dropped from a ten/twelve in jeans to a four.

My old babysitter, Sherry, who was the mother of two of my best friends, and still cared for Ashley after school, was not subtle. The first time she saw me, in my new jeans and a tight-fitting tank top, she said, “You got skinny.” She circled the skin around my arm with her fingers. That night, Mom told me, “I just need to know how much you weigh. Just get on the scale.”

I weighed one hundred and eleven pounds. When I had left for camp, six weeks earlier, I had weighed one hundred and twenty seven. I told Mom I weighed one eighteen.

That same summer, Ashley started puberty. I stood outside the bathroom with Mom and watched as my sister looked at her growing breasts in the mirror, picked one up, let it drop, and then repeated with the other one, like they were alien intrusions stuck to her body.

“Sometimes, I think God is laughing at me,” my mother sighed, a few months later, when it became clear that my sister was going to have the C-cup breasts Mom and I never had, the kind of physical trait we couldn’t trace back to any female on either side of our family. Ashley went so far as to lift Mom’s shirt one day while she was giving Ashley a shower. My sister looked at my mother’s petite chest, like mine, and said, “Too small.” The difference between my sister and me was that she saw these changes in her body as inconveniences, but not reflections of who she was. She would stick her arm in the air and sniff her armpit and go “ewww,” and then ask Mom for “tickle.” Tickle, of course, meaning deodorant, because it tickled when she put it on. She would try to pull a

shirt over her ample chest and then lament, “too small!” but not with any vitriol towards herself. It was the shirt’s fault, not hers.

Mom didn’t take me to the doctor to talk about my weight. I gained a little back because it was nearly impossible to be as active as I had been at camp, and I think that calmed her fears. Maybe if I had been seen by a professional then, I wouldn’t have spiraled as badly as I did later that year. But I don’t think any sort of medical intervention would have prepared me for everything that would happen my freshman year of high school. Not just me, but Ashley too.

A List of Ashley-isms

Ashley talks like her tongue is too big for her mouth. She cannot close her lips without a lot of effort, so most of her phrases, especially those that begin with m, or p, or b often don't sound like they were intended. For example, she can say "Mom," because she has a lot of practice. But if you ask her to say "pool" it comes out sounding like "tool." Even when I was still in elementary school, I liked to put my friends through tests. If they tried to understand her, even if they couldn't fully figure out everything she was saying, then they passed. If they, instead, listened to my sister jabber on and then turned to me for translation, without even trying to acknowledge her, they failed. Ashley knew when she was being treated like she didn't make any sense, and it offended her.

When we were younger, and Ashley first got her hearing aids, our family developed a series of shorthand signs and phrases for different things. "Eat," was easy enough to understand, but Ashley still signed, putting her fingers up to her lips like she was about to take a bite of a cookie. "I'm mad," was reinforced with the stomping of a foot and crossed arms. "On" was perhaps the hardest for someone outside of our family to understand. The word, "on," accompanied by a closed fist brought up to eye level and twisted back and forth with Ashley's wrist, meant "I have to go to the bathroom." It worked because it allowed her to subtly cue someone when she needed help, and was also fast, if she realized she needed to go immediately, which seemed to happen a lot.

Because Ashley can't hear well, she doesn't use prepositions or articles much. Instead of saying, "I am going to make my lunch," she says, "I make my lunch." Instead

of “I have to go to the bathroom,” she now says, “I go bathroom.” This replaced “on” when Ashley was about thirteen, but she never dropped the hand signal that went along with it. If she is upset, Ashley will often say, “I’m mad, Christina.” Or “I’m mad, no cheese.” Or “I’m mad, school.”

At some point, Ashley figured out that “Oh my god!” was an exaggeration used when things weren’t that bad, but when she wanted to be dramatic. “Oh my god, no yogurt!” she’ll yell from the kitchen table at breakfast, banging the heel of her hand against her forehead like she’s in some comedic silent film. Around the same time, she also learned that calling our mother by her first name was a good way to annoy her, and also insult her. “Shirley, Shirley, Shirley,” Ashley will sigh, shaking her head, when Mom invariably forgets one of the hundreds of steps to getting Ashley ready for school. “Shirley Phillips! I need help!” she’ll yell from the bathroom before her shower.

Ashley cannot pronounce my name. To her, I am not “Christina,” but “It-e-nah.” It’s like my name with all the hard sounds taken out. It’s the one word that my sister has not improved over the years. She could definitely say my name now, at least the hard “c” at the beginning, and the “st” in the middle, but she chooses not to. I like to think it has become a nickname, one unique to my sister.

Around the time we were living in our condo in New Hampshire, Ashley figured out how phones work. Or, she conceptualized them enough in her head that she could play pretend. She would hold her hand up to her face, palm against her cheek, and have long elaborate conversations, pausing to hear what the other “person” was saying, and nodding her head along. She would even include the short, clipped phrases, like “no” and “oh, go ahead,” so if you didn’t know any better, you might think there was someone on

the other end of her palm, speaking back to her. At the end of every “call,” she had a signature sign off. “Thank you, bye,” she would say, and then she would bring her palm back down, and press her thumb into the center of her hand, making a clicking noise with her tongue, to mimic the buttons for hanging up.

She had the same mannerisms on a real phone, with the same, “Thank you, bye” when she was done speaking. We could be talking about her dance class, and if Ashley was tired of talking on the phone, she would end the conversation right in the middle. “I ride the bus to school. Too small, outta my way. Christina? Thank you, bye.” And I would be left holding a disconnected phone, trying to remember what exactly was going on in Ashley’s life that made her busy enough to treat me like the secretary to her high-powered businesswoman.

Cheap Plaster

It was six-thirty in the evening, and Ashley was screaming.

I was in the living room, which was a sunken in space below the dining room, kitchen, and bathroom of the first floor. While I tried to print out a homework assignment from our perpetually jammed printer, Ashley threw a conniption in the bathroom.

It isn't a coincidence that my sister started hating showers around the same time she hit puberty. Especially whenever Dad was helping her. It's the kind of thing I didn't consider until I was much older, how inappropriate it was for him to be helping her in the bathroom. But it was. And it is.

Yet, by product of necessity, my father was the one who got Ashley ready for bed when my mom wasn't around. I was only thirteen or fourteen, so I wasn't expected to do it. And because I was young, and undoubtedly selfish in my own desire to not have to shampoo my sister's hair or help her wash her body, I did not offer.

This is not to say I know my father was sexually inappropriate with Ashley before he moved out. But that doesn't mean the situation they were both in was ever appropriate. And even if I didn't see it, and though my mother understood, she didn't have any real alternative because she was working late, Ashley understood.

It explains why she was so violent whenever he gave her a shower. Imagine not being able to step in and out of the tub without someone to hold onto, because of the slippery floor and wet tiles. Imagine having someone else wash your hair, because you don't have the coordination to do it thoroughly yourself. Imagine needing someone else

to dry you off, help you into your pajamas, and brush your teeth. Now imagine that person is the opposite sex.

There were dents in the wall in the bathroom. If they were from Ashley or Dad, I don't know. Dad had put holes in the wall before, when he was mad, but I don't know if it was Ashley banging around or him. The bathroom was small. Barely wide enough for one person, let alone two. It was easy for me to bump my elbows or knees if I wasn't careful. So I did not think about the thuds and scuffling I could hear when I was sitting less than ten feet away on the computer.

But dads are put in these situations often. Single fathers give their daughters baths when they are young, and fathers care for teenage and adult females with special needs in homes every day. The same can be said for mothers with their sons. Nonetheless, I can understand why Ashley was upset. I can understand why she put up a fight, and how frustrating it must have been for both her and my father, who nightly had to struggle with my sister in order to meet the most basic of her hygienic needs.

Ashley fought with my mother as well. A few nights after I was typing in the living room, I was trying to put together a poster for an English assignment at the kitchen table when I heard familiar shuffling and hollering from the bathroom.

“No shower!”

“Ashley, you need to take a shower.”

“No. I'm mad. Uh uh.”

And on it went until Ashley wore herself out. Or, more likely, she got sick of being naked in the cold bathroom and figured at least she would be warm in the shower.

The house felt smallest in the evenings because though it was broken into two and a half floors, it was loud. In my bedroom, I could hear my mother and Ashley in the opposite room, my father in the kitchen, the television in the living room. In twelve hundred square feet, we were suffocating each other.

Things Not To Say To A Fourteen-Year-Old

I stood on the staircase, staring over the railing, and Dad was in the kitchen, slamming dishes into the dishwasher.

“Just try asking him to not make so much noise,” Mom had coached me in the bedroom, with the door shut, as we listened to him banging downstairs. I shook my head.

“No, he won’t listen to me.” It was around seven in the evening, and I had spent the last thirty minutes hiding out in my room, trying to focus on my homework, but too upset by the ranting and raving coming from the kitchen that I couldn’t think about anything else. I don’t remember what he was mad about, not that it mattered. It seemed like every night I was around after dinner, which usually I wasn’t because of field hockey practice, Dad was taking out his issues on the mismatched plates in the sink.

“Christina, please just give it a try. He definitely won’t listen to me, because I’m the one he’s mad at. Just be nice, and tell him you have trouble concentrating when he’s making so much noise.”

I went downstairs ready for a fight. I was fourteen, most definitely of the age where I craved conflict, but even more so the age where I wanted a reason to be mad at someone. I knew Dad probably wasn’t going to take me talking to him well. But if he got mad at me, Mom would feel bad, because I had told her so, and then I would feel more justified.

“Dad?” I asked, staying on the stairs, leaning around a pillar.

A sigh. “What, Christina?” It always felt like he was sighing my name those days. Whenever I’m talking to someone and they say my name in the conversation, be it a salesman trying to personalize a sale, or a friend trying to make an emphatic point, I flinch.

“It’s really hard to do my work when you’re banging around like that.”

Of course there was a better way I could have said it. Absolutely, I could have started by asking him to please quiet down, instead of accusing him, putting him on the defensive. Years later, I would remember giving that same advice to a friend who was trying to confront her boyfriend about his own anger issues.

“Start with a question. Don’t put him on the defensive. Always phrase things as though you are concerned, and not annoyed, even if you’re pissed. Because if you’re pissed, he’ll get pissed.” Advice from one battered woman to another, it would take both of us years to learn that this was not actually how arguments were supposed to work. It occurs to me now that it was the exact same advice my mother had been giving me. It was born from fear.

I stepped back up a stair when the dishwasher door slammed.

“Oh, well, you know what? It’s all my fault, isn’t it? It’s just all my fault.” Dad liked to win arguments by playing the manipulation card. It would take a long time for me to understand that when you start an argument by calling yourself the bad guy, sarcastically or not, it puts you above the person you’re talking to. Because it dismisses their argument before they can even begin.

“Dad, I just want you to stop banging things around like you’re trying to break them!”

“I’m always the bad guy, right? It’s always my fault shit doesn’t get done, bills don’t get paid, the house is a mess.”

“I just want you to stop acting like a baby!” I yelled, on the defensive now too, red faced. “You are acting like the bad guy! Nobody wants to be around you,” I finished.

He swung on me, wet finger poking into my face. “And you’re just a goddamn parrot of your mother.”

We Need to Talk, but Probably Won't

Whenever I hear people talk about their parents' divorce, it involves sitting down at the kitchen table, with both parents, maybe after school or on the way to Grandma's house.

"Your mom/dad and I have something to tell you," one parent will begin. And then they will explain that they can't be together anymore, but they still "love you very much" and everything will be okay.

I don't know what parents tell their kids are the reasons for getting divorces in these situations. I suppose it could be a lot of things.

This type of conversation is as much of a mystery to me as what it must have felt like to grow up in one house. By the time I went to college, I had lived in thirteen different houses. By the time my parents got divorced, I couldn't remember a time when they were in the same room enjoying the same thing together.

I don't remember when Dad stopped sleeping in my parent's bed. My memories of him sleeping always involve the blue glow of the television in the living room. There was always a bed pillow on our couch.

It must have been years that he lived in our house and didn't sleep in the bed. And we didn't have comfortable couches either. They were usually futons that were never unfolded, or cheap, polyester things that started to sag in the middle after a couple of months, probably, I now realize, because Dad was always sleeping on them.

Really, I think the beginning of the end of my parent's marriage was the day Ashley was born. Sometimes, I wonder why my father didn't leave sooner. Why he stuck around for twelve years, and then reappeared periodically, and almost always with some sort of vitriol, for the next twelve.

The Wrong Way to Fall

About two months after my fight with Dad in the kitchen, Mom and I were at a barn about an hour away from our house, at a barn in northern New Hampshire, where we both rode horses on Saturday morning. Ashley hadn't stopped riding since she first started hippotherapy, and I hadn't either. Ashley's lessons were expensive and sometimes reimbursed by state disability services, but Mom and I would work at horse shows and muck stalls to pay for my lessons. For a while, at the barn I rode at in Arizona, Dad would build jumps and mend fences on the weekend to help contribute as well.

My coach in Arizona, Tim Tompkinson, was a tanned man who wore a perpetually dirty forest green collared shirt and lived in a little trailer at the edge of the huge riding facility where he taught. The facility had dozens of other instructors that taught a variety of riding styles, and probably close to thirty people boarded their horses at the barn, coming in when they could to ride and take care of things, but mostly leaving the hard work up to the barn staff.

Tim had five horses, of varying temperament that he used to teach kids how to ride. He always was a children's instructor, except for with Mom. When she came every weekend to watch me ride, and stayed late with me to make sure I cleaned up my equipment and swept the barn, and started showing up with me in the early mornings to muck stalls, Tim asked her if she wanted to take lessons herself.

Mom, raised in a poor factory town in New Hampshire, had dreamed of horseback riding for almost as long as she dreamed of flying airplanes. Her first dream

had come true when she convinced her parents to sign her up for flying lessons, which she had to pay for by cleaning planes, filling gas tanks, and doing other odd jobs around the airport. I suppose it was unsurprising that she came to horseback riding the same way.

Soon, we had a ritual. Saturday and Sunday mornings, Mom and I got to the barn around six in the morning, when the air was still cool and none of the owners had shown up to ride. We cleaned stalls, set up jumps, cleaned tack, and let horses into their pastures or brought them back inside. If there was a horse show, we got there even earlier, to help set up the arenas and organize prizes, which we would hand out throughout the day. On Saturday afternoon, after I had my lesson with Tim, Mom entered the ring, tall and terrified on the oldest, slowest horse Tim owned.

He started her off easy because Tim knew Mom couldn't fall. She wasn't light on her feet, or particularly coordinated, and as an adult, she had more ingrained fear than a kid, making it more likely that she would tense up and panic in any situation. She did fall off once or twice, but we had a hard and fast rule in the riding community: once you fall off, get right back on.

Now, four years later, we were at a different barn, and Mom took her lesson with me so that we could cut down our commute. It was a small facility, owned by a woman who didn't have any boarders, who didn't particularly like kids, and whose house was connected to the barn by a snow-protected walkway. When the snow was especially bad, usually for most of the winter, we would meet her about a mile from her house, at the indoor arena she shared with other horse owners, to do our lesson.

Covered arenas are a nightmare waiting to happen. An indoor arena protects from the elements, sure, but for some reason, the animals get more jumpy with a roof over

their heads, a door closing them in rather than a fence. It was a cold winter morning after about a foot of snow and ice had fallen, when we entered the ring for our lesson.

I was riding a temperamental Arabian that my instructor was trying to break, a colloquialism for training a horse, so I had trouble right off the bat. As the weather heated up, snow and ice began sliding off the arena roof in thick sloughs, making loud cracking noises that caused Jasper to buck and attempt to gallop through the wooden walls. Thankfully, I had spent years riding difficult horses, mostly because I was completely fearless, so I managed to keep in the saddle.

Mom did not have as much luck. She was on an older, tamer, fatter horse, a quarter horse with a mild temperament named Silver, but that didn't keep her from panicking every time the snow made its thunderous descent from the roof to the ground outside. The first time she fell, I watched her go down. Silver bucked, and Mom pitched forward, sliding off her right side, flat and heavy, and landing with all of her weight on her right arm and shoulder. The sound was dense. I remembered yelling, "Roll! Roll!" at her as Silver pranced away, disturbed by the loss of weight on her back, her hooves stepping high around Mom's still form.

Tim had taught me how to fall. He spent an entire hour showing me how to fall off a horse from any direction: over their head, off the side, and off the back. He taught me how to curl up to protect my head if I was near a fence or a jump, how to roll as soon as I landed to reduce the impact, how to hit with the strong parts of my shoulders and torso to avoid joints. He made me fall over and over again, from a standstill, from a trot, and from a canter. I would ride around the ring in circles, waiting for him to yell, "Now!"

and then I would pitch myself in whichever direction my weight was leaning, letting go of the reins and trusting myself to land safely.

This sort of training would probably save my life, when later, I was in an indoor ring with an unbroken horse who panicked, and started galloping around, bucking as she went, rubbing her side against the walls and on posts in an attempt to get me off her back. I had to push off her back with my foot, nearly standing up and launching myself, so that I could get far enough away from her that she couldn't kick me with her hoofs as she sensed me fall. I had fallen more times than I could count, sometimes in really dangerous situations, but I had never gotten seriously hurt. Unfortunately, Tim never taught Mom to fall. He knew how hard it was to teach an adult a child's tricks. Like learning a language, you reach a certain age and lose the ability to process things the same.

Of course, after she hit the ground, Mom crawled to her feet, and, when Jan handed her the reins, walked back to the edge of the ring and mounted up again. But she was stiff, afraid, and, based on the fall, probably sore. So five minutes later, when another sheet of ice slid off the roof, I wasn't surprised to see her go down again.

She hit the ground hard, like the last time, but managed to land on her tailbone and rock forward with her weight so it wasn't quite as hard of a fall. But as Jan watched her tumble to the ground, and saw me attempt to rein in a bucking Jasper, she decided it was enough for the day.

In the car, Mom couldn't move her right arm. She cradled it to her chest and was pale.

“I think it’s just bruised,” she said. But we both knew it didn’t matter how bad she was hurt. I was fourteen, and didn’t know how to drive, much less in snow and ice, and there was no way Dad would drive an hour out to get us with Ashley.

By the time we got back, Mom was in shock. Her blood pressure had dropped so much that she couldn’t stand. She was shaking, her eyes glazed and unfocused. As soon as she pulled into our parking spot, I sprinted inside to grab a blanket and the phone.

Ashley was at the table, cutting paper, and saw Mom in the window.

“What’s wrong, Mom?” she asked?

“Nothing, Ashley! I’m just getting her a blanket. Want a cookie?” Ashley looked from me to the car, and then back at me, and I think she could see the pleading in my eyes. Or maybe she couldn’t resist the cookie.

“Okay.”

“Dad!” I called from the kitchen as I pulled a cookie out of the cupboard. “Dad! I need you.”

I could hear him stomping up the stairs from the basement, where he spent hours doing who the hell knew what.

“What?” he asked, coming around the corner.

“Mom fell off the horse. I need to call an ambulance.”

“Why do you need an ambulance?”

“Because she can’t get out of the car.”

He swore. Poked his head out of the front door, saw Mom in the driver’s seat, and turned back inside.

“Dad?” I asked, and watched him retreat back into the basement. Ashley started crying.

“Okay, okay, Ashley, hold on one second.” I grabbed the phone, called 9-1-1, and gave them directions to our house. I ran back out to the car, locking the door behind me so Ashley wouldn’t be able to follow, and put a blanket over Mom’s shoulders.

“Where’s your father?” she asked when she saw me. Her teeth chattered uncontrollably and I could hear Ashley yelling in the dining room window.

“He’s downstairs.” I looked at her, and she knew enough to not say anything more. This was a situation better handled without him.

“Will you give Ashley dinner while I’m at the hospital?” she said. “Just make her a grilled cheese or something, and let her watch TV. I can give her a shower when I get back.”

I nodded as the ambulance came around the corner. As the EMTs loaded Mom into the stretcher, one pulled me aside.

“Do you want to meet us at the hospital?” I looked at the house again, where Ashley was standing, hands pressed against the window, watching like a bodyguard.

“Yeah, Dad will probably drive over and meet her there. I’m fifteen, so I can’t drive yet,” I added.

When they pulled away, I went back inside and found Dad in the basement, banging around in a file cabinet.

“Dad? They took her to Southern Medical.”

He sighed. Then, I heard shoving and banging, and his heavy footsteps up the stairs. He didn’t say anything to me as he walked past, just shoved the basement door

shut behind him and stormed out of our front door. I watched him pull away in his pickup truck before making Ashley's grilled cheese. Several hours later, Mom called the house, since we didn't have cell phones, to ask if Dad would pick her up at the hospital, because her collarbone was definitely broken and she was on pain medication. Since I didn't know where he was, I told her I would take care of Ashley until she could call around and find him.

A few hours after that, Mom came through the front door with a sling. Dad walked in behind her. Ashley was sitting at the table, cutting up a magazine, while I read for school.

"Now Ashley," Mom said as she came through the door. "I hurt my shoulder, so you need to be careful, okay?" She gestured to her collarbone, which she had shattered in the fall. Ashley looked at her collarbone, then at Dad, and lunged.

Her fists could barely reach his chest, but she pounded furiously, screaming at the top of her lungs, trying to push him out the door. He grabbed her arms and tried to hold her down, yelling at her to stop.

Mom stood in the door, a stricken look on her face as Ashley attacked over and over again, put herself between them and trying to keep him away. Finally, Dad turned and stormed out the door again, and we heard the roar of his truck.

Ashley calmed down almost immediately after he left, and let me help her take a shower while Mom stood by, woozy from the pain medication, and loaded Ashley's

toothbrush with paste. After she was in bed, I found Mom standing in front of the bathroom mirror, her shirt off, tracing the skin over the broken bone over and over again.

“Why isn’t it more bruised?” she asked, and I didn’t know it then, but she was thinking back to when Ashley broke her collarbone when she was two. How there were two huge handprint sized bruises on her chest and back. “Christina, why isn’t it more bruised?” She was crying, shaking, and I couldn’t do anything but turn on the shower water, letting it run over my hand to make sure it wouldn’t scald her skin. She cried while she stood in the shower, letting me shampoo the hospital smell from her hair and the adhesive of the IV from her wrist. She shuddered with residual tears as I helped her pull a shirt over her head, and slide her pajama pants up her legs.

Over the next month, whenever Dad got within five feet of Mom, Ashley panicked. She clung to Mom more than usual, never letting her out of her sight. Like she was guarding her.

Push

We learned several years before Mom broke her collarbone that Ashley had digestive problems. She had been getting pneumonia and infections in her lungs since she was an infant, and more than once had choked on her food. It turns out that, like most things, Ashley's digestive track is a little slow. She went to Boston Children's Hospital to have what is called a "swallow study," where essentially she was given some dyed liquid that she had to ingest, and the doctors watched it travel through her stomach and intestines and then kidneys and bowels, to make sure things are working properly. It takes the average person ninety minutes or so to digest food and move it from the upper intestines to the lower intestinal track, and within four hours, the food has been broken down and the extras excreted. As the doctors and my mother watched, Ashley's dyed food went down her esophagus, and some of it spilled over into her trachea, which led to her lungs. Normally, there is a flap called the epiglottis that blocks the trachea when you swallow so nothing gets into the trachea, but Ashley's epiglottis did a shitty job stopping things like liquids and small crumbs from sneaking into her lungs. That explained the frequent pneumonia: every time Ashley ate, and especially when she drank too fast or ate anything dry and crumbly, some of the food was slipping into her lungs and causing infection.

Aside from that, the food that did make it into Ashley's stomach just...stayed there. For hours. It was like her digestive system was working at quarter speed.

Everything Ashley ate moved much more slowly than it should have, or, if it moved at the regular pace, it wasn't digested at all.

Ashley's doctors recommended a feeding tube, which would have a port in Ashley's abdomen where fluid supplements could be directly injected. She could still eat, on occasion, but the goal was to make her swallow as little as possible, in hopes that her aspirating would stop.

The feeding tube, installed when Ashley was twelve, was a disaster from the beginning. At some point during the operation, the surgeon nicked an artery, so Ashley just kept bleeding. Ashley was bent over in pain, crying, running a fever, refusing to use the feeding tube. She kept us up into all hours of the night. Mom brought her to a consultation at Dartmouth in Hanover, and they said that not only was the tube irritating the artery and causing pain, but Ashley digested the food so slowly that she would need to be on continuous feedings, so essentially dragging around a feeding pole with a bag on it, for the tube to be effective. They disagreed with the Boston Children's team and said that in order for my sister to have a normal life, it made more sense for her to have an adjusted diet. Together, Mom and the doctors at Dartmouth decided removing the tube was the best option.

The feeding tube was removed a few days after Mom broke her collarbone.

A few days after that, Dad shoved Ashley to the ground. And Mom and I saw it.

He came home tense, as he usually did during those years. The set of his shoulders and the grimace on his face were enough to set Ashley off. When he slammed a dish into the sink, she launched at him, screaming and crying and swatting at his stomach.

And Mom watched, from halfway down the stairs, as he shoved her across the floor and onto the ground, where she hit hard and slid into the wall.

I like to think he didn't mean to push her that hard. That maybe he was just reacting quickly. Except he had about one hundred pounds, almost two feet, and a solid carpenter's build on her. And she was just one week post-op, with a festering wound on her stomach and in her intestines, that made her body burn and ache constantly. When she was hurting like that, and unable to understand why, except that it was because of a tube in her stomach that kept her from eating, it's no wonder she went off at the slightest provocation. It was her way of telling us how wrong it all was. It also (conveniently, unfortunately) revealed exactly what my father was capable of.

“Young People”

When Mom told Dad to leave, he didn't fight it.

“Well, he had somewhere to go,” she told me. I don't know where he went for the first few months, but by the time the snow had melted, and I was entering my second semester of my freshman year of high school, my father was living with another woman at her farmhouse in Hollis, a wealthy farming city that shared a border with Nashua.

There are many confusing things about my parent's divorce, and the subsequent accusations of child abuse that my mother raised against him in order to get full custody of my sister and me. But I remember the day I met the guardian-ad-litem, the woman who would serve as Ashley's and my representation during the trial, with the sort of clarity that comes with moments in our lives that make huge ripples in our future.

Because the guardian-ad-litem worked while I was at school, the school guidance counselor and psychologist arranged for us to meet in her office, in order to make the meeting official and to not disrupt my school day too much. I went in the morning, and got out of my Latin class. I remember being excited for this, because like all fourteen year olds, I loved an excuse to avoid work.

While I walked through the school hallways, which were deserted in the middle of the class period, I was excited. I was ready to be able to tell my side of the story to someone for the first time, someone that wasn't Mom or a police officer or Mom's lawyer. I hadn't really slept the night before, because I had been organizing my thoughts and how I would present my side. The guidance counselor's office was on the first floor

of the school, near the entrance and the cafeteria, and it was the kind of nondescript door that I passed it every day on the way to lunch without ever registering it was there. After that day, I made a point to avoid that hallway, even if it meant taking a different stairwell and adding five minutes to my trip to eat.

The guardian-ad-lidem, an older woman with graying black hair and glasses, looked at home in the office of the guidance counselor. She had set up her files on the desk, with a legal pad and pen in front of her, and gestured for me to sit in a chair across from her like she owned the place, opting out of using the sofa and comfortable chair in the corner of the room that the guidance counselor used whenever she had meetings with students.

The guardian asked me what I thought about my parent's divorce. She asked me to explain why I thought I shouldn't have to see or live with Dad. I told her about seeing him push Ashley, about the way he yelled and lost his temper. I told her about how he used to hit me with a wooden paddle so hard that I had night terrors when I was two. I recalled the time when I was eleven that he threw a glass at the wall, punched the plaster near my head in the kitchen, left fist imprints in the living room and the bathroom and the basement. I talked about the time he threw Ashley's cat, Maggie, into the living room wall. I told her about how he didn't go to Ashley's doctors appointments, how he didn't like doing stuff with my sister. That he favored me, but not by much. That he called me a parrot. That he told me I was a liar.

I remember when I cried, which was often, the guardian-ad-lidem pushed a pile of tissues toward me, but her face was serious, skeptical. Ever since that appointment, I refuse tissues when I'm crying. I find it insensitive. I've sat in front of countless

therapists, sobbing all over my shirt and refusing to accept their tissues as a matter of pride.

She offered no words of comfort. She did not tell me she understood, or that she was sorry for what had happened. At the end of the appointment, she said, “Christina, I think you are confused. Sometimes, when we like one parent more than the other, we listen to that parent. Sometimes, young people like you don’t know when they are being manipulated. I think your mother has turned you against your father, and I don’t think you shouldn’t have to see him.”

I burned red with shame and fury.

“But I don’t want to have to see him. Why should I have to see him if I don’t want to?”

“Well, young people don’t always know what is best for them.”

I hate the phrase “young people,” probably just because of that woman. Every time I hear it, I cringe, and I taste bile creeping in my throat. Every single time.

“I am not being manipulated. Mom wants us to get along, she wants me to do things with him, and tells me to tell him how I feel,” I insisted. “He called me a parrot! What kind of dad does that? What kind of dad doesn’t listen to their kid when they’re crying and upset?”

I waited until the guardian-ad-lidem was gone before I started sobbing. The school guidance counselor sat with me while I convulsed and snotted all over her office. “She didn’t listen to me,” I said. “She didn’t believe me.”

“Let’s call your mom. You can’t go back to class like this,” the counselor said.

“No, I don’t want to. I have to go to Geometry. I have a test today.”

“I’m sure your teacher will understand. This was really hard on you, and you have every right to be upset,” she kept assuring me, but it wasn’t enough. Because she wasn’t the one who was supposed to represent me in court. That woman had made up her mind and walked out of the door without a second glance at me.

I did end up going to Geometry. I stood in the hallway outside of my Latin class while I waited for the bell to ring so I could go get my backpack. I remember walking up and down the hallway, running my fingers along the grooves of the light blue lockers. I remember opening my locker door, and putting my face inside it, trying to breathe, using the confined space to calm myself down. I didn’t talk to anyone for the rest of the day beyond what was necessary. In fact, I stopped talking to people at all when I didn’t have to. For the rest of the semester, I sat through my classes in a daze. I moved from one to another without comprehending them, and avoided friends in the hallways, or else glazed over while they talked in groups. I slipped away, because I had failed.

That's So Funny

There are many times when I am in a public place, and become aware of how loud my laugh is. It's the kind of laugh that makes people flinch, especially when I am caught off guard by something I didn't expect to be funny. It's ugly and completely unlike my speaking voice, and I should probably be embarrassed by it. But every time I catch myself laughing, which is probably more often than most people, it puts me at ease. The kind of ease that comes from reclaiming something that had been so elusive, for so long, and welcoming it home.

It was the spring of my freshman year of high school that I discover I had lost my laugh. I first noticed about a month after the visit with the guardian-ad-litem, a couple of weeks after the charges of child abuse against my father were dismissed, and about two weeks after he was granted supervised visitation with my sister, every other week, for a couple of hours at a time. I had to see him once a week, usually over a meal. Other than that, we didn't see each other at all. This did nothing to reduce the sting of being dismissed as brainwashed by the state of New Hampshire, thanks to the lawyer who was supposed to be on my side.

My ability to laugh genuinely disappeared along with my sense of self-certainty. I became obsessed with how other people perceived me. In school, I had a hard time talking to people, because I felt like they were always judging me, and that I needed to impress them. I didn't feel like I merited any positive attention without earning it. And because I thought I earned it, I also thought it could be revoked at any time.

I first noticed during a sleepover at the house of the captain of the freshman girls' basketball team. I was not a starter, not even really a second stringer, on the team. I was there mostly because I was more determined than anyone else to do well in drills, and I had a lot of endurance. I was the girl the coach would throw in to play one-on-one defense against someone particularly tenacious, because I could stick to them like Velcro. As a result, I never really felt like an accepted part of the team, which consisted of some of the more well-dressed, popular girls in our grade. The ones who understood how to use concealer properly and wore sweatshirts from Abercrombie, who had friends in other grades and went to parties.

Throughout the whole sleepover, I felt like I was balancing over a precipice, and any wrong word would send me hurtling down a mountainside. Everything I said, I analyzed beforehand, and afterwards, just to make sure it was funny/smart/not nerdy/cool. When I got a laugh, I could relax for a moment. *Okay, Christina, you are accepted. People like you.* A few minutes later, I was back in panic mode. *Kristen and Sam have way more friends than me. Look how much everyone likes them. And look at Brittany. Everyone loves her. I bet she has a ton of friends. Way more friends than you. You are the least popular person here.*

It's hard to imagine now, because I am so far from that point. But I had a constant stream of insults and reassurances running through my head at high speed. I craved moments of peace, when I felt like I belonged, that I was worthy. But every time I felt that way, I was so aware of feeling that way that it was not actually happiness at all. Talking up and talking down. On and on.

It really shouldn't have come as any surprise that this made it impossible for me to really process anything going on around me. During that sleepover, I remember someone would make a joke, and I would have to say to myself, *yeah, that was funny. You should laugh.* And then I would laugh in a way that was utterly empty of amusement. I envied the girls who dissolved in a fit of giggles at an inside joke. I envied inside jokes. They were reminders that I was on the outside. By the time I left the sleepover, I was so exhausted that I spent the rest of the day curled in bed, avoiding everyone. When I went back to school, it was more of the same. In the hallways, I noticed if another one of my friends talked to someone I didn't know. *Look how many more friends they have.* I imagined that every time I walked away from a conversation, it immediately dissolved into discussion about me, how much I sucked, how lame I was. Or, even worse, they forgot about me entirely.

At the same time as I was completely overwhelmed by the thoughts in my head, I was also losing my ability to appear to be functioning well. In my first semester of high school, I got A's in every class. In the second semester, I nearly failed World History because I just stopped doing the homework. I know almost nothing about World War I, because that was what we covered that semester. I was barely getting by in Geometry, and ended up with a B-, and English, my best subject, slipped to almost a C. At the same time, I started sleeping more, hiding out in my room a lot, and spending hours wandering around our neighborhood in the dark after school so I wouldn't have to go home. I was still very thin, and ate cereal and bagels and ice cream almost exclusively. On the weekends, I didn't spend time with friends unless they asked, and each encounter left me exhausted.

At the same time that I was spiraling into a deep depression, marked by persistent anxiety, I was required to attend court-mandated counseling to deal with my parent's divorce, given how ugly the proceedings had been. There were a couple of counselors that the state approved, which meant we didn't have to pay a copay, so naturally, we tried those first. Sometimes I was forced to sit in a room with my father, and we would talk at each other without ever accomplishing anything. He refused to acknowledge that I was mad at him, and I refused to budge on my insistence that he treated me poorly. More often, I was in the counseling session by myself, with a counselor who was clearly overworked and underpaid, in an office designed for little kids, with a child-sized chair that I sat on and pictures of mood faces on the wall. From my seat, I had to look up at the counselor, which made me feel even more coddled and not respected.

I only went to this one counselor a few times, because on the last visit, I emerged from her office and ran outside to where my mom was waiting in the car only to start crying so hard I almost threw up all over the front seat.

"I think it's clear that you have severe depression and that you are a very troubled girl," she had said to me not ten minutes before. "You are not in your right mind, and you need some serious help."

When I emerged from the office shortly after, I climbed in Mom's car and told her, "The counselor thinks I'm crazy and I don't ever want to see her again."

Ashley didn't escape the counselor either. While I was told I was brainwashed and troubled, Ashley was just ignored. The counselor told my parents that she could not understand my sister's language, and that Ashley was not capable of communicating her needs effectively. Which is to say: the woman didn't bother to try. If she could have seen

my sister when she came home from school in the afternoon, maybe, or even spent time with her while Ashley was puttering around the house on the weekends, she would have known my sister was capable of “expressing herself effectively.”

On the way to one counseling session, my sister sat in the backseat since I had beaten her to the front, and kicked at me through the leather.

“Too loud, music,” she said, when I turned up a song to drown out her singing. “I’m mad, Christina front seat. I’m mad Christina music.” She shook her fist at me for good measure. When I turned around to look at her, Ashley waved her wrist at me. “Go away, Christina.” She crossed her arms over her chest, kicked at my seat one last time, and faced the window.

From the driver’s side, Mom sighed.

“Can you two not bicker for five minutes, please?”

Mom was wearing her teaching clothes, a pair of dark blue slacks and a light blue button up shirt, and her hair was messy from the wind. Earlier that day, she had stood in front of a group of twenty or so freshman college boys and lectured about flight safety, and before that, she had sat in her office, which was covered with pictures and sculptures Ashley and I had made over the years, alternating between filling out paperwork for her divorce lawyer, meeting with freshman advisees, and ignoring the professor down the hall, who liked to fart in his office with the door open.

“She keeps kicking me.”

“Shut up, Christina!”

“Ashley,” Mom snapped, turning around when she stopped at a light. “Why don’t you save it for the counselor, huh? Tell her how mad you are.”

Yet, when my sister went into her session fifteen minutes later, she sat in the corner, staring between my mother and father, silent, as she picked at her fingernails in a nervous tick she had developed since moving to New Hampshire.

A Window Booth

Life calmed down for a while once Dad moved out and the court straightened out custody agreements. Together, my parents decided Dad and Ashley would meet on Sundays at Sherry's house for an hour or two. Mom made it clear that Dad was welcome to any of Ashley's events, such as her Special Olympics basketball and bowling tournaments, and that he could come to medical appointments or ask my mom about my sister's education and life plans, though she would have the ultimate say. As far as me, my mom told me I could invite Dad to whatever I wanted, and that she wouldn't keep me from him.

By then, I was fifteen, and in my sophomore year of high school. I was trying a new antidepressant and going to counseling once a week with a psychologist I had chosen, who held his sessions in the attachment of his house, less than a mile from mine. His office was covered with statues and pictures from different countries, and he had an affinity for elephants.

Dad and I agreed that we would conduct our weekly visits with dinner and trumpet lessons. Dad bought me a trumpet sometime when I was in middle school, on a whim, and I wanted to learn because I knew how much he liked jazz, and I think part of me still hoped that if we could connect with something the way we connected with jump roping when I was a kid, we could have an actual healthy relationship. Much deeper, though, I don't think I knew how to have a relationship with him without doing something he was interested in.

If there was ever a reason for me to believe in divine intervention to prevent me having a healthy relationship with my father, it was that damn trumpet. I had about as much desire to practice as I did to study for math quizzes, which is to say almost none. I only practiced once or twice a week, right before my lessons, and it showed. On top of that, I found out that I had a serious allergy to nickel, and that the brass coating on my nickel trumpet mouthpiece did little to prevent the cheap metal from leaving blisters on the skin around my lips. After every lesson on Wednesday nights, I woke up the next morning looking like a poster in the school nurse's office for herpes prevention. Dad bought me a gold mouthpiece, which stopped me from developing oozing blisters, but then my trumpet instructor discovered I was one of those people genetically incapable of whistling, which, according to him, meant I would never advance beyond managing basic scales and slow, simplistic tunes.

“No, purse your lips a little more,” he said, and I would pucker in a way that felt completely absurd in front of a man who reminded me of Vizzini, the con man in *The Princess Bride* with the unfortunate lisp and shiny bald spot. “Inconthevable!” I could picture my instructor saying, every time I tried to whistle and succeeded only in spitting all over my chin. I'm sure Dad knew it wasn't working either, because he sat outside the classroom reading a magazine during the torturous hour-long lesson, and no doubt heard every sharp note and pathetic sputter that the instructor managed to coax out of my trumpet.

Despite this epic failure of a bonding experience, Dad and I did manage to find some good in our weekly visits. Before my lesson, we went to an old-timey diner half a mile away from the music school, and sat in the same booth, and ordered the same thing

every week. After a month, the waitress would come up and say, “Two slices of pepperoni and the nightly special?”

Five months later, my lessons ended, and so did my dinners with Dad. When I didn't ask for another round of lessons, and neither of us could come up with something else to do that justified driving half an hour to the restaurant for dinner, we just stopped seeing each other. Dad never complained to his lawyer that I wasn't holding up my end of the custody agreement. Mom asked me if I cared that Dad and I weren't seeing each other once a week, and I told her it didn't bother me, so she didn't push it. She later told me my counselor had called her a week before, and, without breaking confidentiality, insisted to her that if I didn't want to see my father, she should be willing to break the custody agreement, and in that, the law, in order to protect me from him. I have no idea what I told my psychologist in order to make him that adamant about not forcing me to have a relationship with my father. At this point, I am not entirely sure I want to know. We just stopped seeing each other, except on the occasional holiday when I went to a dinner at their house for Ashley's sake. He stopped sending me birthday cards and Christmas cards, but I barely noticed.

I wonder what that waitress must have thought, when we stopped coming in at 6:30 in the evening for our pre-trumpet dinner. Could she see our meeting for what it was? Did she recognize the conversations of two family members who once shared the same roof, and now don't speak on the phone? I do know she couldn't have had any idea how much that diner meant to me. It felt like our private place, Dad and me, with our booth always waiting and someone who knew our orders. It was the last place the two of

us sat in peace, interacting in a stiff, uncertain version of father and daughter. I would never get that sort of familiarity with my father again.

Humerus

After a field hockey game one afternoon, my junior year of high school, I opened the front door after being dropped off by a friend, and the first thing I heard was, “Okay, Ashley, remember, it’s not Christina’s fault.”

The lower level of our house was empty. It was still early in the evening, but usually Ashley and Mom were congregated in the dining room or the living room. I pulled the door shut behind me.

“Mom?”

“Go away!” Ashley sounded irate. I climbed the stairs to the master bedroom.

“Ashley, no. You need to be nice to Christina. She is here to help.”

“Mom?” I peaked my head in the door. At this point, I knew something was wrong with our mother. Ashley never got more defensive and tense than when she thought she needed to be in protective mode. I didn’t know what I expected. I was hoping maybe Mom just had the flu, or a stomach bug. Instead, there was a sling, much like the one she had when she broke her collarbone, except on the opposite arm.

“Go away,” Ashley warned again from her spot next to our mother in bed. Mom had her good arm wrapped around Ashley’s shoulders in an attempt to hold her back.

“What happened?”

“No! I’m mad!” Ashley made a wild kicking motion with one foot in my direction, so I slid back into the hallway, pulled the door almost closed, and spoke through the crack.

“Did you break your collarbone again?”

Since Dad had moved out, I noticed Mom seemed a lot more down. Of course, I was too young to fully understand the kind of heartbreak she must have felt at the time, but I knew it was a lot of work and adjustment for her to manage the whole house on her own. It was much more peaceful, but Mom had even less time to spend with friends or at work, because she needed to pick up even the small things our father had used to do. I don't blame her for wanting some time by herself, but what I heard next tugged at a part of me that felt deeply uncomfortable and sad for her vulnerability.

“Well, I had some time after I taught my class before I had to get your sister, so I decided to go ice skating.”

Growing up, the only television we were allowed to watch while eating dinner was figure skating. If it were an Olympic year, or we happened to catch a world competition, Mom let me bring my food into the living room to watch the skaters spin on the ice. She also signed me up for ice skating lessons when I was six, and bought herself a pair of skates so she could do loops around the rink while I learned to spin and jump. She liked skating far more than I did, but was about as coordinated at falling on the ice as she was falling off a horse.

“Oh, Mom,” I said.

She started crying. Ashley shook her fist at me.

“I knew the second I landed that it was broken. I heard it crack. It's not my collarbone, it's my humerus. I laid there on the ice for almost half an hour before the paramedics could get me on a stretcher.”

“Oh, Mom,” I said again, and it was awful, picturing her lying there on the cold ice in the middle of a cool afternoon, alone.

“I just, I was trying to do something fun for myself, you know? It’s been so hard, I just wanted to have some fun, and look where it got me.”

There’s something to be said for the first time you see one of your parents without clothes. The first time you have to help them into the shower, shampoo their hair, and then put on a shirt.

I had been giving Ashley showers since I was in middle school, when she would let me, of course. I was maybe more familiar with seeing a vulnerable, naked body than most people my age. But that evening, while Ashley was asleep in the next room, and we spoke in whispers to avoid waking her up, I reached a level of trust with my mom that, in most circumstances, wouldn’t have been reached until she was much older. Perhaps never. Nursing homes are a huge part of our culture for a reason. Though they are our kin, we don’t like to see our parents, or even our siblings, in a place of vulnerability. We aren’t trained for it.

Years later, after my mom got chronic pancreatitis, I would recognize the moles on her back and the curve of her waist in my palm without looking. I would have the finesse to shampoo her hair and slide her legs into pants without thinking about it.

I remember, at sixteen, taking it in stride with a remarkable amount of composure. I knew how to test the shower water with the inside of my wrist to make sure it wasn’t too hot, knew where to grip my mom’s arm and hip to help her step into the shower on her unsteady legs. These were all things I had done with Ashley. Rinse, shampoo,

conditioner, body wash. Turn the shower off. Use a towel around my arm for grip while I helped Mom step out of the shower. Sit her on the toilet to dry her shoulders and head first, the parts of her that felt the most cold, and then her legs and back. Maneuver the sleeve of the shirt through the injured arm first, so that it wouldn't be jostled when I pulled it over her head. Reposition the splint as soon as possible, to keep her arm from moving while I helped her into pajama pants and brushed her hair.

The entire time, my mom was relatively quiet, trying to hold back her tears. I think in a lot of ways, she felt like she had failed at being a mother because she tried to do something for herself. She knew that breaking her arm meant she wouldn't be able to take care of Ashley as well while she healed, and that would put additional strain on both me and my sister. She also couldn't take the pain medication because she still needed to drive to work and teach. I wished then, and now, that there was some way to alleviate that guilt. To help her understand that it wasn't too much of a burden on us for me to help her and Ashley in the evenings. I didn't wish she hadn't gone ice-skating. I just wished she hadn't fallen, if only because of how hard on herself she was for it. Not because it made me have to get up earlier or spend more time at home helping out for the next month. It was much harder to see her suffer than do any of that.

Dear Diary

In the mornings before school, Ashley would get her bowl for her cereal and her yogurt, fill a Sippy cup with orange juice, sit at the table, and write in her journal.

She didn't write words, necessarily, at least not any that we could understand. Ashley knew how to write her name, "love," "yes," "no," and the alphabet and numbers. Instead of filling her pages with these words, she would write left to right, line by line, in a curling script that had a lot of loops and circles.

When Ashley was concentrating, she would lean over the notebook, tongue sticking out of her mouth, and breath slowly and deeply as she wrote. She always wrote for one and a half to two pages. Then, she would close the notebook and announce she was ready to brush her teeth and get dressed.

Every Friday afternoon, I went to my counselor's office and spent an hour discussing my week, some of the issues I had been having, how I was feeling about my anxiety, and the things I wanted to improve about myself. There was a lot of crying, but I also laughed, because laying out my problems for an adult made them seem less monstrous and more sensible than they were in my head. Though my friends didn't know everything about what was going on at home, I could still rant to them when I wanted to, and we had plenty to commiserate about so far as school and sports and our peers.

Ashley did not have that level of communication with anyone. I don't think she ever will. She has all of the feelings of rage, joy, and confusion that I experienced, but not necessarily the words or the communication skills to express them. Instead of being

able to talk to a counselor about why she was afraid every time Mom got hurt, or why she lashed out at me when I bossed her around, my sister was forced to draw a connection between her world and ours, and translate her message in the ways she could. She had a sparse understanding of American Sign Language, and enough of a spoken vocabulary to tell us she was mad, or happy, but little ability to define it in greater terms.

Like me, Ashley also has a tendency to bottle up her feelings until the littlest thing sets her off. For me, it's a survival tactic: I act like everything is okay until I run myself into the ground, because I don't like asking for help. For Ashley, I think it also comes down to attrition, but in a different way. It takes her more effort to convey how she feels about something than most, and a lot of times, she just doesn't have the words to explain what's inside her head. Eventually, it breaks her down until she's mad about the color plate she's eating off of, or the way her shirt tag keeps scratching her neck. When she reaches that point, it's almost impossible to work backwards to the origin point of her distress.

So she writes things down in the morning, to be read by no one, and files her notebook away. I like to think I can read my sister pretty well, but sometimes it sucks that there is so much between us that goes unsaid. The closest we ever got to understanding each other was at Sunrise Academy, huddled together in the bathroom while I slathered us with sunscreen.

Eyes and Lips

On the day of my prom, I left school an hour early so I could go to get my hair done by our hairstylist, a woman who was good friends with Mom and who was patient enough to cut Ashley's hair even though Ashley tended to move around a lot when she was in the chair.

Ashley joined us for the appointment, because Mom knew she wouldn't have time to get Ashley after school while also helping me get ready, and Ashley wanted to get her hair done too. The more we made Ashley feel like it was her special day too, the more she would tolerate being dragged to pre-prom preparations and picture taking.

I sat in the chair while Ashley flipped through a woman's magazine. I got several calls and text messages from Stephanie and Lauren, my two best friends, about makeup, food, underwear, and when we were all meeting before pictures. We complained to each other about the cost of the limousine another friend had hired. We complained about our dates, all of who seemed suddenly too busy to respond to us. When I hopped off the chair half an hour later, Ashley stood up.

"My turn!"

The hair stylist dug up a little tiara comb that looked like it was from the 80s with its fake rhinestones and flower pattern. Ashley sat very still while she pinned it to her hair. I checked the time on my phone.

"Relax. We have over an hour until you need to get to Steph's," Mom said.

In the car, Ashley insisted on sitting up front, and pulled down the visor so she could look at her tiara in the mirror. From the backseat, I leaned forward to inspect my own hair, already starting to fall out of its updo. Ashley grinned at me through the mirror.

“Too small!” she said, pointing to my head. “Too small” was Ashley’s refrain for everything, from the amount of ice cream she got for dessert to my bras, which I left all over the house, to the pair of shorts I tried to wear to a party one night. “Too small!” Ashley had shouted from the dining room table as I opened the front door, and Mom poked her head around the corner. “Nah nah nah nah,” she said, and I had to change.

At Stephanie’s house, I ran upstairs to put on my dress and do my makeup, leaving Ashley and Mom in the living room with the other mothers. Stephanie’s mom had set out snacks for us, and when I came downstairs, Ashley was sitting by herself on the couch, a napkin full of M&M’s in her lap, chocolate stuck in her teeth. She was still wearing the tiara, and it clashed with her bright tee-shirt, elastic hem sweatpants, and high-top sneakers.

“Too small!” she said when she saw me in my dress.

As I went to walk outside onto Stephanie’s lawn, where our dates were now standing in their rented tuxes, Mom stopped me.

“Will you please do her eyes and lips? She’s been so good so far.” The first time Ashley had asked me to do her “eyes and lips,” for a birthday party she was going to, Mom and I had no idea what she was talking about. She just kept licking her lips and jabbing at her eyes, until finally, she went into the bathroom and dug around until she found one of my lip balms, brought it back out to the living room, and held it up in our faces like we were a pair of idiots. Ever since then, whenever Ashley was going

somewhere she deemed important, be it a dance recital or a party or a Special Olympics bowling tournament, she wanted her “eyes and lips.”

I grabbed a pink lipstick from my mom’s purse and some light pink eye shadow. I knelt in front of Ashley, and wiped the chocolate off the corner of her mouth.

“Christina! I got em-ems!”

“Yeah, I can see that,” I said. “Close your eyes please.”

Ashley squinted her eyes shut and puckered out her lips. As soon as my finger touched her eyelid, she flinched back and tried to open her eye.

“Ashley, close your eyes so I can put on the makeup.”

For the second time, she flinched and opened her eyes the second I touched her. Finally, I settled for cupping the back of her head and putting the eye shadow near her eyebrow line. When I pulled out the lipstick, Ashley tried to make a kissing face with her lips, but it looked more like she had just shoved a bunch of ice cubes in her mouth. When I finished applying the lipstick, she kissed the air at me, her version of smacking her lips together.

“Very pretty,” I said, already standing up and tottering out of the door in my heels.

It was tradition at my high school to go to the local park to take photos before prom. I rode over with my friends and date in the limousine we had rented, and Mom and Ashley followed behind in the car. I didn’t notice when they weren’t in the park because I was too busy taking pictures with people and squealing about dresses and hair and who was going with whom. I found out later that Mom had been crying, and had run the car into the curb, getting a flat tire. While Ashley stood to on the sidewalk in her tiara and

makeup, one of my classmate's dads helped Mom change the tire. I only saw them for five minutes before I hopped back in the limo and went to the one fancy hotel in town for prom. I didn't take any pictures with Ashley or Mom. My sister and mother drove home from the park on the spare tire, ate dinner, showered, and went to bed.

Adulting

It did not surprise my mother at all that when I applied for college, I looked almost exclusively at schools south of the Mason Dixon line. I wanted to get away from the things that reminded me of the darker moments in middle and high school. I was sick of driving by the counseling building where we had gone for required family counseling, the restaurant where my family had once had semi-peaceful dinners together, and the grocery store near our house that Dad still shopped at, despite now living twenty minutes away.

Ashley had developed a fondness for cutting up paper, and it became a sort of therapy for her. I would leave her stacks of unopened envelopes sent from schools in New England that touted their access to ski slopes, hiking trails, and bus shuttles to the big cities like Boston and New York and Philly. I poured over brochures from colleges in North and South Carolina, Tennessee, and Georgia. Schools with girls wearing Lily Pulitzer and wedges on the front, boys in button-up oxfords and Sperry Topsiders. If Ashley had any idea I was getting ready to leave home, she didn't acknowledge it. She didn't comprehend college, because nobody explained it to her, and when she cut up my mail, she did so without a thought about my leaving.

Mom did not discourage me from applying to expensive, small, and liberal arts colleges in far-away locations. I'm sure she remembered that conference for parents of special needs children that she had attended when Ashley was still breast-feeding. She would get to watch one child escape our house and go wherever she wanted, around the

same time she had to start planning for how to care for the other child when she aged out of high school.

We spent a lot of time on college tours during the summer before my senior year. We would take weekend trips, and leave Ashley with Sherry or drag her along with us. Mom had told Dad to not pay child support if he agreed to not get involved in medical and extracurricular activities involving my sister and me, so I know we didn't have much money to be traveling all over the South to look for schools, but I think Mom understood that it was something she would only get to do for one child. Also, I don't doubt she wasn't living somewhat vicariously through me.

As I applied to schools that were at least a day's drive away, I didn't consider the future of the rest of my family. Despite growing up with someone I knew would never get to live independently, I still thought a lot like people who didn't have the experience. Everyone talks about, and cares about, special needs children. But when they become adults, they seem to sink back in people's minds. I'd heard people get uproarious about the quality of Special Education programs in high schools, but rarely had I heard anyone talk about work programs, living facilities, and continuing education for adults with intellectual disabilities. What would Ashley do when she aged out of high school at twenty-one? What would my mom's life be like, as she got older, and still had to take care of my sister? And what about where I fit into that?

Stairmaster

“Well, it looks like a country club. Not bad.”

The night before I was scheduled to move into my dorm, Mom, Ashley, and I drove around campus in the dark so they could get an idea of what it looked like. Despite going on over twelve college tours together, this was the one school I applied to that Mom hadn't seen. And, naturally, the one I decided to attend.

“You picked well,” she added, as we drove past my dorm, as she undoubtedly began to understand why the school carried such a hefty price tag. She hadn't told me anything about college tuition when I applied, and instead made it seem like because I could apply for FAFSA, we wouldn't need to fork over a ton of money in loans for me to go. I hadn't understood that she was taking out up to \$20,000 a year in parent plus loans to get me to school every year. A few years later, when I confronted her about it, she just said, “I wanted to let you go wherever you wanted to go. After everything you went through, I wanted to do this for you.”

“But I could have been happy somewhere cheaper!” I had practically yelled.

“Don't say that. Don't make me think it was all for nothing.”

The funny thing was it was probably true that I would be happy at a number of different schools, and Mom knew it. I had lived in three vastly different parts of the country growing up, and hadn't stayed in one house for more than a year until my parents bought their condo in Nashua when I was in seventh grade. I was adaptable because I never really put down roots anywhere. But even knowing this, my mom wanted to give

me the chance to choose something with absolute selfishness, and she purposely didn't explain to me the repercussions, both financially and emotionally for her, because she knew I would have given up going down South in order to stay near her and Ashley. And I, in a move spurred on by this one opportunity to do what I wanted to do, without considering my family, did not bother to figure out my mother's sacrifice myself.

On move-in day, in ninety-degree heat, we walked slowly up the grassy hill in front of my dorm, my mother holding one of Ashley's hands, me holding the other. I lived on the fourth floor, and there was no elevator. At the bottom of the stairs, a group of upperclassmen boys who clearly spent a lot of time at the gym were waiting to help carry things up to rooms.

It took Ashley a solid fifteen minutes to get up the stairs. I remember the boy who offered to help carry my first box kept turning around on the stairs to wait for us, eventually putting the box down at every landing, while Ashley stepped, one foot then the other onto each stair. Other students and their parents passed by once, twice, several times with boxes before we made it to the top, and when we got there, Ashley was soaked with sweat and red in the face.

On that move-in day, the uneven brick walkways and winding paths that made Furman so beautiful looked instead like really inconvenient traps for getting a wheelchair stuck. The hilly campus, which made for a nice view, also meant it took us twice as long to get anywhere because Ashley had to walk up and down the slopes. Though she was only there for a day, my sister left her mark on Furman. When I walked to the dining hall with friends between academic buildings, I would remember how my mom and I had to

lift Ashley's wheelchairs up the random single stairs on the path. When I jogged by the science building, I noticed the way the sidewalk sat on a steep incline. Furman was handicapped accessible, but not handicapped convenient. Even when she wasn't there physically, my sister was still with me.

While I unpacked my clothes and my sheets and blankets, and started unloading pictures onto shelves in my half of the room, my sister sat silently on my bed, watching. She held a Sippy cup filled with water from the fountain in the hallway, and Mom had changed her into one of my shirts because hers was soaked with sweat. When they left that evening, Ashley seemed confused as to why I wasn't coming with them.

"Where's Christina?" she would ask every couple of hours for the next few days, on the flight home, at breakfast in the morning before school, and when she got home at the end of the day.

"She's at school, honey," Mom told her.

"When home, Christina?"

"She'll be home in a couple of months."

Eventually, Ashley understood that I no longer lived with them. But it never stopped her, even to this day, from repeating the question as soon as she gets on the phone with me.

"Hi, Christina," she always begins. "Where are you?" It sounds accusatory, usually, like a parent calling a child after a missed curfew.

"I'm at school, Ashley."

"When home?"

It didn't matter how long I was gone. She still asked when I was coming home when I was a senior in college. To her, home was always with Mom, and nowhere else.

The Guardians

During my first semester of college, my family began preparing for my sister's entry into adulthood. This was a thing I thought absolutely nothing about until my mom kept mentioning "guardianship" and "social security" and "post high-school" plans over the phone and I finally asked, "Wait, what happens when Ashley turns eighteen?"

People always talk about services for special needs children, but an adult with an intellectual disability faces a very different set of challenges, and oftentimes, these types of challenges aren't really addressed. I don't know why people don't seem to think about what it means for someone to become an adult and still need to be dependent on the government and their families, but it was certainly not something I was ever prepared for, even when I went to "siblings" oriented meetings and read books for siblings in special needs families.

In New Hampshire, and in most other states, before a child with an intellectual disability turns eighteen, the state and the immediate family and caretakers draw up a plan for who will manage finances, healthcare, and other parts of the soon-to-be adult's life. My sister qualifies for disability support from the government, but that also comes with stipulations. Only a certain portion of that money can be attributed to her living costs, such as rent and food and medical supplies, and the rest is set aside for programs like a day-work program or extra-curricular activities.

Up until this point, my dad and Kathy, the woman he had moved in with from work, kept out of Ashley's life. Because my dad wasn't paying child support, he didn't

care where money went for her sports and dance classes and clothing. He never came to doctor's appointments or to her activities, or any of her school planning sessions and case work appointments. However, the moment my mom brought up guardianship, he and Kathy hired a lawyer, and announced that they wanted guardianship. What ensued was a long, expensive, and absurdly complicated legal battle between my parents to hash out Ashley's future and the arrangements for her living situation once she was eighteen.

In the end, the accusations against my father regarding child abuse were largely ignored by the court, as well as his complete disinterest in Ashley's life until she was eighteen, and he was granted co-guardianship with my mother. This meant that Ashley would live with him and Kathy for half of the time, and my parents would split holidays every year, and each would be given one week to take vacation with my sister. Dad had to sign off on all medical procedures, be informed of all appointments, and my parents were expected to communicate with each other every day that Ashley was in their care.

Suddenly, it seemed that something we had all largely moved on from was once again a huge part of our lives. I had to listen to my mom complain about Dad's rude emails and odd behavior at appointments, I had to figure out when Ashley was going to be home when I was scheduled breaks from school, so that I could coordinate seeing her, and all of Ashley's activities, like dance and horseback riding and Special Olympics basketball, were debated about. If they fell on Dad's days, he didn't want to take her. If Mom offered to take her, he refused. If Mom signed her up for an appointment during his time, he cancelled it. If he made an appointment, he wouldn't tell Mom. And on and on. They fought at the doctor's office, in the parking lot of our apartment complex, and on the phone. Ashley came back from Dad's house tense and exhausted, and threw fits every

time she had to go back. She was spending half her week in one home, with one set of rules and expectations, and the other half of her week in another home. It was absurd. Nobody would like living half their time at one place, and half their time at another, and have to sit between two parents while they spit insults at each other. But Ashley was disabled, and not capable of “self-advocating” according to the state, so this was “the best solution.”

For a while, this was an inconvenience for me, but didn't really impact my day-to-day life. I still didn't speak to my father at all, unless I happened to see him when I was home with Ashley. It wasn't until Mom got sick that it became apparent to me how important Ashley's adult rights and the responsibilities of her care would be.

The Turning Point

In the early morning of January 2, 2010, I found my mom collapsed on our living room floor. Ashley was at our dad's house for the weekend, so earlier that evening, Mom and I had gone to a restaurant that had just opened in town that was known for its burgers and thick cut fries. The food was absurdly greasy, just the way I liked it, and afterwards, we had slumped on the couch to watch some shallow television before heading to bed early. Whenever Ashley was with Dad, I made an effort to spend the days with Mom instead of going out with friends, because I knew how much it sucked for her to be alone in the house at night. At the same time, as much as I loved my friends, I always treasured the time I spent with my mom. It didn't feel like sacrificing anything to stay in with her, because we knew each other better than anyone else.

"Mom, what's wrong?" She was sprawled out in the middle of the living room of our apartment, which split the apartment in half. My bedroom and the kitchen were on one side, and her bedroom and the single bathroom were on the other. She had been trying to get to me.

"It hurts. It really hurts." She clutched the middle of her stomach and rolled over onto her back, before gasping in pain and curling back up on her side.

"Your stomach? What can I do?"

"Call an ambulance," she said. This was the same woman who had driven an hour on icy, bumpy roads with a broken collarbone. The same woman who's gallbladder burst not long after giving birth to my sister, who had sat for hours after the pain medication

for her C-section had worn off, insisting that something else was wrong. That this new pain hurt more than giving birth. This was the same woman who had broken her humerus, and not taken pain medication so she could continue to work and drive. My mom was no wimp. That's how I knew something was wrong.

And still, we tried to convince ourselves it wasn't serious.

"Do you think it was dinner?" I asked, as I rode in the back of the ambulance with her to the hospital.

"Yeah, maybe," she said as the paramedic took her blood pressure. I don't know if she was just saying that to make me feel better, or if she wanted to believe it badly enough herself. But I don't think either of us had any idea how bad it actually would get.

A day later, Mom was released from the hospital with the diagnosis of a swollen bile duct, which they had inserted a stint into to open the passage back up. The bile duct allows passage of stomach acids and pancreatic enzymes through the digestive system, so a blockage could easily cause that kind of pain. Easy fix. I went back to school less than a week later.

Then, less than a month later, Mom called me in the middle of the day.

"Don't panic," she began. I took a deep breath, picturing a car accident, another fall on the ice, another broken bone.

"I'm back in the hospital. It's my bile duct again."

"How did you get there?" I asked, remembering how I had needed to call the ambulance last time. That first question, though I didn't know it then, would come to define the rest of my life. What did you do because I wasn't there to help?

“One of my friends from work drove me over. I’m fine. They are doing an ultrasound to see if the stint came out. Please don’t worry.”

“Well, I am worrying, Mom. What about Ashley?” The guardianship agreement stipulated that my parents split the time they had my sister fifty-fifty. The schedule was absurd. Mom had Ashley Mondays and Tuesdays, and alternating Wednesday nights, while Dad had her the other Wednesdays, and then Thursday and Friday. They switched off weekends. I had a hard enough time remembering what day of the week it was, much less which week it was in Ashley’s living schedule.

“She’s with her dad. It’s his weekend. I should be out of here tomorrow, I think.”

“What can I do?” I asked, knowing full well that I was a thousand miles away and the question had very few answers.

“Just focus on school,” she said. It would be a refrain I heard often.

We learned that Mom got a mild case of pancreatitis, an inflammation of the pancreas, as a result of the bile duct blockage. A few days of no eating or drinking, an IV with pain medication, and the pancreas recovers. She went home.

And then, a couple of weeks later, another call in the middle of the afternoon. Another, “Don’t worry.” The doctors scheduled an endoscopy, which involves inserting a tube with a camera down the throat to look at the organs in the abdominal cavity. The endoscopy would tell them if there were any problems with the bile duct, pancreas, liver, stomach, and spleen. But they were most concerned about the pancreas.

The pancreas is the bitch of all organs. Doctors who specialize in gastroenterology are always searching for ways to work around the pancreas, to disrupt it as little as possible, because the moment it is touched, it swells with fury and indignation.

Essentially, my mother and her surgeons found themselves in a never-ending catch-22: her pancreas kept hurting, but in order to look at what was wrong, they had to accept that she would definitely end up with acute pancreatitis after the operation, and need to be hospitalized for at least a week until the swelling and pain went down. If nothing was wrong in the first place, she would get sick. If she was already sick, as they suspected, they might be able to fix the problem, but in doing so, make her sick anyway.

This sort of uncertainty was new to me. Having been in biology classes since early high school, I thought I had a good understanding of how medicine worked: find the problem, fix the problem. But now, we knew that no matter what, my mom would be ill for the next five to seven days, at least, and we weren't even sure we would find the problem in the first place.

It turns out, there was something wrong: my mother's bile duct was swollen again, meaning all of the fluid that was supposed to flow through the duct and into the liver and kidneys for detoxification was backing up, and causing swelling and irritation. The surgeon cut a slit in the bile duct and put a plastic tube, a stint, into the hole to make the duct wider. And everyone watched as my mother's pancreas swelled and reddened in fury at the invasion, sitting nestled against the duct as it was.

By the time I finished my second semester of college, it was clear that my mom's bile duct/pancreas problem was not a one-time, or even three-time, thing. I was home for summer for about a week before I drove Mom down to Boston, where she was checked into Beth Israel Deaconess Hospital for another endoscopy, and another stint. The doctors at Beth Israel were within the Boston health network, which was extensive and

included the Harvard Medical School and Boston Children's. It also meant that I needed to drive over an hour both ways to visit.

Mom was in the hospital for about two weeks this time, because the stent caused an especially bad case of acute pancreatitis, which meant she needed to be on an IV for food and fluids much longer in order to recover. I insisted on visiting every day. If it was my mom's days to have Ashley, I woke up early, got my sister dressed and dropped her off at school, and then drove into Boston with rush hour traffic. I had to leave by three in order to get Ashley from her after-school care, and I would give her dinner and her shower, and then put her to bed and repeat the next day.

On days when Ashley was with Dad, I got up even earlier to beat the traffic and usually stayed later. Mom and I would watch hours of Animal Planet and TLC in between conversations about my future. My first year of school had proven I wasn't really prepared for college, and that Biology, my chosen major, wasn't exactly my forte. But I was stubborn, and convinced myself that switching out of Biology into an "easier" major would make me look lazy. I was also convinced I would become a doctor, not because I actually wanted to, but because I figured it was necessary, given that I had so much experience with hospitals and taking care of people. I was efficient at this. I could get up early and spend the day in the hospital surrounded by sick and dying people. I stopped feeling sick whenever I saw needles or tubs of bile and vomit. I was fine.

I learned something else about myself: I loved driving in rush hour. Especially in the afternoons. Beth Israel was right smack in the middle of Boston, down the street from Fenway and next door to Boston Children's. I had to drive down Storrow, a narrow, fast moving road with dozens of exits and little warning for lane merges, to get to and from

the hospital, as well weave through the crowded, multi-lane curving streets that passed between Boston University buildings and crowded Brownstones. During morning rush hour, I weaved in and out of other commuters with relative ease, since most of us weren't quite awake and nowhere near in as much of a hurry to get to work as we would be to get home at the end of the day. Then, as the afternoon rolled around, I honked and flipped people off and rolled down my windows to yell at pedestrians with the best of them. I managed to squeeze my mom's Volvo station wagon around huge trucks delivering shipments to restaurants, narrowly avoided collisions with zippy sports cars, and used the nose of the car to nudge pedestrians through the crosswalk like they were confused and stumbling ducklings. For all that I was still and composed at the hospital, and upbeat and efficient while I took care of my sister, I could be as ugly and obnoxious as I wanted on the road and it didn't matter. By the time I hit New Hampshire highways as the sun was setting, I felt subdued. I would turn on NPR and drive in silence to our apartment, then turn on the television and keep it at a low hum throughout the evening so the apartment felt less alone.

Deferred

As much as Ashley hated when I bossed her around, when our mother was in the hospital, she was relatively easygoing. I think it was easier to listen to me when Mom wasn't around because she understood that I had the power to deny her dessert or plunk her in the shower with the water set to cold if she didn't listen to me.

"Hello, Christina," Ashley said every morning, when the alarm woke us up. "Where's Mom? What name friend?"

"Hello, Christina," she greeted when she climbed into the car after school. "Where's Mom? What name friend?" As much as Ashley was concerned about our mother, she was equally concerned about my social life. I like to think it was because she wanted to hang out with my friends with me, but I am equally certain it's because she knew that when I didn't go out, something was wrong. Namely, that I was too worn out or emotionally drained from dealing with stuff about our mom.

"No friend, Ashley," I would say. Or, "You're my friend, Ashley." She, appropriately, rolled her eyes at this. Ashley still slept in the same bedroom as our mom, usually on the trundle next to the bed or, when she could get away with it, in the main bed itself, and I let her curl up next to me, and spoon me into her chest when I laid down to go to sleep. "There there, Christina" she would say, patting my head.

By the time the summer ended, Mom had been in and out of the hospital at least three times for pancreatitis-related problems. My fall semester at school, I flew back alone and moved into a new dorm on a hall filled with members of my sorority. The first

few months involved a lot of heavy drinking in our rooms with the doors closed, and hikes across campus to the fraternity halls for parties. Sometimes, there would be weeks without my mom calling to say she was ill. But I still learned to be wary of phone calls out of the blue, especially in the early afternoon, when she would normally be working. Almost every time, I knew the moment I picked up and said “hello,” like she had a specific intake of breath that signaled, “I’m back in the hospital” before she spoke the words.

In the spring semester, the hospital visits were almost weekly. It got to the point where my mom had to call my dad in the middle of the night to ask him to come take Ashley so she could go to the ER. I was missing assignments and hiding out in the library because I couldn’t focus, could barely stand to be around people because I couldn’t bear listening to them complain about their problems. I was bitter about how carefree my friends’ lives seemed. I was also getting increasingly worried that if my mom couldn’t take care of Ashley, our dad might try to get full-time guardianship. And that scared me more than anything else. I knew, since we were kids, that he didn’t have the patience or dedication to take care of my sister in the best way. And, based on what he had mentioned in meetings for guardianship, I had no doubt he would try to institutionalize her, which, to me, was always the absolute last option. Ashley needed a social life, and to be in the community. She needed to interact with all kinds of people. And she needed her family.

In late February, I was on my way back to my dorm from a lab when Mom called. “Hey, what’s wrong?” I said when I answered, already assuming this wasn’t a call to catch up. And that was the moment I think I fully understood what I needed to do.

“It’s back again,” Mom said, meaning the pain, the vomiting, the fever that meant pancreatitis.

“I think I need to come withdraw, and come home,” I said, stopping to stand on the steps next to the entrance to my dorm. In the afternoon, the hall would be full of people studying and planning for the night out. A friend from class passed me, waved hello, then retreated when he saw my face.

“I can’t ask you to do that,” my mother said. She didn’t say no. She didn’t tell me I was being ridiculous. So, without going inside, I turned and started walking towards the administration building where the dean’s office was located.

“But you need me to,” I said. “And I need to. If you can’t take care of Ashley, we might lose her. And I can’t focus here, Mom. I can’t focus because I’m wishing I was there to help you.”

I could hear her crying over the phone, and I was crying by then too. I was a girl, on her phone, walking across campus on a sunny afternoon, sobbing not with anything but relief that I would be able to go back and help. It felt like pounds lifted off my shoulders, to ditch the burden of being a student and return to what was familiar, to do what needed to be done to help my family. It was easier then to say goodbye to my life away from them. Then, and years later. No matter how much it hurt, it was always easier to say goodbye to the separate life I built for myself, because it never felt like a real identity. It always just seemed like I was playing pretend.

The day I moved out, which was less than a week later, my roommate posted a photo on Facebook of our two beds pushed together. “The Queen’s abode,” another girl had said about it. When I saw it in the airport, waiting for the second leg of my flight home, it felt like I had been shot in the stomach, and the bullet settled there. I would find out later that another girl who lived across campus, who I hadn’t ever thought would come to my defense, had stormed into our dorm. “You take that photo down right now,” she had said. Another girl in my sorority, who lived across the hall, and was the kind of person everyone wanted to be friends with because she had this effortless coolness, made me a couple of mixed CDs that she decorated with the phrase “Keep ya head up.” She gave them to me on her way to dinner as I was getting ready to leave. Here was a girl I wanted so badly to think I was cool, who I assumed always thought I was clingy or lame. I held onto that CD for years, and still have it now. Ashley likes to dig it out of my center console and play it in my car.

Morning Rituals

Our house was always full of bowls and spoons. Ashley liked to use a bowl for every single food she ate, and never wanted to cross-pollenate her meals. If she was having macaroni and cheese, it would go in a separate bowl from the fruit she ate with it, and the ice cream she had for dessert. If Ashley talked my mom into buying M&Ms, those also got put in a bowl. I once found a bowl in the sink that had what appeared to be the remnants of a granola bar.

When Mom stopped being able to eat, she resorted to drinking Ensure and other chalky meal replacement shakes. Every time I came home, I would find the fridge and cabinets empty, save for about a dozen Ensure bottles, a block of cheese, a bunch of yogurt, peanut butter and jelly, bread, and granola bars. I figure Ashley must have noticed that she was the one making all of the messes in the kitchen once Mom stopped eating, because she developed a love of doing dishes that had skipped right over me.

Had I not felt guilty about the money and waste using paper utensils caused, I would never own any sort of cutlery or dishes. That is how much I hate touching anything that someone has eaten off of. Asking me to load the dishwasher was worse than asking me to scrub the sinks and tubs when I was growing up. Ashley, on the other hand, had no qualms about filling up the sink with soapy, brown dishwater, and splashing it all over the countertops as she wiped down each of her bowls by hand.

Now, when I had gone to college, Ashley could care less about doing dishes, or helping out with anything else in the house. She made such a huge mess herself, what

with clothes everywhere, paper piling up, books and markers and pens scattered around the house, that she seemed totally unbothered by everyone else's' mess. The first morning after I got home in February of that sophomore year, I was woken up by the sound of a shoe hitting the wall outside of the bathroom.

“Christina shoes outta the way!”

It was five in the morning. Ashley had to be at school by seven fifteen, and I had set an alarm for a much-more-reasonable five thirty to drag her out of bed. Clearly, I was the one who would be dragging. I shuffled into the hall and saw the bathroom door wide open, the light on, and watched as my other running shoe came flying out and hit the wall with a thud. Mom was still in bed, and I was planning on letting her sleep until I got back from dropping Ashley off at school.

I peeked my head around the bathroom door.

“Why are you throwing my shoes?”

Ashley was naked on the toilet, holding a bowl that looked like it had about a cup of shredded mozzarella cheese in it. Her hair was sticking up in every direction, and there were marks on her face from her pillow.

“Christina shoes bathroom!”

“Is that cheese? Who said you could get cheese?”

Ashley gripped the bowl tighter and snarled at me, which was impressive, considering she was the one with no clothes on.

“Mom.” She scooped another handful out of the bowl.

“Yeah, uh huh.” I leaned out of the bathroom door and poked my head into our mother's room, to see her curled up on the side of the bed with no pillow. Judging by the

stack of pillows on the other side of the bed, which appeared recently vacated, I assumed Ashley had managed to wriggle her way onto our mother's mattress instead of sleeping on her trundle.

"Mom, sorry to bother you," I said.

"No." she grunted. "I did not tell her she could have cheese." She lifted her head up from the mattress. "Ashley! Listen to your sister!"

From the bathroom, "Christina shoes! Outta my way!"

Five minutes later, I started grabbing bowls out of the cabinets and setting them on the table when I heard Ashley, now fully dressed, huff from behind me.

"What now?"

"I do myself," she pouted, picking up the bowls that I had set on the table, carrying them back to the cabinet, and grabbing a different set of bowls.

"Okay, okay, fine. Do you want a banana?"

"I do myself!"

I raised my hands in surrender and sat at the table while I watched Ashley attempt to haul a carton of milk, a cereal box, three bowls, and a banana out of the kitchen. She sat down in her chair, picked up the banana, and began twisting at the stem with her entire fist. She stuck out her tongue, huffed again, dropped the banana on the table, crossed her arms, and then looked at me.

"I can't get it."

"Oh, do you want help now?"

Ashley scowled, nodded, and I peeled the mangled banana and watched her break it into small chunks with her fingers before dropping it into a bowl. Fifteen minutes and a lot of frustrated grunting later, I ducked into my room to pull on some clothes to drive Ashley to school when I heard the kitchen sink running and an alarming clattering of dishes.

“What on earth are you doing?” I asked when I saw the water splattered all over the tile, and soaking the front of the shirt I had just dressed my sister in.

“Clean up,” Ashley said, waving the sink hose at me like it wasn’t obvious.

“Why don’t you let me do that?”

“All by myself!”

By then, Mom appeared in the kitchen to get her pain medication. She sighed.

“Just let her do it. I usually just wipe up after. I think she just wants to feel helpful.”

“But she’s making more of a mess!” I dodged the flying water coming from Ashley’s direction. Mom watched my sister flood the kitchen with the same face I’m sure she gave me when I was four and tried to make play-doh out of peanut butter and flour. This was clearly a battle not worth fighting. And, as much as Ashley seemed determined to make the biggest mess she could, I understood that she really just wanted to be helpful. She was seventeen, and wanted to be given some independence and responsibility, and, in the same way I had started obsessively researching narcotics and their drug interactions and the digestive system when Mom got sick, Ashley took it upon herself to help keep the house in working order.

By the time we made it out of the front door, at seven-twenty, Ashley was wearing a new shirt and a new pair of pants, since she had soaked through her first set of clothes, a sweatshirt and winter coat, both zipped all the way to the top, a hat and mittens, her hood, and a pair of clunky boots. In the car, I watched her struggle with her seatbelt with her mittens as the hat kept falling over her eyes.

“Do you want to take some of that off while we drive?” I asked, trying to discreetly line up the seatbelt buckle with her aggressive jabbing.

Ashley paused and looked at me through seven inches of fabric. “No.” She clicked the seatbelt into place, and spent the rest of the drive adjusting her mittens and fussing with her hood while I rode with the heat on low to keep her from overheating. At school, I followed her through the hallways much the same way I had when I had been a senior, this time in a pair of flannel pajama pants and my mom’s snow boots.

Star of the Show

Ashley joined a special needs dance class at a local studio shortly after I went to college. I started taking her to classes on Monday nights during that spring semester I was home, and discovered that even if I wanted to watch Ashley dance, I couldn't, because she would spend the entire class looking back at me in the mirror and waving or laughing instead of doing her dance moves. And on the rare occasions she *did* dance, she would immediately seek me out for confirmation that I was watching.

As a result, I had no real idea what to expect when we drove to Ashley's recital in June. Ashley was supposed to be at the auditorium at two in the afternoon, and she had woken me up at six thirty in the morning to tell me I needed to do her eyes and lips. In the car, Ashley sat in the front seat in her costume, a bright yellow, red, blue, and green colored tunic that was a forgiving stretchy material and went down to her knees, and spent the entire ride looking at herself in the mirror and singing loudly to a *Glee* CD I had heard so many times it would run like a soundtrack in my sleep. I had attempted to pin her giant feather hairpiece into her hair with a lot of hairspray, but it kept itching her forehead and sliding down her face.

It appeared I wasn't the only one with difficulties. The rest of Ashley's class was assembled on a set of chairs specifically reserved for them backstage (in an effort to keep track of the nine special needs teenagers and adults who tended to wander wherever they wanted). One was holding her feather headpiece and systematically picking the feathers off of it. Another was cringing away from her mother as she tried to pin it to her hair.

Ashley sat down beside her friend, Betsy. Like Ashley, Betsy felt most comfortable in situations where she knew exactly what was going to happen. She chattered at the flustered dance instructor nonstop.

“Jen, Jen,” she said, “Jen, I am going to dance, and then go sit with my family, right?”

“Jen, Jen. I am allowed to have one piece of cake after my dance. I’m on a diet.”

“Jen, my dad bought me flowers. Do I get my flowers after I dance?”

On Ashley’s other side, her friend Marquis was talking herself through the dance and doing miniature dance motions in her seat.

“Hi Marquis,” Ashley said, patting Marquis on the head.

“Don’t touch my hair,” Marquis responded. Then she smiled, “Hi, Ashley. It was just your birthday!”

Marquis, who has Down syndrome, is really good at remembering birthdays. I had told her mine once, years ago, and every year around late July, she reminded me that my birthday was August 24th. Marquis also was probably the best dancer in the class. From what I had seen, she had a tendency to correct Ashley and other dancers when they weren’t following along, or otherwise ignored them and focused on herself in the mirror until she perfected the moves.

Mom and I left the group to find our seats. Twenty minutes later, the special needs dance class shuffled on stage, the first performance of the night. After they danced, we, their families, would meet them at the wings of the stage and bring them back to sit with us for the rest of the performance. This was partly so that they could watch the other

dances, and partly so that the busy dance staff didn't have to worry about caring for the group, who would be stuck sitting backstage, while running the rest of the show.

There were nine or ten dancers that year. Most could walk on their own, but one, Courtney, had a wheelchair that she was very adept at spinning in circles when the dance called for it. The dance instructor and several helpers tried to arrange the group in two lines, staggered so that everyone could be seen. Betsy called out to her dad from the stage, trying to see him through the lights. One younger girl sat down in the middle of the stage and crossed her legs. Ashley waved, and slapped Marquis on the butt as Miley Cyrus's "Party in the USA" cued up.

"Where did she learn to do *that*," Mom whispered in my ear, horrified, as I cackled.

Jen stood at the front of the stage so the group could follow along. Ashley throw her hands up and nod her head "like yeah" at the appropriate times, and do an absurd shimmy of her hips that seemed not at all related to what anyone else was doing, but which garnered several laughs from the audience. Marquis did the entire routine with a straight face, completely serious, and didn't miss a move. The rest of the group performed with varying degrees of accuracy and enthusiasm, and about halfway through, the neat two lines had dissolved into a cluster, where everyone was in danger of hitting one another. At the end, they all bowed to a standing ovation, and Ashley blew kisses at the audience and winked. When she came off stage, she high-fived anyone who would get near her.

"Woo-hoo!" Ashley said when she saw me. She fist pumped and grabbed the flowers I was holding for her. "M&Ms?" Back at her seat, I snuck her M&Ms while she

watched the rest of the show. I honestly think she thought that the other performances in the recital were designed as a reward for her after her performance. She cheered along with all of the doting parents, clapped and bobbed her head to songs she recognized, and afterwards, pranced around the emptying auditorium, waving her flowers, and high-fiving everyone. If someone told her, “Good job,” she would smile indulgently and say, “Thank you,” like she was just politely acknowledging what she already knew. On the way home, she demanded a cheeseburger from McDonalds with no pickles, and a chocolate milkshake.

Nuts and a Lobster Fork

Dad and Kathy got married in the summer before I was starting my junior year of college. At that point, I saw Dad once a week, when I dropped Ashley off at their house in the countryside of Hollis, New Hampshire, but we didn't speak more than to exchange hellos and update each other on the status of my sister's prescriptions and schedule. Dad's brother, Uncle Erik, was coming to the wedding, and I think he probably was the one who told Dad and Kathy to invite me. I decided to go mostly because I was pretty sure that if Dad and Kathy were busy getting married, they wouldn't have time to pay attention to Ashley, who was at their house that weekend. And I hadn't seen Uncle Erik in several years, and part of me still wanted to keep connected to that side of my family if I could.

When I pulled into the crowded driveway of the "estate" as my mom liked to refer to the sprawling farmhouse with a pool, tennis court, and massive outdoor kitchen and garden in the back, Ashley sat up in the front seat and, seeing the balloons at the front door, turned to me and said, "Party?"

"Yeah, Ash, remember? Dad and Kathy are getting married."

As far as I can tell, Ashley understood marriage as a bunch of standing around and talking in fancy outfits followed by a party with food.

"Cake?"

I laughed. "Yes, there will be cake."

Ashley was already pulling off her seatbelt. "Let's go let's go let's go."

I wished, in that moment, that the only thing that mattered to me about this wedding was the cake. I followed Ashley up the front drive, and she grabbed my hand.

“Let’s go, Christina.”

I took a deep breath. “Let’s go.”

Dad’s wedding was small. There were about ten relatives from my side of the family that I hadn’t either talked to in years or don’t remember meeting at all. Uncle Erik got me a drink and gave me a big hug, but otherwise, I was pretty much ignored. Kathy’s family clearly knew who I was, but mercifully left me alone. When the ceremony was set to begin, Ashley and I stood off to the side in the backyard, while Dad and Kathy situated themselves at the top of the garden, next to a little pond with fish in it. It was hot and sunny, and Ashley was sweating in her dress.

“I go bathroom,” she said, tugging at my arm. Everyone was gathering around the garden, so we slipped back into the house without being noticed. In the bathroom, Ashley watched me adjust my hair and take deep breaths in the mirror.

“Okay, Christina?” she asked, reaching out to pat my leg. I wiped at the skin under my eyes and shook out my arms, trying to push the anxiety out of my body.

“Yeah, I’m okay.” Ashley nodded, but when we went back outside, she did not let go of my hand. She kept it there through the short ceremony, and leaned her head against my shoulder as I turned my face and looked out over the fields behind the house when Kathy and Dad kissed. I don’t have any memory of my parents being affectionate with one another, and I wasn’t ready to see it between my father and his new wife. Ashley

didn't seem bothered, probably because she also had never seen our parents kiss or even hug each other. I'm glad for this.

As far as I knew, Ashley had never shown an aptitude for seafood, mostly because my mom and I didn't like cooking it because it made the house smell. But when Dad appeared at the table we had chosen in the back of the reception area with a fully cooked lobster, and put it down on my sister's plate, she looked more excited about that than she had been about cake.

"She eats lobster?" I asked, watching as Ashley tore a claw open with surprising ease. Dad began pulling meat out of the lobster and dropping it on a plate in front of my sister. Ashley picked up a tiny fork, which I could only presume was designed for this kind of thing, and started dipping lobster meat into melted butter and shoveling it in her mouth.

"Oh yeah, we have it all the time," he said. "You want some?"

"No. Lobster and crab make me sick."

He looked at me like this was new information, which it probably was, considering he had never made lobster when he lived with us, despite having grown up on the coast as a child. Beside me, Ashley had finished the entire lobster on her plate and was looking around for the cake.

"I think she wants cake," I said, when Dad started to walk away.

"You want cake? Aren't you full?"

This, to my sister, who has a separate stomach for dessert, and doesn't consider something a party unless it has cake.

“She wants cake.”

Dad disappeared, and Ashley poked me in the side. “Christina, I need drink.” Her Sippy cup was empty of the apple juice I had put in there earlier.

“Alright, I’ll be right back. Stay here, okay?”

When I returned, Ashley was sitting in front of a piece of carrot cake, full of walnuts and raisins, and about the size of a Tic-Tac box, with almost no frosting. Rather than digging in, my sister sat there staring at the piece like there was some kind of mistake. She knew she couldn’t eat nuts, because she had been denied nutty desserts since her special diet had been put in place almost a decade ago. I wanted to hit something. I looked around for Dad, but he was already on the other side of the courtyard, talking to some people I didn’t know.

“Hang on, Ashley. Let me get you some more, okay?” Ashley looked up at me and then turned around to search for Dad and Kathy. For the first time, I think it occurred to her that she was not an important part of this party, and that she was being shepherded to the side. Nobody else was at the table, and without me, she would have been alone. I felt like I could taste the fury in my gut, at the fact that Dad made such a big deal about making Ashley “a part of the wedding” but had proceeded to ignore her in favor of his new family. That he had given her food that could make her choke, and hadn’t thought twice about it.

I went back to the dessert table and grabbed another, bigger, piece of cake, and when I got back to Ashley, I scraped the walnuts off the frosting and did my best to pick the bigger chunks of walnut and raisin out of the cake. I handed it to Ashley, who had sat silently and watched me through the whole encounter. Her face lit up, even though the

cake was mostly just a mushy mess of frosting, because I think she had resigned herself to not getting any at all.

“Thank you, Christina!” She scooped some up with that absurd tiny fork she had used for her lobster. “Mmm, mmm, mmm!”

For the rest of the afternoon, we sat together, surrounded by people we didn’t know, while I ate the walnuts and raisins out of several pieces of cake, and gave the rest to Ash.

Suck It Up

The refrain, “well, when you’re an adult” got thrown around a lot when I was growing up. Like the line between not being able to drive and being able to drive, that moment before and after getting my license, I assumed, wrongfully, that one day I would be a teenager, and the next, I would be an adult. I suppose if I had been cut off when I turned eighteen or something to that effect I might have felt that change more harshly. But instead, I spent most of college thinking, “Wait, is this what it means to be an adult?” when I got my first rent bill, when I got my first credit card, and when I had my first W-2 that summed more than \$1000.

Of course, there wasn’t one defining moment that made me an adult. But there was a defining series of moments, which began when I was in my junior year of college.

The first was in November. Since the semester I had gone home to care for my mom, her situation just got worse. The acute pancreatitis that she got occasionally became chronic pancreatitis, a condition where the pancreas is inflamed all of the time. When this happens, it no longer does a good job of producing enzymes for digestion or blood sugar control. Because the pancreas is always inflamed, it always hurts. And, because it always hurts, the rest of the organs in the abdomen go into high alert, and work harder to compensate the deteriorating pancreas. Over time, chronic pancreatitis causes liver disease, digestion problems, stomach infections, and eventually, kills you. It is more common in men, and in alcoholics, because just like the liver, the pancreas is damaged from heavy drinking.

My mother was different. She hadn't had more than a wine cooler a week in over twenty years, and her liver wasn't damaged from alcohol, so that wasn't her problem. Instead, one exploratory surgery found that she suffered from a rare birth defect called pancreas divisim; essentially, her pancreas was split down the middle, with two separate parts, one functioning, and one not. Over time, the functioning part of her pancreas became overworked, while the nonfunctioning part did nothing but cause problems, and now, her whole pancreas was permanently inflamed.

The doctors learned of this birth defect in November of my junior year, when my mom was getting so weak and in so much pain she was barely able to drink water. She had been on narcotics for almost four years, and it made her sleepy, slow, and almost zombie-like. One day before I was scheduled to take an exam in my animal physiology class, my mom called from the hospital to tell me that she was going to have a surgery that would open up her abdominal cavity to investigate the cause of her pancreatitis. She would need someone who could be there when she woke up, and take her home, and she couldn't find someone else on short notice. I emailed my animal physiology professor from the airport to tell him I had to fly home for an emergency. I gave him the rundown of my mom's problem, in brief, and told him to talk to my advisor in the biology department if he had any questions, because my advisor had seen me through withdrawing my sophomore year, and could confirm my story. The professor emailed back and told me I could take the exam on Tuesday of the following week. It was Thursday, and I was planning to fly back late Sunday night. I was relieved, because it meant I wouldn't have to take the exam with no sleep and little preparation. I spent the whole flight home studying, and sat in the waiting room during my mom's procedure

with note cards spread out on the chairs around me, trying to learn the breathing process of fish and the respiratory rate of reptiles under certain temperatures.

My mom emerged from surgery far sicker than before, because the operation had irritated the pancreas and left her with a deep incision in her abdomen. I spent most of Saturday and Sunday giving her pain medication and changing her dressings on two hour cycles, setting my alarm so I would wake up half an hour before her medicines were set to wear off, so I could give her another dose before she started feeling pain, as recommended by the nurse who had cared for her before she went home. When I hopped on a plane Sunday night, I emailed my professor from the airport to confirm I would be taking the exam Tuesday. He replied an hour later with a curt email: he didn't want to wait until Tuesday, because he didn't think I deserved the advantage I was receiving by taking the test later. He didn't think it was fair to the other students that I got special treatment because I decided not to be at school when I needed to take the exam, because I had decided other things were a bigger priority. It was that moment, as I sat exhausted, tears running down my face in the middle of an airport terminal, that I realized that he had every right to schedule my exam when he wanted, and that he had every right to not be sympathetic to my problem. I was absolutely livid, and hated him for it, but that wasn't going to change the situation. I had to suck it up and take the test when he wanted me to.

I showed up the next morning for my exam with less than seven hours of sleep under my belt in the last seventy-two, and took my exam with shaking fingers and twitching eyelids from the amount of coffee I had ingested. I handed it in without a word,

and walked back to my apartment utterly numb, slept for twelve hours straight, and then headed straight to the library to catch up on the other work I missed.

For the next year, things continued much the same. My mom was almost always on some sort of narcotic or alternative pain therapy, like antidepressants or anti-nausea medication, and every time I saw her, she had shrunk a little bit more. I watched the woman who I knew as strong and determined become listless and slow. She was weak from not being able to eat much, and drowsy from the medication she was under. She looked like she had aged a decade in only a couple of years. As she continued to lose weight and the pain continued to ramp up, spreading across her abdomen until nearly the entire expanse was tender to the touch, my mom's doctors began looking for more radical options. It wasn't enough to just keep her comfortable anymore. That was becoming almost impossible.

There were two options: one, a pancreatic transplant, which could take years to receive and had a high chance of failure. The other: a radical new surgery designed at Johns Hopkins and recently being performed by a specialized team at Dartmouth called a complete pancreatectomy. Because my mom was relatively young, and had a healthy liver, and was mobile, all of which would contribute to a good recovery, she decided the pancreatectomy was the best option. The surgery was scheduled for December 12, 2012, so I could be home from school break (one semester before I was set to graduate in May, 2013) and help take care of things.

At the time, I was taking my four required classes and one extra class in order to make up for the semester I had taken off from school. Only three of those classes, the

science subjects, had exams that I had to sit for, and all were either right before the surgery, or after. I managed to convince my professors to let me take my exams early, on the day the university set aside before finals week called “reading day” so that I could be home in time. As much as it sucked, because I had only a weekend to study before the exams and I had to take them all at once, it was kind of refreshing to leave campus just as everyone around me was officially entering panic mode.

None of my friends from home were back from school yet either when I flew into New Hampshire, two days before my mother’s operation. The night before we were to drive up to Dartmouth, the two of us went to a local pizza chain, and I snapped a picture of her eating a small slice of pizza that I uploaded to Facebook with the caption, “The pancreas’s last supper.” We were scared, but optimistic. We were ready for my mother to get her life back.

The Longest 36 Hours

We arrived at Dartmouth around six in the morning. My mother's surgery would happen in two parts, and take most of the day. In the prep room, I signed the form certifying that I would be present to care for my mother when she was released from the hospital, and watched her sign the accompanying form explaining that she could die, and would not be revived under "extreme" conditions. Our signatures looked nearly identical, my handwriting over the years unconsciously looping and weaving just like hers.

The surgery functioned in two parts. First, the surgeon, Dr. Smith, a bouncy, bald, and excitable man, sliced a long incision into my mother's abdomen, pulling the skin apart to expose the peritoneum, a fluid sac that holds the organs of the abdomen. While I tapped my foot on the floor in the spacious waiting room, watching the sun come up over the New Hampshire mountains, Dr. Smith coaxed the pancreas from where it sat behind the liver, and began snipping and clamping off the nerves, blood vessels, muscle, and fascia attached to the organ. By the time my stomach rumbled around noontime, my appetite raring in spite of itself, Dr. Smith pulled the pancreas from its nesting space in my mother's torso, and placed it in sterilized paper, that was then put on ice, where it was transferred to the transplant doctor who had been flown up from Boston, for the second half of the operation.

When I finally stood up from where I had been crumpled in a chair for seven hours in search of something to eat, the transplant team had delicately scraped islet cells

from the pancreas, cells, that, if successful, would be put into my mother's liver, which would take them up as its own, and start producing insulin.

I went to an Au Bon Pain for lunch. No matter the size of the hospital, its cleanliness, whether it was tile or carpeted, or if there was free Wi-Fi, I could always count on the consistency of cheaply made breakfast food under a yellow sign.

As I sat at one of the tables crowded around the food court of the hospital, which was bustling with nurses, medical students, and families of the sick, Dr. Smith cut the delicate tissue around the liver, intestines, and stomach. Then, we all waited.

I finished the yogurt parfait, threw the container in the trash, returned to the OR waiting room, and watched the wind blow snow around the steep mountain slopes in the distance. The sun moved across the sky and cars pulled in and out of the parking lot five floors below me. Families shuffled in and out of the OR prep and recovery room. And I waited.

Dr. Smith, leaving my mother exposed on the operation table, gathered the islet cells from the transplant surgeon.

When Dr. Smith returned with the islet cells, the surgical team descended on my mother again, pulling back the cover from her open skin, injecting the islet cells into their new home in the dark red, healthy, liver.

When the sun set on the western hills, now shiny with ice from the dropping temperature, I sat alone in the waiting room, fingering the yellow napkin I kept with me from lunch, a magazine open on the chair beside me. Dr. Smith came into the room, covered in the sterile dress of the OR, wiping his brow with a handkerchief. The

receptionist at the desk, the third one I'd seen that day, watched from behind the glow of her computer screen as he sat down in front of me.

“It’s going well. It’s going really well,” he said, in his quipped, manic manner of speech. He rubbed his de-gloved hands together and leaned forward. “We are going to start reconstructing everything now. Putting it all back in place, sewing up tunnels, clearing passages. We’ll get creative. But my point is her pancreas is gone. It was in pretty bad shape but we got a lot, a lot of healthy islet cells, and her liver is squeaky clean, not being an alcoholic and all like most of my patients, so I think this is good. This is really good.”

I sat there and stared a stray bit of blood on the corner of his smock, wondering if it was hers.

“Okay, um, good. I’m glad to hear that.”

“So what I’m saying is, go home, get some sleep, come back in the morning. We have a few hours left here, but the dangerous stuff is over. She isn’t going to wake up for a long time, maybe tomorrow afternoon, and you won’t be able to see her tonight.”

I sat in the chair, fingering the napkin, now soft and fraying from my repeated twisting. “Oh, okay,” I said. Dr. Smith looked at his watch, and then jotted down a number on a pad.

“Here’s my cell number. How about this: since I don’t know when we’ll be done, let’s go by the rule ‘no news is good news.’ I’ll call you if something doesn’t go as planned, but if everything is fine, you won’t hear from me until tomorrow. Come into the ICU waiting room in the morning and you’ll be able to see her as soon as she’s ready.”

“No news is good news,” I repeated, and then again, in my head. I looked at the napkin.

Dr. Smith patted my shoulder, shaking his head and chuckling. “She’s a fighter, a real trooper.”

I nodded and watched him walk back through the OR doors. I sat in the chair for a while, in the dark waiting room, clutching the napkin. Finally, I stood up, waved to the receptionist, and drove to our family friend’s house, ten minutes down the road. Our friends were out of town, so they had given me the key. I slipped through the door, and lay down on the couch, the phone next to my ear.

On the morning after the surgery, I found the critical care waiting room filled with people. I was the only person who looked younger than fifty. I asked the receptionist at the front desk if I could see my mother. She told me only adults were allowed in the ICU. I showed her the paper that certified I was my mother’s guarenteer. I showed her my license. I watched her look from the living will to my license to my face, and back again. Twenty-one. I was old enough to decide if my mother should be kept on a breathing tube, old enough to hold my family together.

“It’s going to be a couple of hours,” she said, after hanging up the phone with the nurse’s station on the other side of the sealed door. “She is just starting to wake up and they need to replace her drain.”

It was 7:30AM. I hadn’t eaten since noon the day before. I found myself back at the Au Bon Pain without realizing it. I brought the parfait back to the waiting room.

There was a small television monitor in the right-hand side of the room. It was more crowded than when I left, now 8:15. People stood under the television, necks craned, holding cups of coffee and granola bars. I walked up to stand beside a tall man with gray sideburns and a rumpled polo, who clutched a pair of pajamas and a blanket in one arm, running his fingers over the soft material absently.

“Breaking news: there has been a shooting at an elementary school in Newtown, Connecticut. Multiple casualties. The shooter is dead. We will keep you updated as we learn more details.”

A chopper on screen circled over a brown and tan school, a red jungle gym, a blue slide. Crowds of children, in pink puffy coats, rolling wheeling backpacks, holding Spiderman lunchboxes, ran with teachers from the school. And we stood there, in the waiting room, clutching our food and watched as somewhere else in the country, unimaginable tragedy unfolded. I was there for three hours, glued to the screen, trying not to think about my mother and her swollen, torn, abused body, spooning a yogurt parfait in my mouth, watching the death toll rise and rise and rise.

Later, while my mother slept fitfully on her stretcher, I perched in the corner of her room because the nurses hadn't given me a chair (nobody sat in ICU rooms for hours on end), and watched the news over and over, saw all the replays, stared at the EMTs, the stretchers, the canvas body bags lining the school. To my left, my mother breathed in and out, her body swollen from being pumped with fluids. Her eyelids were purple, her fingers hidden beneath layers of IV tubes, tape, and medical tags.

In the corner of my mother's room, a window looked out across the parking lot to another part of the hospital. As night descended again, I could see people in their offices,

facing computers by the windows. I watched the nurse shifts change, the doctors dip in and out, a technician eat her dinner.

Around seven in the evening, my mother woke up enough to look at me and ask if it had gone well.

“Yes, Mom, you’re fine. Everything went okay.”

“So many tubes,” she said, looking around. Her eyes were bloodshot, making the light blue stand out even brighter in the shadowed room.

Around that time, the critical care doctor came by. Since my mother had her surgery, I learned that there were multiple doctors who were in charge of her care. Dr. Smith and his team were the ones who determined how the surgery proceeded, another doctor from gastroenterology and his group of five nurses managed my mother’s medications and long-term recovery. But the nurses in the critical care unit were charged with keeping my mother comfortable and stable in the precious couple of days after surgery, when things were most likely to go wrong. These nurses knew very little about my mother’s surgery, her condition, or her history. They knew enough to feed her properly, clean her bandages, and give her medicine. Their head, the critical care doctor, I would soon learn, did not take well to being told what to do by a team of surgeons from another unit. His unit typically saw elderly post-stroke or heart attack patients, people who were dying from cancer, who needed to be kept comfortable.

This doctor, whose name I never bothered to learn, came into my mother’s room with a nurse following behind, taking notes. He did not acknowledge me, instead pulled the sheet back from my mother’s arm to look at her tubes.

“Make sure these are getting swapped out, we don’t want any collapsed veins. Hey, Shirley,” he said after a beat. “How are you doing?” He prattled on without waiting for her to respond. “You’re looking good here, your surgeon keeps pushing us to give you more pain medication...well, we’ll just see about that.”

I stood up, and put a hand on my mother’s other arm. The doctor held a heart shaped pillow, one that I had seen throughout the hospital, some Red Cross gift they were giving to patients.

“Got you a pillow,” he said, and tossed it on my mother’s stomach.

“Ahh!” Her agony made me see red. I snatched the pillow, and leaned over her.

“Are you kidding me?” I said, nearly violent with anger. My fingers twitched on the pillow. “What the fuck are you doing?”

The nurse at his side leaned into his ear as he finally, *finally*, turned to look at me.

“Ms. Phillips’ daughter. She just had her abdomen sliced open, we need to keep things off of it.” The doctor continued to stare at me, ignoring the nurse. Another nurse rushed in, grabbing the pillow from me.

“Shirley, Shirley can you hear me? What is your pain level?”

My mom peered at the nurse, squinting from the pain. “A ten,” she moaned. The doctor left the room without another word.

Over the course of her nearly three week stay, I would drive from Nashua to Dartmouth, an hour and a half without traffic, every few days. Because my parents had co-guardianship of Ashley, I would take care of Ashley half of the week, and she lived with Dad the other half. When I wasn’t getting Ashley ready for school, I did my best to

keep busy in our empty apartment. I took long runs. I watched horrid documentaries like *There's Something Wrong with Aunt Diane* about a woman who drove her car the wrong way on the highway and killed her daughter and three nieces. I built a wall of catastrophes around myself during those days at home, to protect me from the catastrophe at Dartmouth.

When I got to drive up to Dartmouth for a few days a week, I would spend hours sitting in my mother's hospital room. She was moved after a week to a "step-down unit," which I think was code for, "well, you're not about to die like you were, but you still can't go prancing around the hallways with an IV pole in a pair of slippers." The nurses were less overworked, the unit was brighter. She had a bigger television. I read dozens of magazines about fashion and gifts and the "Ten Ways to Please Your Man," and texted my friends about my breakup. When they asked about my mother, I deferred.

"She's getting better. It's good," I would say. And for a while, it was.

“I Help”

The day before Mom was scheduled to go home, Ashley came back from a weekend with Dad. Our parents rotated holidays every year, and this year, we had Ashley for Christmas because Dad had her for Thanksgiving. On Christmas Eve, I drove up to the hospital with Ashley in the car, and in the hour and a half drive, we listened to a Taylor Swift album twice, shared a bag of M&Ms between us, and I coached Ashley on how Mom would look and act when we took her home.

“Remember, Ashley, Mom has a big owie on her stomach,” I said. I poked the scar from Ashley’s removed G-tube. “You remember your scar here?” I asked. Ashley nodded. “Well, Mom will have the same type of scar. Only bigger. So you need to not touch her stomach and be very careful around her.”

Ashley nodded again. “Mom come home?”

“Yes, Mom is coming home.”

“I help?”

Since Mom had surgery, I had been trying to figure out a way for Ashley to help out when Mom came home. I knew she would probably freak out, like she had when Mom broke her humerus years before, and that every time I tried to help with anything, or even touched Mom, Ashley panicked and thought I was going to hurt her. I hoped that if I gave Ashley jobs, like getting Mom a cup of water, or helping Mom fluff her pillows, that my sister would feel like she was a part of the process, and maybe she would then understand what I was doing.

“Yes Ashley. What are you going to do to help?”

“Um. Brush Mom hair?”

I nodded. “Yeah, Mom would like it if you brushed her hair. She might let you help her shampoo too. Like she does when you’re in the shower.”

“Okay!”

At the hospital, Ashley and I found Mom sitting up in her bed, fully dressed, her bag packed.

“Mom, I help!” Ashley announced as she walked through the door. Mom smiled, and looked at me.

“The nurse showed me how to use the feeding tube and there’s a bunch of stuff that we need to take to the car for the it,” she gestured to the stack of boxes next to her clothes

“Do you think you can explain it to me when we get back?” I asked. When Mom nodded, I looked at the port of her feeding tube, and it looked simple enough, with it’s two openings, one to put food in and one to keep everything sealed. I didn’t want to insult my mother by suggesting the nurse show me how to do everything, because I knew Mom already felt guilty enough about me spending my Christmas break looking after her. If we both pretended it was simple, it seemed like much less of a sacrifice.

The process for Mom’s at-home care looked like this: every three and a half hours, she could take a narcotic for pain. It lasted almost four hours, so I set timers around the clock to give her the medicine before the medicine began wearing off, since

that was what the nurses had been doing at the hospital for the past couple of weeks.

Every twelve hours, Mom got another long-term pain medication, so I had another alarm set for that one.

There was a feeding schedule: every four hours, we were to hook up one bag of feeding solution to an IV pool that had a spinning mechanism that fed the food through her feeding tube like the kind I had seen on dialysis machines for processing blood. The “food” was a yellow, thick liquid that had essential nutrients and was broken down to enter the intestines below my mom’s stomach, part of which had been removed during surgery because of extensive damage from her chronic pancreatitis. Before giving Mom any food by the feeding tube, the ports had to be “flushed” with sterile water, so I would fill up a syringe with ten milliliters and push it through the port. Then, I had to crush up a tablet of pancreatic enzymes, which replaced the ones Mom’s pancreas had supplied her body before it was removed. She would take these enzymes, harvested from pigs, for the rest of her life to give her digestive system the essentials to break down food, but they could normally be taken by mouth. But until the feeding tube was removed, in a couple of weeks to a month, they had to be crushed and mixed into sterile water and fed through the feeding tube. It took approximately an hour to go through one bag of food, and once the bag was empty, the machine on the IV pole would beep loudly until it was turned off. I ended up setting an alarm for fifty minutes after I started each feeding, in order to stop the machine the second it finished, so if Mom was asleep, she wouldn’t be disturbed.

I charted all of this out before we left the hospital, so that I wouldn’t have to fuss with it once we got home, as well as take care of Ashley. The schedule had me getting up and doing something approximately every two to three hours, but since I had no other

commitments, I figured I could just catch up on sleep between each alarm. Of course, by the time we got home, all of that didn't really matter. My perfectly crafted plan still went to shit.

A Failure

My mother, my sister and I arrived home from the hospital around 10:30 at night on Christmas Eve. In the car, Mom had thrown up twice, but otherwise spent the drive asleep thanks to her pain medication. Her attending nurse had helped me time the dosages so that they were in full effect while we made the two-hour drive from Dartmouth Hitchcock Medical Center in Hanover, New Hampshire to our apartment in Nashua, New Hampshire. When I pulled out onto the highway, I could feel the weight of the situation settling in my bones. In the front seat, Ashley was flipping through her stack of CDs, deciding between Taylor Swift and Alicia Keys. In the back seat, Mom leaned against the window, allowing the cool glass to help with her nausea. In the trunk, there was a bag with an IV pole, thirty or forty bags of processed food for a feeding tube, a gallon sized plastic bag full of narcotics, another gallon sized bag with sterile gauze, Steri-strips, Neosporin, and medical tape, and my mom's overnight bag, filled with clothes from her two-week stay at the hospital.

This was a test.

Since I was old enough to remember things, I have had a stupid level of confidence in my ability to do what it takes to get things done. It's the kind of confidence I hadn't had shaken yet: if I set my mind to something, I could achieve it, no matter how high the stakes. I believed I could take care of Ashley, and of Mom, and that in less than twelve hours, we would sit around the Christmas tree together and open presents and

watch bad Christmas movies. I believed this because I wanted to believe it. I wanted to believe that being an adult was as simple as saying you could handle something, and then doing it.

It took me three trips in the icy weather to get everything inside. On the first trip, I held my mother's arm on one side, and my sister Ashley's on the other, as they both slid unsteadily across the badly salted sidewalk. On the second trip, I grabbed Mom's duffel of clothes. I also hauled up a two-gallon plastic bag of medications, and Ashley's backpack with her Poise adult women's underwear and a change of pants, a Sippy cup, and hearing aid batteries. On the third trip, all hell broke loose.

As I wrestled open the door that led inside the apartment building, I could hear Ashley screaming from our apartment fifteen feet down the hall. I managed to drag the IV pole, ten bags of liquid food, a carton of sanitary water for flushing out a drain, and my purse down the hallway before any of my neighbors poked their heads outside their doors. I shoved the front door open with my shoulder and saw Ashley barreling toward me with her coat half off. Mom was bent over at the kitchen table, blood and yellow bile streaming out of a tube protruding from her swollen and stitched stomach.

"I can't figure it out, I can't get it," Mom cried, as she tried to close the valve on feeding tube. The tube jostled against the tender flesh of her abdomen, which had a large, almost foot long incision stretching from sternum to groin, sewn up with dissolvable stitches and covered with layers of thick gauze. I could see where her bile had wet the gauze, making it translucent, irritating the bloody incision beneath. I dropped my wares in the doorway, turned to Ashley, and spoke in the most level voice I could muster, with a fake, strained smile on my face.

“Ashley, why don’t you go in the bathroom while I help Mom?” My sister was panicking. At nineteen, she was four-feet ten inches tall but a solid one hundred twenty pounds. Her glasses were askew, and she stood in the wide wrestler’s stance she had adopted in order to keep her balance on unsteady legs.

Ashley launched at me.

Ashley may have been much shorter than me, without the physical coordination or the mental aptitude for fighting strategically, but she fought with instinct and pure adrenaline.

As Ashley swung her fists at me, provoked by our mother’s panic, I reached my longer arms around her shoulders and attempted to bear hug her from behind. It worked for the most part, except she got her fingers free and ripped a chunk of my loose hair from my head, and flailed the hairy fist at my face, striking me across the cheekbone and nose. I could hear Mom crying louder, begging her to stop.

“Ashley, Ashley, Ashley,” I said, getting a firm grip on her hands, using my height to bend her forward at the waist into a straight jacket position. “Ashley, you need to calm down.”

I was quiet, but forceful.

“No! No! I go bathroom!”

Ashley tactic number one: when Ashley feels out of control, she usually claims she needs to go to the bathroom, because it gives her an excuse to distract people from the chaos around them. I think she assumes that if she cries for help, she can protect the person she is worried about. In this case: my mother.

Sensing a break, I said, “Okay, go to the bathroom,” and started walking, with her hands still in my arms, toward the bathroom.

“No! No!” Ashley started flailing again. I bent my knees and picked her up from behind, my hands around her waist, and waddled us the last few steps to the bathroom before depositing her inside the door. When she turned to swing at me again, I pulled the door shut and held the handle tight.

“Let me go! Let me go!” She threw her weight against the door.

“Ashley, I need to go help Mom!” I was yelling now too, and could feel the flimsy door bend under our yanking.

“No! Let me go!” Ashley shrieked like someone in a medical soap opera who just found out their loved one was killed. Whether she ran out of steam or gave up, Ashley let go of the door, and I could hear the sound of her ripping clothes over her head. Ashley tactic number two: get naked and demand a shower. At least she was busy.

I jogged back out into the dining room, where, in the twenty seconds that had passed, Mom still hadn’t figured out the temporary feeding tube that had been installed after her surgery. It was designed to help her digestive system recover from the removal of her pancreas by bypassing her stomach and dumping nutrients directly into her intestines. We had been sent home with a bunch of supplies and instructions, but neither of us had ever seen this type of feeding tube before. Ashley had a feeding tube for a couple of weeks when she was eleven, but it had been far simpler and more stable. This one looked like a hack job from an “Operation” game: there was a bunch of tape and bandages around a hole with a thick tube protruding several inches out. At the end, there were two twisting ports designed to keep fluids flowing in the correct direction.

“What’s wrong, what’s going on,” I said, pulling Mom’s bloody hands away from the tube. I gagged at the smell of bile and blood around us, and gripped the slippery tube.

“I can’t get it, I can’t get it,” she panicked, raising her voice to be heard over Ashley’s screams, which had started up again in full force. I held the tube up, trying to use gravity to keep liquid from spilling out of it.

“Okay, hang on, where are the instructions?” With one hand I dug around the box holding the IV pole, before giving up and looking at the tube again. Both of the two ports needed to be closed in order for the tube to seal. Each port twisted in the opposite direction: the one closest to the stomach moved counterclockwise, and the secondary, backup port moved clockwise. I sat there for a couple of seconds, twisting one port and then the other until finally the tube sealed shut and fluid stopped spilling out. At the same moment when I reached over to grab paper towels off the counter, Ashley came out of the bathroom, naked, still screaming, and started hitting me over the head with her fist, as Mom tried to block her hands.

I started crying then, too. Between my mother’s weeping and my sister’s shouting and the smell of bile and blood on that cold Christmas Eve, I felt utterly helpless. Like Ashley, I was stuck in a situation I had no idea how to fix.

I think I always knew that having a special needs sibling meant that eventually I would be the one who would take care of Ashley. And I had even pictured it: I would have a house with an attached apartment for Ashley and my mom, who, since I was a teenager, had been telling me how excited she was to be a doting grandmother. I would have a steady job and roots down, a family of my own. I would be ready for the responsibility.

In that moment, on the dining room floor, I realized something: Ashley and I wanted the same thing. We both wanted our mother to be well, and the loss of her health had deeply imbalanced us. But I had no idea how I could communicate that to Ashley. It was like we were speaking two different languages through a soundproof window, incapable of reckoning. Unlike so many times before in our lives, where my sister was dependent and I was capable, we were both simultaneously helpless, just trying to understand one another.

12 Alarms

I ended up calling Dad from the living room with Ashley screaming in the bathroom and Mom crying at the dining room table after Ashley panicked. In the time it took me to walk from our apartment to the car, load up with the last of our supplies, and walk back, Mom had tried to open her port to hook up her feeding machine, managed to fully open the tube so that nothing was keeping her insides in the tube, and freaked out enough that Ashley noticed, and panicked as well. Perhaps if I had been there when Mom decided to hook up her feeding tube, I could have prevented the mishap and also distracted my sister by telling her to get ready for bed or even to get Mom a glass of water, like we had talked about in the car on the way up to the hospital. That hadn't happened, and my absence during the crisis had turned me into an enemy intruder. The second I came through the door, Ashley was on alert. She didn't know how to help Mom, and probably didn't anticipate this level of freak-out from our normally calm mother. And here I was, telling her to calm down while also visibly panicking. It was enough to set my sister off. She wanted to help Mom, just like I did, but we were fundamentally incapable of understanding each other when it mattered most.

Dad was in Utah with Kathy to visit her family for Christmas. In tears, I told him that Ashley was freaking out because of Mom's surgery and she couldn't handle all of the equipment and Mom's obvious pain. It was so obvious in retrospect that this would be harder for Ashley to cope with than any other time Mom was sick or injured, but both Mom and I had been so determined to have Ashley for Christmas, to not give Dad the

satisfaction of thinking we couldn't handle it. Dad called Uncle Erik, who was in Boston visiting my cousin, who had moved there to go to graduate school. Uncle Erik and my aunt, whom I wasn't especially close with but whom Ashley adored, agreed to take Ashley for the next few days, until Dad got back from Utah. It seemed out of the question that Ashley would be able to stand being around Mom when she was on the feeding tube until Mom was feeling a bit better, and we figured the contraption out.

Uncle Erik and Aunt Carol had taken care of Ashley before, so they knew the basics, and, still in tears, I packed up Ashley's overnight bag with a bunch of clothes, her medicines, and training pants, and a few presents from under the tree. She was still crying in the bathroom, and Sherry ended up coming over to help me calm her down and get her dressed. It felt like betrayal when I said goodbye to my sister. She had tears running down her cheeks, and she kept saying, "I'm sorry, Christina. It's okay, Christina. Momma okay? I'm okay," as if to convince me, and herself, that we could handle it. But we couldn't. I couldn't handle it. I sent a long list of Ashley's medicine schedule, nightly rituals, diet restrictions, and favorite foods with her, and left a long email in Uncle Erik's inbox thanking him and explaining how Ashley liked to spend her days, and how she needed to know her schedule up to a week in advance. I reminded him that she liked pancakes with syrup and whipped cream on Christmas morning, and that she liked to do her own dishes. And then I sat in the living room, watching Mom's feeding tube machine spin yellow liquid into her stomach, and cried.

We're All Adults Here

Though Ashley did not go to college, because she was in her special education high school program until she was twenty-one, we both entered the work force at around the same time. After surgery, Mom was able to return to work and continue caring for Ashley for her fifty percent of the time, but things were never the same. The prolonged use of narcotics and her long-term pancreatitis had left her with a lot of conditions that removing her pancreas couldn't fix: there was nerve damage in her stomach, impaired digestion from the beating her digestive tract took for years, and scar tissue, which is common after a major surgery, and is the kind of problem that never really goes away. When the body is cut open, it heals by building stronger tissue to protect itself. Only this stronger tissue is also less flexible, and more likely to cause pain.

I don't know if I was just overly hopeful about Mom's recovery, or if I just didn't fully understand that she would never be the same person again. Even though she could eat, didn't end up in the hospital with infections, and was able to more or less get her life back, she looked like she had aged ten years in less than four. She was weaker, more prone to getting sick, and still had bouts of nerve pain that sent her to the ER in the middle of the night.

All of this came to a head when Ashley started her work program after graduation. I was in the second of three years of graduate school, where I was employed by the university to teach freshman English classes in exchange for a small stipend and waived tuition. For me, the burden of finding a "real job" and paying off my loans, as

well as figuring out a way to have my own independence while also being available for Mom was crushing at times. I hated the independence. I felt overwhelmed by bills and taxes and health insurance, and wished I could crawl back into my bed at home and leave all of my unopened mail for Mom to deal with.

Meanwhile, Ashley was relishing in her newfound independence. She managed to get a spot at a local work program for adults with intellectual disabilities. Most states have seriously underfunded resources for adults who are still considered dependents, and for a while, we worried that Ashley would be stuck at home after high school, because we couldn't find a place that was both able to care for her during the day but also give her the kind of responsibilities, social interactions, and intellectual challenges she craved. The program she joined, which was based out of the local community college, had around twenty adults with intellectual disabilities at one time, ages twenty-one to twenty-five. They each had a one-on-one aid, and a schedule that included volunteering at the nursing home, handing out food at the soup kitchen, and helping care for animals at the shelter.

The first time I visited home after Ashley started her program, to drive Mom to an operation to help “clean out” some of the scar tissue that was developing in her abdomen, my sister showed me a giant calendar she had pasted on the fridge. Every day, she had several activities, from work to bowling to swimming. She woke me up at five-thirty, just like in high school, to announce she needed to “get ready for work.” She showed me her lunch, which she packed every morning by herself, and dragged me around the community college to introduce me to her peers and teachers. She pulled out her wallet, which had an ID and a debit card for the account my mother monitored that held her social security payments and bi-monthly paychecks from the various jobs she worked,

and then showed me the forty dollars she had tucked in the back, which she used “to buy groceries.”

“Oh, you’re shopping now?” I asked, thinking about my currently empty wallet, and also about my food pantry at my apartment at school, which was full of peanut butter, oatmeal, and discounted holiday chocolate.

“I buy my groceries,” she said. Mom, who was lying on the couch, added, “They go grocery shopping on Tuesdays, and I send a list so she can buy the food she wants to eat.”

I tried to remember a time when I got excited about grocery shopping for myself, and couldn’t. “Um, that’s cool?”

A few weeks later, I was back at school, working at the university press between taking classes and teaching my two sections of freshman English when I got a call from Mom. Like before, whenever I got a call in the middle of the day without prompting, I assumed it was serious. I ducked into the stairwell outside of our quiet office.

“Hi, what’s up?”

“I’m at the ER. And...and,” she trailed off, and I could hear her crying and saying something to whomever had just come into the room.

“Christina, they won’t believe me. I told them I don’t have a pancreas, and they keep saying I’m just drug-seeking. They won’t call Dartmouth and confirm with them. I don’t know what to do.”

Because Mom’s pancreatectomy was such a new procedure, it didn’t surprise me that the local hospital had never heard of it. Nonetheless, they could have found out by

looking at the giant scar on her abdomen and opening her chart. Instead, they were dismissing her pain, which could range anywhere from scar tissue to an infection, as just my mother trying to get narcotics.

“Okay, is anyone there with you?” Mom worked outside of Boston, so most of the people she knew from work lived at least an hour away. Her local friends also worked full time, and few of them could come in the middle of the day or night to bring her to the hospital.

“No. I don’t know what to do. They are sending me home.”

“Okay, hang on.” I tried not to sound panicked. “I’ll call Dr. Gardner, and get back to you.” Dr. Gardner, my mother’s internist at Dartmouth, had given me his nurse’s number so I could reach her if something like this happened. When I called her, the nurse told me Dr. Gardner was out for the week, and that the local hospital would need to call the nurse herself to talk about how to treat my mother. I got back on the phone with Mom. I was still hiding out in the stairwell at work and hoping nobody had noticed my absence.

“Mom, the nurse says they need to call up to Dartmouth. Can they do that?”

“They won’t listen to me. They just keep telling me I’m lying.” She was crying again. I put my phone on speaker and started looking up flights that left South Carolina that afternoon, mentally going through a list of people who might be able to cover my classes for the next couple of days. Last time this had happened, Mom had gone home in a taxi and hid out in bed, throwing up and running a fever until she could get a friend to drive her to another hospital for treatment. Eventually, that hospital had her driven to Dartmouth in an ambulance, and she had been in for a week with an obstruction in her

intestines and serious dehydration. I knew if things didn't get fixed soon, the same thing might happen again, or worse.

"Mom, I'm going to try to come home. It's Wednesday. I can be home tonight, and then take you up to Dartmouth first thing. Okay?"

"No, don't do that. I'll figure it out."

I pulled up flights from an airline that I had collected miles on with my credit card. Almost everything was way out of my price range, even with the mileage I had accumulated.

"No, I might have to drive, but I can be there in fifteen hours. I'll take care of you."

"No, no. Can you call Dr. Gardner again?" I sighed.

"Mom, he's not in. Let me call the nurse again, I'll see what I can do."

For the next half hour, I sat in the stairwell at work, and called the nurse at Dartmouth, the emergency room at the local hospital, and finally, the patient services hotline at the hospital.

"Hi, yeah, so my mother is in the ER. And she is being dismissed by her doctor. I need someone to get on the phone with me right now, or I will call my lawyer and the local newspaper and have them down at your hospital in an hour to handle this gross negligence."

I was bluffing, remembering the way Mom had threatened the hospital in Arizona when I had appendicitis. If there was one thing I had learned, it was that bad press would get things moving.

“I’m sorry, can you repeat your problem?” The poor woman at the help desk was typing furiously in her computer, and I could hear it from the other line. Shaking and trying not to cry, I bullied the receptionist into putting me on the phone with the attending physician at the emergency room.

“Hi yes. Have you looked at the medical file? Because I think if you open it, and spend some time reading the history of my mother’s condition, you’ll be embarrassed by your negligence. And that would not look good for you.” At this point, while the doctor huffed on the other line and opened the file, muttering about patient confidentiality and proper treatment, I had taken to kicking the cracked tile in the stairwell with my high heel. While I still had the doctor on the line, I said, “I am going to give you the number for my mother’s specialist at Dartmouth. Since you clearly don’t seem inclined to deal with this issue, nor is your facility capable of understanding my mother’s procedure, I would consider having her transferred to Dartmouth to have this sorted out.” Before he could answer, I gave him the number of Dr. Gardner’s nurse and hung up. I called Mom back.

“Hi, so I think they’re getting in touch with Dartmouth,” I said. I paused when I heard voices in the background.

“Oh okay they just called Dartmouth. They’re going to give me fluids and narcotics and drive me up there tonight when a bed opens up,” she said, sounding relieved. By then, I was pacing up and down the stairs, my shoes off and propped against the closed door that led to my office. I called up to Dartmouth, again, to talk to the nurse, and confirm the transfer. I snuck back into my cubicle. My boss hadn’t noticed that I had been gone for forty-five minutes. When I left an hour later, to a text message from Mom

saying, “getting ready to drive me up now,” I crawled back into my bed and passed out for two hours, almost missing my afternoon class. By that evening, she was in Hanover, where a CT scan had showed a severe blockage in her digestive tract, just like before.

That evening, I called Ashley, who was at Dad’s house because it was his week, and she asked, “Mom, okay?” Nobody had said anything to her, but she must have noticed Mom was in pain when she left a couple of days earlier.

“Yeah, she doesn’t feel good. But she’ll be okay.”

“Christina come home?” Ashley was pressing the phone against her mouth, so I could hear her breathing.

“No, I don’t think so. I’ll be home in a few weeks for Christmas,” I said.

“Okay. Mom okay. Mom stomach all better.” Ashley seemed to be saying it both to placate me and to convince herself. And at that moment, I felt like I understood Ashley more than I had in the last few years. I had spent almost all of my energy that afternoon trying to get people to understand, and trying to read a situation from a thousand miles away, and it was exhausting. It reminded me of the way Ashley must have felt when she saw our mother on the floor of our apartment, crying and trying to fix her feeding tube. Ashley had wanted to help, had wanted to fix things, but like me, she had just done the best she can. For her, it was throwing a fit in the bathroom and attempting to keep me from “hurting” our mother. For me, it was calling doctors and making their lives difficult until they finally gave in. It took our mother being sick for me to understand the powerlessness my sister must have felt on a regular basis. It was exhausting.

A Little Hill

I knew, since I was old enough to understand that Ashley would never be fully independent, that I would someday be my sister's caretaker. I had this idea of what that would look like: I would be in my mid to late thirties or forties, probably, and married, with kids and a house. I would build an attached apartment for Ashley, with its own bathroom and bedroom and living space. That way, my sister could have friends over and decorate how she wanted to. I also imagined that my mother would live there too, that they would have their own space in my house, and we would have family dinners together and Ashley and Mom would play with my kids. I can still see the house in my head: one of those places with a large front yard and a big front porch with a porch swing, with a separate front door for Ashley's apartment. I figured by the time I needed to care for Ashley, I would have a flexible, steady job, a comfortable salary, and the kind of stability I thought all adults could get if they planned things right.

I might not be alone in my allusions of preparedness for the future. At some point, most families reach that moment where child becomes caretaker, and it doesn't always happen the way life insurance commercials make it seem, in well-lit, impeccably decorated homes over coffee at the dining room table. Most families do not have to also tackle the issue of adult siblings with disabilities, and so maybe it's okay that I feel so wholly unprepared. The difference between Ashley and my mother is this: my mother understands that she needs help, and that when she is sick, she has to put her trust in me. My sister understands that she relies on people, too, but for her, there is the constant

reminder that I am her age, that I am just as young and clueless as she is. And while she might not understand that without her disabilities, she would probably be going through the same sort of twenty-something crises that I am facing, she does recognize that we are afforded different opportunities. That I sacrifice to take care of her, and that her reality will never have the same freedoms that mine has.

Ashley has to watch me go out with friends and move around the country and live with a boyfriend and own a car. She has to let me clean her up in the bathroom and cook her dinner. I have to watch Ashley wake up every morning and only worry about herself. She gets to volunteer at the humane society and bowl on Wednesdays, and then spend the money that Mom gives her from her earnings on cheese and bread and orange juice at the store.

Sometimes, when I am driving to the bank to pay a bill I forgot last minute, while also berating myself for forgetting to stick a letter in the mail and put the wet clothes in the dryer, I wish I could just hand over everything to someone else. I am selfishly jealous of Ashley, because her life maintains the sort of simplicity that I will never have. But then I remember what it must have felt like to see our mother in pain, and not be able to understand it or know how to help. I imagine how it must feel for my sister to want to take a shower by herself, but not be able to get in and out of the tub without someone holding her arm. I think about what my future might look like, not a decade from now, but maybe just a few years from now. I've experienced what its like to have to care for an ill parent, and also for my special needs sister, and the understanding that it might become my permanent life someday soon scares the shit out of me. What scares me even worse is what my life will look like if it's just me and Ashley, facing the world alone.

I was having one of these moments of internal crisis when I was in my third year of graduate school. I was home for the summer, working part time at a public radio show, and Mom had to go to New Jersey for work. She left Ashley with me for the five days she was gone, rather than send my sister to Dad's. It was a Saturday when Ashley woke me up at six in the morning because she had an accident in her sleep, and needed to shower and change. This happens at least three times a week, so it wasn't a big deal for either of us. We shuffled into the bathroom, I gave Ashley a shower, and, as I stood there turning her shirt right side out then back inside out again before realizing I was falling asleep on my feet, Ashley reached her arms around me from her position on the toilet, and hugged me to her.

"I love you, Christina," she said, patting my back. "Run, run, run?"

After we went back to sleep for a couple of hours, we drove to a local running trail. Mom bought a jogger stroller, which is specifically designed to hold an adult and be easy to run with, about a year before, when she took up running during one of her stretches of good health. I unloaded the stroller in the parking lot of the trail, buckled Ashley in with her Sippy cup and a granola bar, and began pushing. I hadn't taken Ashley out in the stroller by myself before. Usually, Mom and I would go together, and I would coach Mom through a couple of slow miles while Ashley cheered her on. As we started down the path, Ashley leaned her head around the side of the stroller to look back at me.

"Woo-hoo!" she said, pumping her fist. "Faster, faster!" Despite the fact that I was in good shape, I was not prepared for the amount of energy it took to push my one hundred and twenty-five pound sister. We reached a hill, so miniscule I wouldn't have

noticed it otherwise, and I felt like I was pushing a giant bolder up the side of a mountain. I slowed to a pathetic walk-jog, my arms straining, sweat running down my face. Ashley noticed, and from her seat, I could hear her cheering me on.

“Come on, Christina. Go, go, go! You got it!”

Together, we crested the top of the hill, Ashley in front, waving her Sippy cup and chanting us onward, and me behind, sweating and huffing and propelling us with the muscles in my legs.