

My Mother's House

written by Guest Contributor | September 3, 2021



The Jungle Room

It was meant to be a “formal” living room, the kind where not much living actually happened. My mother decided to decorate it toward an exotic animal theme. She hung giant, framed pictures of regal-looking lions next to similar pictures of tigers and cheetahs. She outfitted the coffee table with an ornamental chess set comprised of monkey game pieces, each one holding a banana. She placed two plush leopards like guards on the backs of both love seats and tried to tie the whole concept together with a large zebra-print rug as its focal point. The jungle room, as we started calling it, shared a wall with the real living room, the room where we gathered, alone or as a family, and spent the majority of our time, usually watching TV. No one really considered the jungle room beyond its odd contrast to the rest of our otherwise cookie-cutter house, in its equally uninteresting Pennsylvanian suburb filled with much of the same. That is, until my sister decided it was the perfect place to hook up the family computer.

The Computer Room

We were lucky to have a stay-at-home mom. My father's income at the regional electric company granted our family that privilege. How she entertained herself when my siblings and I first reached school-age was anyone's guess. She cooked and cleaned and sometimes used the computer to create greeting cards on a late '90s word processor called Creative Writer. If she did other things, I never thought to ask. When I lost a tooth and got a typewritten note from the tooth fairy on a piece of computer paper with the Creative Writer watermark, I realized she had been my mother all along.

Especially during my middle school years, I spent a lot of time in the

computer room, accidentally downloading viruses onto our ancient Compaq desktop, deliberating way too long over which song to place on my MySpace profile page or who to put in my top eight. But as the millennium marched forward, so did my family and the way we accessed the Internet: with Wi-Fi and laptops and smartphones. The computer room, once again, became another unused space in the house – much like the dining room where we ate exactly one of our meals each year, at Thanksgiving, and where my dad had given up any semblance of domesticity by placing his 600-pound gun safe in one corner.

Though often unoccupied, the computer room featured its jungle décor and that Compaq for years – from 2001 when we first built the house until 2014, when the room transformed once again.

My Mother's Bedroom

Out came the love seats, along with the leopards and zebra rug. My dad boxed up the Compaq and moved it to the basement. Then he bought a television and placed it on the Compaq's former desk. In the space leftover, he brought in: one hospital bed; one motorized wheelchair; one medical lift machine designed to hoist someone from a wheelchair to a bed and back again; two small, three-drawer Tupperware containers filled with sweat suits and medical supplies; and finally one mother, my mother, for whom this new set-up was necessary.

In the last two years of her life, my mother would rarely leave this room, relying on us – her family and nurses, friends and neighbors – to come to her. This is the room where she eventually died.

A Different Time, A Different House

My mother was officially diagnosed with multiple sclerosis in 1999. She was thirty-four years old; I was seven. At first, my family looked to the future with optimism. My younger brother had won his battle over leukemia just a few years earlier. We thought we could tackle this next disease, too. It would be hard, but we were ready for it. Besides, my dad told my siblings and I when both he and our mother sat us down to break the news, "many people live with MS and are okay."

"Will you die?" I asked my mother, feeling scared but also giddy, as if the fear was masquerading as excitement in my small, hummingbird body.

I remember she laughed, but it was my dad who answered: "Not for a very long time."

Relief wilted my body deep into the back of the couch. She would be fine, she would be okay. She might have trouble walking, or seeing, or talking –

sometimes. For the most part, not much would change. It couldn't.

And for a while, a short time at least, that was true. She kept the house tidy, she cooked her famous chili once a week, she packed our lunches and designed us little notes for our lunch boxes, she volunteered at school, she sang in church choir, she had friends over for cake and coffee, she took me out for clandestine banana splits whenever I felt sad or sick, she tucked me in every night, she loved me more than anything in the world.

Then, my dad moved us back to my parents' hometown so we could be closer to family. Maybe he knew something he wasn't telling us. Maybe he knew we would need all the help we could get.

Consolation Tub

I turned nine the year we settled into our newly built house, back in the town where both my parents had grown up, where they had met and married and bought their first home together before moving upstate for my dad's job and eventually starting a family.

My mother had been living with the knowledge of her diagnosis for a little over a year; she could still walk without aid, though she often used me as a stabilizer when she started to stumble or feel weak. She called me her human cane so often I started to resent the nickname, the way her hands clawed into my neck every time she dragged her left foot, the stares from strangers when she yelled at me in frustration anytime I moved too fast or not carefully enough. A small consolation for me was the fact that at least she could drive and get us out of the house, even if the cost meant moving through the mall at a snail's pace, trying to anticipate her next move before she made it and often guessing wrong, taking the brunt of her anger at something neither of us could control just to avoid another fight and an even angrier reaction.

By the time I turned twelve, things were much different. After suffering two unpredictable seizures, my mother and father decided it wasn't responsible for her to continue driving. Her license lapsed, never to be renewed again. With that, what little agency my mother still had disappeared, basically overnight.

Summer became my least favorite season, when the house sat stiff and hot and there was no escape. The only reprieve my younger brother and I could find was in the blissfully walkable distance to the community pool. Our sister, being seventeen with a job and infinitely more social obligations, drove what used to be our mother's Jeep Cherokee wherever she liked, always out of the neighborhood and rarely with us along for the ride. My brother and I spent all day at the pool if we could, scrounging quarters from the keg my dad kept his loose change in to buy the hot dogs and nachos and Mountain Dew that counted for our lunch in those days.

But, more often than not, my brother headed to the pool without me. Just as she had singled me out to be her human cane, my mother started singling me out to do extra chores. I fetched her bottled water from the garage fridge, I cleaned up dog poop in the backyard, I loaded the dishwasher, I folded laundry, I made my bed every single morning – all because she told me I had to. As an adult, I wish I could say I did these chores because my mother and father needed the help and I wanted to help them. But, like most of my middle class preteen contemporaries, I bucked against the responsibility; I did it, sure, everything she asked of me, with reluctance and a scowl and a burning indignation in my heart.

The chores, though, I could have accepted more willingly if it weren't for her penchant to ground me whenever I hadn't done them to her standards or with the humility she thought they deserved. If I so much as rolled my eyes at something she said, and she happened to catch me, my mother punished me by keeping me inside. I was still at the age where I had to listen to her, though we could both tell I was growing out of it, and quickly. Too many times, I remember flying up the stairs in righteous anger and slamming my door – risking another week's worth of punishment – only to quietly sneak into the blue-walled bathroom my siblings and I shared to draw a cool bath, away from my mother and the rest of the world. I'd linger in the water for hours, reading and feeling sorry for myself, while my brother swam in the real pool with our neighborhood friends who weren't at all surprised to find out I wasn't allowed out again.

Maybe this version of myself, the twelve-year-old me, knew, somewhere deep in my body, that my mother was grasping at straws. Her own body was steadily betraying her year after year. She started losing independence at the same time she watched her kids begin blossoming into their own. Facing the real possibility of losing control of everything, even your most basic of motor functions, what wouldn't you fight to keep a handle on? Your slick, hard-to-catch daughter, budding from a girl into something else entirely, right before your eyes? How infuriating I must have seemed to her, petty and mean and naïve as only a child can be, lacking enough empathy to see things from her point of view. I could only think in terms of myself in those days, already beginning to mourn an idea of a mother/daughter relationship I knew we'd never have.

Formal Living Room, Take II

In 2018, two years have passed since my mother's death. Gone are the hospital bed, wheelchair, lift, soft sweatpants, even the TV. Gone, too, is the wall between living rooms. It's been knocked down so the two once separate spaces can flow easily into one another as a single, cohesive room. Light from the back window glints on the newly installed faux-hardwood floors, preceding a beautiful view of the yard beyond. I take in this view quietly from my seat in the Steelers-embossed Lay-Z-Boy, the only piece of furniture that has seemed to survive this latest remodel and which has since been placed in the

precise spot my mother's head rested when she was lying on her hospital bed, watching the TV mounted against the dark wall, the wall that no longer exists, the wall that was taken down to give this room accessibility.

Behind my head, on an antique hutch I've never seen before, rests a studio portrait of my dad embracing his new wife. They're facing the window, same as me, which is bright, capturing a brilliant sky and a lush swath of green grass. The sun feels warm and pleasant, and I admit something to myself that I won't admit to my dad and definitely not to his new wife. Some of the changes they've made to the house I grew up in are, objectively, nice. They've opened up a space I thought would be dark and blue forever.

But, I can't help thinking in the next moment – imagine knocking that wall down before my mother's death. Imagine she had a way to look, not toward something inward and closed-off, but out. Imagine she had a way out.

One or More Insurmountable Staircases

I used to fantasize about what it would be like to have a different mother, one who could attend my high school track meets, or my college graduation, or my sister's wedding; all of which, and more, my own mother ended up missing.

I was twenty-four years old, attending grad school literally thousands of miles from home, when she died. She was just a few months shy of her fifty-first birthday, which seems so much like a young age the older I get. My dad was fifty-six years old. He met his second wife on a dating site just two weeks after my mother's funeral. They bonded over their widowed status; her second husband had died earlier the same year.

From the jump, we clashed. She was conservative and God-fearing where I was queer and agnostic. She demanded my respect as a given instead of something she needed to earn, though she did not respect me, or my sexuality, in the slightest. I watched my father grow distant in a way I never truly considered possible. He had always been there for me when my mother could not, both in a physical and emotional sense. When I lost my mother forever, I didn't gain a new parent in my father's new union. I ended up losing him, too.

His wife painted over the blue walls of the bathroom with a mellow shade of hunter green and stained the sink cabinet to look antique. She told my dad to move his gun safe to the garage before she turned the dining room into a place where people could eat again. She remodeled the kitchen, knocking out the house's only first-floor toilet to make room for a large pantry. She replaced all of my parents' furniture with her own bulky tables and couches and kitschy farm-style décor – her taste leaning heavily on that old, trunk-as-coffee-table, barn-wood-pantry-door aesthetic. Even the front door changed, from navy blue to a bright, loud red. Our upstairs bedrooms were now guest rooms where only her kids and grandkids actually stayed and felt welcome.

I don't even hate all of these changes. I especially like the red front door. But I can't help noticing how every sign of my mother's life and death in that house has been removed, painted over, or boxed in the basement. Every ramp, stair lift, accessible aspect of the house erased as if, with my mother and her debilitating illness gone, there are no longer such needs.

I can't help thinking about my maternal grandfather, sitting on his living room couch a month before his death, lamenting that he'd never put in a bathroom on the first floor of his house. There was a toilet in the basement and a toilet on the second floor – and a steep set of stairs to navigate when he needed to use either one, something that had become daunting when cancer weakened his back and shuffled his steps. What will my dad and his wife do if the flights of stairs in their home were to become, God forbid, insurmountable?

The Gap Between Where You Are and Where You Need To Be

My father no longer sleeps alone, his furniture covered in a thick layer of dust. Now the wood surfaces gleam; the wood surfaces belong to his new wife. Her king-sized four-poster bed takes up much of the master bedroom, its clothing dark and rich in color.

When my mother slept here, the bed was much smaller. She'd often fall from it on her way to the ensuite bathroom, which was just a few feet away. I couldn't honestly count the number of times she was stranded on the floor until one of us found her. Sometimes, when my dad was still at work, my brother and I were the first ones to stumble upon her, especially in our community pool days, my summer of constant grounding. We'd come in from playing outside to hear her distant cries for help. We'd follow them to this room where, sure enough, she'd be sprawled on the ground at the foot of her walker, body awkward and stiff. Mom! we'd exclaim, before starting what would become a familiar routine. My brother grasped her ankles. I held onto her wrists, thin as bicycle handles. Between us, we'd one two three heave her back onto the bed.

Sometimes, we'd be overwhelmed by the absurdity of it all and start laughing. My mother, lying helpless on the floor, wasn't funny. It scared us, and made us terribly sad. Yet, we laughed and laughed. We laughed so hard, it turned into crying. My mother would start crying first, the switch so abrupt, it left my brother and me bewildered, then embarrassed to be caught so off guard. "Mom, it's fine," we'd tell her. "Please stop."

Even as kids, we were letting her know, by our reactions, what she was allowed to feel and express, and what she wasn't. In the last year of her life, the years when she used to fall from bed to bathroom felt like they had happened to another person. It was hard to imagine a time when she was still mobile enough to fall, let alone have the autonomy to move somewhere on her own.

Unfinished Basement

The basement remains the only unchanged part of the house, filled with Christmas decorations, broken bikes, litter boxes, exercise equipment, and my name written in faded white chalk at least twice on the concrete walls. Next to my dad's weightlifting corner is a spray-painted tag: The Buff Club. He used to work out here with buddies from the neighborhood before my mother got really bad. She used to work out here, too. At least a handful of times before she abandoned the free weights and resistant bands, and settled in front of the living room television for marathon viewings of *Judge Judy* and *Days of Our Lives*. My dad was always irked at how quickly she seemed to give up on herself. Perhaps it was easier to blame her for what was happening to our family, its deterioration, than it was to confront the existential terror of living in a world where bad things happen for no discernible reason at all, despite all your good deeds and good intentions. It's that reminder of utter indifference that scares us most. We make up reasons just so there can be one to take all the blame.

My mother was beautiful, and vain, and lazy. She was stubborn as a mule, and incredibly lonely. I wouldn't be surprised if she had suffered from an undiagnosed mental illness, maybe multiple illnesses. It was easy to blame her for being sick, and then blame her sickness for every problem in our family, because of these traits. Sometimes, she even blamed herself. She threatened to commit suicide more than once throughout my childhood, always citing a variation of this reason: life would be so much easier for us if she wasn't around.

I was five and playing in the driveway of our old house. My parents were fighting in their bedroom, which was just above the garage. My mother was screaming and crying loudly, but this was something I'd seen her do often and it didn't scare me. I got scared when she ripped out the window's air conditioning unit and tried to jump out. It was an empty threat, I can recognize that now. She was only one floor up, and my dad grabbed her and pulled her away immediately, as I'm sure she expected him to do. I don't think she wanted to hurt herself. I think she felt desperate, and afraid, and didn't have a better way of articulating this to us. Maybe she felt this was the only way to get herself heard.

I was nine, the diagnosis still fresh and new to our family. We were staying at my dad's parents' home as our new house was in the process of being constructed. I woke up one night to the sound of her crying, my dad trying to calm her down, my grandparents shaken and confused by this dramatic episode. She held a serrated steak knife above her wrist and told my dad she would slice herself open if he came any closer. He was eventually able to talk her into dropping the knife and coming back to bed, but not before he turned to me and my siblings and yelled at us to get away.

I was twelve. I'm always twelve. There had been a fight, I don't remember

what about, just that my mother was mad, and she was mad at me. Maybe I hadn't cleaned my room properly, or I embarrassed her in front of a neighbor, or I had refused to cover my acne with make-up as she was constantly telling me to do. It was a month after she had given up her driver's license for her own safety and the safety of others. On a furious impulse, she'd taken my sister's car keys and driven off. I screamed at her to come back, scared out of my mind that she would hurt herself or be the cause of an irreversible trauma to someone else. Crying, I ran downstairs to the basement to find my father lifting weights, oblivious under the noise of clanging pulleys and synth-heavy seventies rock blaring from the stereo next to his head. He wore a trash bag over his sweatshirt. When he pulled me into a hug, I thought I'd suffocate against the trapped smell of his sweat, which made me cry harder. "She'll be back," he kept repeating when I'd told him what had happened. "It's not your fault."

Even if it wasn't my fault, or anyone's fault, or all of our fault, I still felt terrible. I didn't just want her to come back; I wanted her to have never left at all. She returned a few hours later, body and car physically intact. But something between us had broken. From that point forward I kept her at arms' length, full of contempt and self pity, determined never to let her hurt me like that again.

Kitchen, Cat Level

On the kitchen floor, during a visit before we are estranged, I play with the family cat and try really hard to be civil with my dad and his wife. It is the weekend they've told me to come and clean out my childhood bedroom and I've found the task more than a little emotionally draining.

We are actually getting along until they let me know they've gotten rid of the Internet; just the two of them living there, they don't use it or really need it. I surprise them and, most of all, myself by starting to cry. How can I be expected to get through the night without Netflix? Finally, I say to them, both of them bewildered, "So many things have changed. She should be here."

We know, they try to reassure me. My dad comes to cat level and tries to hug me, but I don't let him. I don't want to be touched. They've ironed out every inch of my mother. They don't want her back like I do. They can't conceive of themselves as they are now if she were still alive. If she were still alive, their partnership wouldn't exist.

So many questions bubble up inside of me. The two of them have opened up the space, made it pretty, but at what cost?

I want to ask my father, don't you know you're going to die someday? Don't you know you're not twenty-five years old anymore?

Twenty-five years old, with the world tickling the palm of his hand. My dad takes my mom, just nineteen, as his wife. Their future rolls out in front of them like a carpet down an aisle in a church where they've just vowed to love each other, in sickness and in health, until death. To his credit, my dad did the best he could by those vows. But I question the validity of such binding words. If I could, I'd go back in time and I'd change them. I'd go back in time and ask my parents different questions.

"Do you, Walter, realize the breadth and depth of your power?"

"Do you, Dawn, imagine a future in which you are cherished?"

Site of Michael Phelps's Last Olympic Race

Imagine we've gone back in time and rebuilt the wall between living rooms. There is the television on the old computer desk; the blue glow of the screen submerges us all underwater. In this corner, a drawer of medicine. In that corner, the wheelchair. Against the shuttered window, there is the hospital bed. On the hospital bed, my mother.

At the foot of her bed, is me. I'm perched carefully on the edge of the mattress so as not to lean my weight against her fragile legs.

On the blue screen, swimmers step onto the blocks, take their marks, leap at the atonal beep. It is August 2016, a month before my mother will die, and we are watching the Rio Olympics together.

Water thrashes white. Streamlined bodies race to touch the wall first. Arms swoop, powerful, with a sustained type of grace. I shout at the screen, "Come on, come on, come on!"

We win, and I punch the air. In my excitement, I lean back against my mother's curved, chicken-bone legs. She huffs in pain and I jump up as if shocked by a current of electricity.

"I'm sorry!" I say, and step into the middle of the room. She cranes her neck to look past my silhouette; I'm blocking the screen, where Michael Phelps has just thrown his arms up in victory.

"Is okay," she slurs, still craning.

I sit gingerly back on the mattress. I can feel her legs behind me, like static, not quite touching the small of my back. She can't move them. I don't start crying, but the sensation is building in my chest. Her tiny legs. I have the sudden desire to be alone, in the darkness, in my room. For so much of our time together as mother and daughter, sharing something as innocuous and calm as a moment in front of the TV felt impossible. Yet here, at the end, we've reached an equilibrium. We don't have time to be anything but quietly present for one another.

"Are you ready to sleep?"

She nods her head, an almost imperceptible movement. I get off the bed and lower my body around hers in a kind of hovering hug; I don't want to hurt her with pressure from my body. Her arms rise a few inches off the mattress, closer to my torso, without actually touching me. It's that static again.

"I love you," she whispers.

"I love you," I whisper back. Then I turn off the TV and leave.

Through the Red Front Door

I flew home from Oregon just in time. At 2 a.m. the night before she passed, I steeled myself to enter the old computer room, née jungle. Her hospital bed hummed. So did the TV. Everything was cast in that dull blue light. I said hello in a falsely cheery voice. I told her about Oregon. I talked about the weather. She didn't say anything, I realized much later because she couldn't. She just looked at me. I've never been looked at like that. Like I was a break in a storm, or a glass of water for someone very, desperately thirsty. She moved her mouth three times. The next day I would tell one of her aides that she had tried to say "I love you" and the aide would laugh at me and say, "That's what you thought she said." Maybe she hadn't been lucid when I came home. Maybe I had projected recognition and relief onto a blank stare.

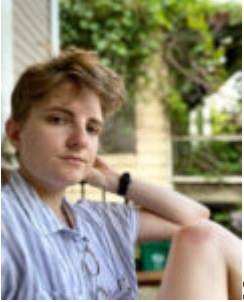
After she died, we drew the curtain across the doorway to her room so that people coming in and out of the front door wouldn't be confronted with her dead body. I kissed her temple. It was waxy against my lips. The cat and I stood guard until the coroner collected the body; it was the first time my mother had been outside in months. I should have known that my life would change as soon as she left that house, but I didn't think about it then. I didn't think about a lot of things.

I didn't think about the price of a house, how that compares to the price of a home. I didn't think about a name on a mortgage. I didn't think about mortgages at all. I didn't think about space, and how it could be changed. I didn't think about choices, and how one could question them. I didn't think about agency, about who has it and who doesn't. I didn't think about narratives, and power, and who has the power to shape a family's narrative. I didn't think about what it means to suffer, to be sick and have the people in your life, the closest people to you, see you as having less of a life because of it. I didn't think about home and what that means when your mother dies. I didn't think about my mother as home.

Now, these are the kinds of questions and thoughts that occupy my most private and reflective moments. Sometimes, insight comes at the ultimate cost. This is the only thing I know to be absolutely true: the walls of my mother's house will change again. In what ways, it isn't anymore my place to

say.

I have walked down the stairs, past the spot in the corner where she took her last breath. I've left through the front door, just as she did. I've said a prayer to no one as I did it, or to someone. I've said a prayer to my parents on their wedding day, a promise of sorts that I would love them fiercely from that moment, and before, and beyond: *You are going to die one day. One day, I'll forgive you.*



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