

Hey there, it's (still) me

*It would have been easier if she died.* Who thinks that about their mother? I stared in disbelief at my mom in her intensive care room at Jefferson Hospital. Hospitals have always made me feel uneasy. The beeping machines, the whoosh of the ventilators, the unpleasant and unidentifiable smells; they always invaded my senses and made it hard to focus. My mom laid propped up in her bed with a feeding tube in her nose. Her hair was matted with dried blood and iodine from her preventative brain surgery that had gone awry. Her face was bruised and misshapen and her eye was dark and oozing. Her previously wrinkled skin was smooth with edema. She looked as if she'd burst if you got too close with something sharp, like a water balloon filled to maximum capacity. She was alive, sort of. But for the first time in her entire life, her future was uncertain. I couldn't see a way through this. I wasn't certain what I was supposed to learn from this. It was too cruel. I was a planner rendered useless as nothing was in my control. I wasn't sure if I'd be planning for a homecoming or a funeral. My thoughts were ugly and confusing and hard to be alone with. *It would have been easier if she died,* I remember thinking in that moment.

My mom was a visiting nurse for most of my life. She finished nursing school when I was just two years old. For most of my childhood my mom was usually running late for a dinner my grandparents made for us because she was "finishing up with a patient." I never resented her for it though; I knew even then her gift was helping people. When I was little, she used to come in the door from work, drop her nursing bags, and hold her arms out. I'd run to one side and my sister Danielle would run to the other. She'd pull us in so tight and hug us for what felt like forever. Her frizzy, chocolate hair was always pulled back out of her face with a tortoise shell

clip but if I close my eyes, even now I can feel the loose strands from a long day tickling my nose. I didn't even care that the laminated corners of her nursing badge dug into my cheeks. Mary Grace Brown, RN, I was always so happy to see her. As we grew, she never missed my jazz festivals or my sisters Irish dance lessons. When I would remember about a school project the night before it was due, she'd stay up all night with me crafting, practicing, and perfecting my presentation. She scheduled her first patient after school drop off so she could start our days off right. When my high school boyfriend dumped me, she insisted we do a full makeover to my room. She let me paint my room a vibrant teal and hung a surfboard on my wall. She helped me move into my first apartment at nineteen years old, and eventually helped me move back into my childhood bedroom with my children after my marriage dissolved. This was who she was at her core. She was everything that everyone needed at all times. Like mortar she filled in the cracks and hardened to keep me strong and standing upright.

There are few better examples of my mom's acts of selflessness than when her brother, my uncle David, suffered a ruptured brain aneurysm a couple of years ago. It was a rude awakening for his siblings. To no one's surprise, she didn't leave his side: I loved that about her. She was there every day, translating medical jargon and leading people in prayer. The first time we truly felt the ground tremor beneath us was when we learned that my uncle's aneurysms were a familial type. They were hereditary and my mom's siblings all needed to be tested. This news felt a little too close for comfort but testing revealed that one by one my aunts and uncles were cleared of brain aneurysms. Then there was my mom, who has spent decades now "finishing up with a patient" and couldn't seem to find the time to fit it in her schedule. As I got older, I felt myself mother my mother more than I could help. I did this whenever I saw her giving too much

of herself away. After 29 years of watching my mother give people an article of her jewelry simply because they complimented it, I recognized a need for my protection. After much nagging on my part, she finally agreed to have the proper tests taken so we could put this all behind us. After all, this was a formality. Her siblings were all healthy.

My mom called one afternoon when my kids were napping. She has greeted me on the phone the same exact way for years, so much so that it became a joke. When her phone would ring in my presence, as she'd reach to answer it I'd do my best MG impression. "Hey there, it's me" I'd say. That always made her laugh. She almost sang it. I have dozens of voicemails that start this exact way, and I could never delete them. This time was different. "Hi!", I said. I remember the silence was broken only by the sounds of her breathing. She mumbled a low "Hey." My stomach rolled up into my throat. "I just. I wanted to tell you that. I needed you to know..." I could tell that whatever she was about to say would become too real for her the second she told me. I held my breath. "My doctor called today. It turns out I have five aneurysms in my brain. I'm really sorry" she cried.

I was so confused. I was beyond confused; I was mad. This marked the start of some of the darker thoughts I would have throughout this journey. *So, you're saying my mom could die any second, but my terrible Aunt D. is just fine? Where are her ticking brain bombs?* And I wasn't just mad for myself. I was mad for my dad, who has been living with a chronic form of leukemia for over a decade. *He can't lose her.* I was mad for my sister, who hasn't yet found her twin flame or had children of her own. *She can't lose her.* Most of all, I was mad for my kids. I remember having active grandparents in my life until I was an adult. My children were all under 10. *They can't lose her.* Nothing about this felt right. My mom takes care of sick people; she's not

sick. In revealing the news to me, she apologized. She was taking care of me even then. She told me she was scared. At just 56 years old, she would need to have open brain surgery almost immediately to clip at least three of them, as they were the most life threatening. After she healed from that, she'd need another surgery to treat the remaining aneurysms. I remember in that moment feeling like it could be a long time before things felt normal again. *I can't lose her.*

Her first surgery was brutal for all of us. It was invasive. It was barbaric. Her skull had been removed and titanium clamps neutralized the threats in her artery walls. She had dozens of staples that snaked their way around her shaved head in what looked like an unending coil. She was in a great deal of pain. She slept for so long, even when she came home. But when she woke from her rests, she was herself. We were relieved, because this was supposed to be the worst of the treatments. After a couple months of recovery, she returned to work. When she was recovered even further she'd require one more small procedure, but it would be done with a tiny little wire through her wrist and she'd be back at the office a couple weeks later. She'd be back to driving my daughter to dance class and finishing her nurses notes in the waiting room. She'd be back to scooping up my babies for those hugs I talked about; the ones she'd give me when I was little. I felt so close to being able to say my mom wasn't sick anymore.

After her second procedure, my dad and I went back to recovery to see her together. We noticed she was extremely swollen on one side of her face and alerted the nurse. The doctors were concerned and kept her sedated to complete further testing. She was in good hands and it was getting late, so we headed home for the night. Selfishly I was relieved for a break from the incessant waiting room chatter of my mom's nervous siblings. We made our way to the hospital first thing the next morning and eagerly called from the car for an update. The doctor asked that

we speak in person when we arrived, which is never a good sign. We were shown to a small room and given the news. My mom had an allergic reaction to the metal used in her treatment. She had a stroke, and a brain bleed behind her left eye leaving her permanently blind on that side. She was paralyzed in her right side, and her speech center was compromised. She'd spend a week or two in the ICU, and two months at a rehabilitation hospital to try to regain some function. We spent weeks prior to surgery convincing my mom that she wouldn't experience an outcome like this. The chances were 1%, things like this don't happen to people like her.

Again, my thoughts were dreadful and all consuming. We were told that this specific reaction has been documented just three other times in the world. As someone who takes comfort in numbers, this infuriated me. I made lists in my head of all the people I knew who I felt should be in her place. My days were spent at the hospital, breathing through my mouth to avoid the scent of IV's and foley catheters. I turned my head when the nurses rolled my mom in her bed to prevent sores. Still, her magenta bruises from her blood thinners would puncture my peripheral vision and my peace of mind. My nights were spent convincing my little ones that "Mom-mom was great" and was "asking for them." I lined her room with their drawings and wondered if they'd be scared of her now that everything was different. Would they cower in fear at the sight of her stitched eye, or would they fight over who gets to push the wheelchair? I wasn't optimistic. I wasn't sleeping. I wasn't me.

My mom would come home one day, but life would never be the same. When I was a kid my mom used to run her fingers through my hair until I fell asleep in her lap. In the hospital I was the one running water through her hair until the dried blood rinsed out. She used to pull out her entire nurse's kit for a rug burn just to make me feel taken care of. At her ICU bedside, it was

me holding firm pressure on my mom's gushing eye wound with a gloved hand while she writhed and begged me to stop. She used to drive me to band practice. Now I was driving her to outpatient therapy. She'd hold my hand during every flu shot and fumble through the lyrics of a song. Now I squeeze hers during dozens of Botox therapy needles while tears stream down her face. She taught me how to ride a bike. Now I was teaching her how to walk, how to stand, how to eat. She'd scribe my birthday cards in her best catholic school cursive. Now I was showing her how to be a lefty. She taught the long complicated true names of flowers. Now I was teaching her that those pretty things in the window were flowers, not "oatmeal" as she called them. She used to call me Jenni-Jen. Now she calls me Jessica, or girl, or whatever object she looks at right before looking at me. Now she calls my kids names I've never heard before. She calls her husband dad, and her dog the names of pets long gone. My mom changed my diapers, now I was changing hers. Her once frizzy, clipped back chocolate hair was now wiry grey and falling out in clumps. It would have been easier if she died. I could think of little else.

But she didn't die. She's here. And she's working tirelessly. And she's never complained. My mom is young. She's blind in one eye and has a field cut in the other. She is paralyzed on her right side. She combs her brain for the right words to express even the simplest thoughts, leaving those around her to anxiously decide if they should finish her sentence or let her keep trying. She will never treat a patient again. My mom is disabled, permanently. Still, she's not outwardly angry. Still, she laughs a lot. She makes up new dance moves with her cane, before challenging herself by leaving it somewhere out of reach and shuffling across the room. "I can keep a better eye on it this way," she'd say when my Dad asks why she made the trek without it. She has this comedy bit where she talks to her formerly dominant now paralyzed arm and asks it to do things.

I'd been given the chance to take care of my mom as she'd always taken care of me and I was wasting that chance on these negative thoughts. I was robbed of so much, but she was robbed of more. I couldn't control much of what happened to our family, to my beautiful mother. But I could control my response to it. I wouldn't continue to wallow on her behalf. I wouldn't waste the precious time I had with my mom, in any form, wishing for another outcome. Pining for an end date to her pain wasn't the answer. Instead, I concentrated on easing her pain. With medicine, with jokes, with home cooked meals, with movie quotes that she mostly remembers, she finds comfort.

I learned to cry with my husband about the way things were and then laugh with my mom about the way things are. He's so good with her, my husband. He tells her he loves her and speaks slowly. My kids adore her as she is because this version of her is all they know and all they'll remember. I label her flowers; I paint her nails. I make her dinner and I dress her up. I fill in the gaps because it's what she's always done without question. It's what she raised me to do. Most of all, I learned to let go. I let go of the relationship I had with my mom to make way for a wonderful new one. I let go of planning because plans change. I let go of what's fair to focus simply on what is. I'm a better person because of my mom, even more so after her perseverance and positivity throughout this entire experience where I've watched my mom redefine what it means to be disabled while I pout with my four working limbs and complete sentences. My mom is stronger than I ever knew. I learned that too.