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Her Name Was Hayley

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Her Name Was Hayley

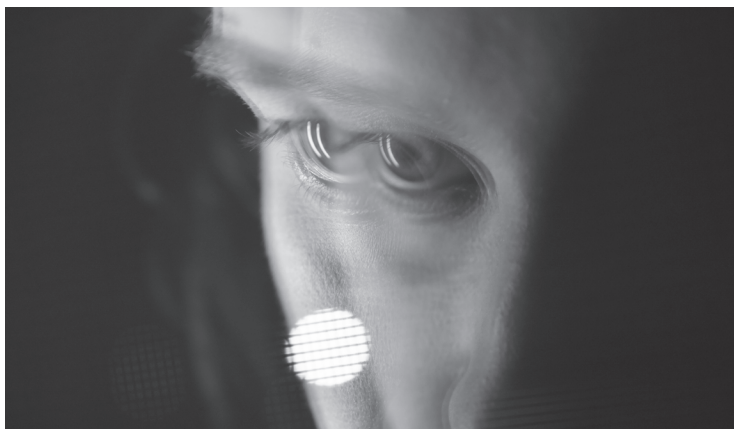
Grace Richardson

She came two weeks earlier than we had expected. The day she was brought home my dad was still struggling to assemble her crib. Screws and various tools were scattered precariously across the tarps on the floor, and painter's tape still covered the walls of her freshly painted pink room. He was worried about the paint fumes—which had dissipated last week—and that she wouldn't like the color he had chosen. He worried about her crib collapsing, her stuffed animals scaring her, and a slew of other unlikely events. Her size intimidated him, like the way an elephant fears a mouse. I was adopted when I was nearly two, so he had never actually had to take care of a newborn. His worry aged him.

My mom, on the other hand, was inexplicably calm, entranced by the little bundle she was holding in her arms. She walked slowly

around our apartment with Hayley wrapped in a series of blankets telling her, "This is your kitchen.... This is your living room.... This is your room," acclimating her to her new space. Hayley was familiarized with every inch of the white walls that encased the apartment. I swore by the end of my mom's exhaustive tour, she even knew which way the grain ran in our hardwood floors and how many paint chips hid within our lofty ceiling. "This is your home" she told Hayley, "this is your home."

For the first month, everything was perfect. The second month came and went, and Hayley began to fuss more than expected, eliciting some worry. *Were we not doing enough? Were we doing something wrong?* By the third month there was a constant, bone-chilling wail erupting from her at a volume that was seemingly impossible for a person no bigger



Layout by Ryley Bonferraro. Photographs by Jes Sheldon.

than a squash. I can't say we didn't expect this; babies cry, it's what they do. They cry to be picked up or fed, but not Hayley. Picking her up would only make her scream louder and putting a bottle to her lips was an attempt in vain. Her whole body was like a bruise you couldn't see; it was tender and sore to the touch. With her skin like pins and needles, picking her up only hurt her more than it soothed her. This was the hardest on my dad—watching her cry and not being able to comfort her. He was supposed to be her protector, but unable to help her, he felt useless. She wouldn't eat, her appetite diminished by her pain. She was rapidly losing weight, and her breathing became labored. My mom thought that she had the flu; her body aches and congestion perfectly masking her illness. But days passed, and then a week, and none of the medication was working. She took Hayley to her pediatrician, and within the span of a fifteen-minute check up, we were told to take her to the hospital immediately for testing. We knew at that moment that she had something much worse than the flu.

"Something is wrong, Mark. Something is wrong with her."

"Nothing is wrong, honey. She's fine. She's a baby. She has a cold," my dad replied. He was trying to reassure my mom, who was now feverish with worry. "She has a cold," he said again, this time to reassure himself.

• • •

"She has cancer."

I was twelve years old when I heard those words coming out of the doctor's mouth, and I could feel my very being begin to splinter. My mouth went dry, and my words choked in the back of my throat. My stomach turned, but the rest of my body, unable to process, showed no response. I did not cry, I did not scream, I was not angry at the world or the powers that may or may not be. I couldn't be. The pain and outrage came later, I assure you, but it was unable to rear its ugly head until I had accepted that this was indeed a reality. No, it was not sorrow nor anger that I felt, but disbelief. At four months old, my little sister had been diagnosed with leukemia.

She had gone in for what we thought was the flu and left with a cancer diagnosis. Nobody expected this and now, nobody could speak, their words stolen from them just like the many years that would be stolen from her. I finally broke the silence, but my feeble question was no match for the crushing weight that the sickening quiet carried with it.

“How...how long until...” I choked out before shutting my mouth, fearing I would be sick.

“Less than a year,” the doctor replied.

My splintered being shattered. The doctor began to apologize and console us, but I wasn’t listening—I was staring at her. She was smiling and cooing and kicking her legs in the air, completely unaware of the pulverizing truth of her diagnosis. Less than a year. The words spiraled within my head, but my brain couldn’t wrap itself around them. Less than a year. This had to be a lie. A lie even bigger than the sugary phone calls we would begin to receive the next day from relatives we didn’t even know we had telling us, “It’s going to be okay.” No, this was worse. Less than a year gave us hope that we would at least have six months to say goodbye, when in truth, we were only given two.

At the time she was diagnosed, she was only four months old. She was too small to undergo the aggressive chemotherapy she needed, as the treatment itself would bring the same grave results. Surgery was our only hope, but it was quickly taken off the table as her cancer progressed past an operable part of her body. They told us that the only thing they could do for the time being was ease her pain and make her more comfortable.

“How did this happen?” my mom sobbed into my dad’s shoulder.

I saw her ask, but I wasn’t listening. It was like those moments in the movies where the sound of everything surrounding you disappears and all you can hear is your breathing and the pounding of your own heart. It was deafening. I tried to escape into my own thoughts but they were just as uncomfortable, if not more so. I wondered how you could make someone, who couldn’t speak and hadn’t lived long enough to even figure out what they liked and disliked, comfortable.

“Did we do this?” my dad asked the oncologist.

I looked at him as he awaited a reply. He looked like he didn’t want to know the answer. Why did he ask? Out of guilt? Did he think the answer would exonerate, or imprison him? The answer, of course, was no, but no matter how many times we heard it, or what tone of voice the doctors said it in, it was never reassuring. For the next two months she had tubes that were longer than she was constantly connected to her body. They helped her breathe, helped her eat, and eased her pain, but they also acted as constraints—or at least I’d like to think that they did. That sounds cruel, but the treatments made her ill, and her cancer made her weak. So I really wasn’t sure at that point if she could even move at all. It’s crazy now to think that the thought of her being restrained was reassuring to me, but it was far more comforting than accepting that she didn’t even have the life left in her to try.

Following her diagnosis, we took visits twice weekly to the Memorial Sloan Kettering Cancer Center. Although they couldn’t treat her, they helped to ease some of the symptoms of her cancer. The hospital itself was dreary, draped in lifeless colors such

“The day she was diagnosed was the day I grew up.”

as off-whites, faded blues, and washed-out greens. It smelled of old people and hand sanitizer, and my skin crawled every time I heard a noise I couldn't discern.

“I don't like the chairs here,” I randomly burst out while walking down the hallway towards the children's wing where Hayley was being treated.

“The chairs?” my mom said, looking confused.

“Yeah, the chairs. They're uncomfortable and plastic-y. We have to sit in them for hours; they should have better chairs. My legs get sweaty sitting in them for too long, and then it makes an awful squeaking sound. I just don't like them. They should have better chairs.”

My mother didn't respond, knowing that my outburst about the comfort level of the hospital chairs was only an analogy for my discomfort with cancer. The children's wing where Hayley spent her time was far different from the rest of the center. It was saturated with deep blues, vibrant yellows, and bright reds, as if color was the key to distracting those who entered from the harrowing reality that existed within. Its purpose was to create feelings of happiness and hope, and although it seemed trivial, it helped. Color wasn't their only tactic—there was also a play area to keep the kids distracted from their diagnoses. It was overdone and lavish,

but constantly being sanitized and wiped down. Germs are a nuisance to us, but to the children with weakened immune systems, they become deadly. Because of this, every corner of every room was dustless, floors spotless, and windows stainless, but not without consequence. The rooms smelled of chemicals and bleach. If you closed your eyes you might even think you were standing near a freshly chlorinated swimming pool rather than a hospital room. Even the bed linens that encased and comforted the ill carried the faint scent of disinfectant. The militant level of cleanliness took away from the childhood innocence that all those bright colors and toys were supposed to exude, but then again, what's innocent about cancer?

She died at six months old, but it felt like she had died the second we stepped back into our apartment following her diagnosis. The phone rang every hour on the hour, but after a day my parents stopped picking up. It was easier to ignore the cancer if they could ignore the phone calls, adopting it like a vow of silence. The news spread and everyone began to hold their breath when they were near us, treading lightly as if the quietude would keep her illness away. Flowers arrived to our house by the dozens, neighbors brought food, and coworkers and friends sent letters giving us their condolences, but these were just duct tape gestures. It was as

“It seemed that everyone, including myself, had forgotten that I was just a kid.”

if the whole world was mourning her before she was even gone, and no amount of pre-made food or delicately worded notes could have made it better. This hurt my mom the most. She would throw the flowers in the trash as they arrived and smash the casserole dishes on the floor. I didn't blame her. To this day, I cannot stand the smell of lasagna and orchids without feeling sick to my stomach. I knew that eventually I would have to watch her tiny and unknowing body bow into the throws of her terminal illness.

But what nothing could prepare me for was that cancer had a smell. A smell that the world does not know to hide from me because it is not inherently bad in and of itself. Cancer smells like tasteful arrangements of white lilies and orchids. Like pot roasts and casseroles. Like warm milk and the lavender lotion my mother rubbed on her back to make her fall asleep. But worst of all, cancer smells like her. Cancer smells like her and I hate it, and I hate that I hate the smell of her but I do. I hated that she would not grow up, that she would not fall in love, and that she wouldn't even get to experience real food. Even convicts on death row receive a last meal of their choice, and it infuriated me that she had become a prisoner to nothing but powdered formula and water.

The day she was diagnosed was the day I grew up. I was only twelve, but I felt forty.

The toys in my room began to seem childish and useless, and the light pink walls, too sanguine.

After that day, more often than not, I was the adult in my home. I had to remind my mom to shower and my dad to eat. I even used my weekly allowance of ten dollars to do the laundry. It seems petty, but for this, I resented her. Hayley had come into my home and broken my parents, my life turned upside-down. I no longer came home to dinner on the table, or a fridge full of food. My clothes were no longer magically washed and returned to my drawers before the start of school on Monday morning. No, instead my windows had gotten dusty and there were crumbs on my unswept floor. There was medicine and baby toys scattered on every surface, and scattered minds in every head to match. I look back on my resentment with regret. I loved her, I still love her, but it's hard to remember that my forty-year-old sense of responsibility did not align with my twelve-year-old maturity. It seemed that everyone, including myself, had forgotten that I was just a kid.

There were things that at twelve years old I couldn't understand about Hayley's illness or why my parents reacted to her diagnosis the way they did. There are things I still don't understand. I never understood why, after that day, they continued to buy her

baby toys and accessories. They would come home every other day with a new blanket or trinket in hand for her to play with. I remember getting so angry one day when my dad walked in with an infant car seat.

“Why do you keep buying her stuff? It’s not like she appreciates it!” I yelled at him, tears streaming down my face. “She won’t even be alive long enough to use that stupid thing—where is she going to go, huh? Are we going to take her on a nice road trip? Are we going to bring all her machines and tubes with us? Where are they going to go, they don’t even fit in the car! You’re so stupid, you’re so fucking stupid.”

That was the first time I ever cursed at my dad. He didn’t even yell at me. He just looked down at the car seat in his hand and said, “Because I have hope.”

...

Some days I wished that I had distanced myself from her from the start, that I had never gotten so attached to the role of “big sister” and that I had not promised her that everything was going to be okay the day she came home. I felt guilty for resenting her presence initially, knowing that I would have blindly embraced her if I had known I would have such little time with her. But in the end, I was glad. Glad to have known her, to have been lucky enough to be her big sister, to share my home and my parents with her, and glad because I knew that she had taken on the inevitable surrounded by those who loved her.

It’s been six years now, since she passed, and the anniversary of her death still stings

like a fresh wound. But, slowly, the wound is beginning to heal. It will scar—I never had any expectation that it was going to mend perfectly—but the skin is growing back thicker in its place. After a year I could say her name without crying; after three, I came to terms with talking about her in the past tense, and now I have even reached the point in my grieving where I can write about her, both fondly and about her pain. In some ways I wish I had been older when she came into our lives, thinking maybe I would have handled it better. But the truth is, death hurts no matter how old you are. Its painful reach knows no age limit, and losing someone you love will always be devastating. Because of her, I knew anger, sorrow, and loss more than I ever thought I would, but in turn it has taught me to celebrate her life rather than mourn her death. My anger and sorrow, although devastating at the time, showed me the value of patience and forgiveness, while my loss helped me to understand the fragility of human life. She had been given a lifetime’s worth of love in six months, and somehow I think she knew that.

In her last week, she slept. She drifted in and out of consciousness, only leaving her crib to be changed or bathed as needed. On April 14th, 2012, we read her last bedtime story. We all sat in the room as my father struggled to read the last pages of *The Giving Tree*.

“I don’t need very much now,” said the boy. “Just a quiet place to sit and rest. I am very tired.”

“Well,” said the tree, straightening herself up as much as she could, “well, an old stump is good for sitting and resting. Come, Boy, sit down. Sit down and rest.” And the boy did. And the tree was happy.