

A Good Death

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When my sister died on a palliative care unit in Peoria, my parents and her fiancé, Ted, waited at her bedside, told that the organ donation coordinators would come to them. Forms had been signed. Eventually, a nurse approached them and tentatively told them the coordinator was in fact waiting for them to leave. Embarrassed, my parents scrambled for their belongings, packed up unthinkingly, and said a final goodbye. The nurse had already placed ice on her eyes.

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When we were growing up, Sheryl had spent the majority of her high school birthdays at the local renaissance fair hosted annually at the park down the street from our home. My mom sewed her elaborate costumes every year - bodices and long skirts and puffy-sleeved tops. She paired these with steel-toed combat boots. Because Sheryl loved the renaissance fair, I loved it too, but in a way that was more guarded and observational than theatrical. I was her younger sister and beholden to copy her in the most annoying of ways. Her favorite movie in high school was *Braveheart*; naturally, mine was too. I wrote an essay in English on the topic of a historical figure about William Wallace just to prove it.

I remember calling her when I was at Stanford and interviewing her with true anthropologic interest about her time as an exotic dancer. No one else I knew had an older sister who had met her first husband—6 inches shorter than her, long hair, e.e.cummings-loving-Mark—at a goth bar and married him two months later. I don't remember the details, but we didn't go to that wedding. It was one of my mom's great heartbreaks to have not attended. No one else I knew had a sister with congenital heart disease with a prognosis in the 80's so poor that she got to do Make-A-Wish as a child, who also worked for years as an exotic dancer (her time as a dancer being my mother's other great heartbreak). I was most fascinated by the economics of it all - it turns out that working as a dancer is akin to a small business. You must pay your bouncer to ensure they escort anyone unsavory out for you - a safety tax. You must decide if you want to report all your cash earnings because if you do, you then get to consider all work-related purchases tax deductible - shoes ("stripper heels" - her words, not mine), makeup, clothes, etc. I found it all very fascinating. She told me that the only interesting famous person who came to the club where she worked was Vin Diesel. I can't help but hold with me the skepticism that it was probably a bald doppelgänger, but I never told her that. She told me it was wonderful exercise - and this from someone who had been excused from PE for most of her life because of her heart. Part of me wonders if this exercise kept her healthy for longer.

She had come to visit me in New Orleans for Mardi Gras only two years before she died. Knowing her lifelong affinity for costumes, for the pageantry of the renaissance fair, for uniqueness on its own, I was sure she would love it. I lived in 'the box' which means that once the parades start, your car is trapped within the route, and much of your travel must be done on foot or by bike while the city was swollen with tourists. I was in my first year of residency at the time with the weekend off. She came with a list of goals: she wanted to see a parade and

she wanted to eat etouffee. This trip brought me to the stark realization of how sick she was becoming. She needed oxygen but refused to wear it, being only 36 years old.

While my roommate and I did our best to curate her Mardi Gras experience from within the walls of our second-floor apartment and balcony, she insisted we go at least once to the barbecue restaurant down the street. She had to pause down each step from our front door to the uneven sidewalk. We walked in slow motion through the haphazardly costumed groups of people heading outwards towards the parade routes. I could see her breathing like she was jogging but trying to swallow the gasps so that I wouldn't notice. Her lips were blue. She couldn't speak but would only shake her head as if to say, *not now, I'm concentrating*. She stubbornly made her way down the sidewalk. Finally, we made it to the restaurant and were seated outside. She ordered a glass of wine, which she held gratefully between her clubbed fingers. "One glass helps open up my lungs," she explained. "Two or more...not so much."

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The last time I saw my sister was after our grandma had a massive stroke. At the time, Sheryl was living at my grandma's house after her second marriage had dissolved. The two of them were an unlikely pair—my frizzy red-headed sister with a penchant for both holding court and for making her audience blush, alongside my grandma, a Bible-thumping Texan with sentimentality for life's memories that made it damn near impossible for her to throw anything away. Her garage was full of boxes, and her house was full of ceramic knick-knack angels, collecting dust on every surface. The two of them watched TV, ate microwavable dinners, and kept each other company like lifelong friends.

When my grandma had a stroke—84-years-old and in her 2-acre backyard picking pomegranates from her tree — Sheryl was left alone to occupy the house. Family members who came to see my grandma in the hospital arrived at her house to stay in a guest room; no one was sensitive to the home Sheryl had made in the interim. To her, we were unwanted guests in the period of her mourning. She yelled at me when I arrived, mortifying my cousins in the next room, but through her anger I could sense her anxiety. She was worried about my grandma and without the privacy for grief she required. I yelled back, insisting that everyone act like an adult despite the circumstances. She laughed - either at her kid sister finally yelling back, or at the notion of a tantrum insisting on adult behavior. She was good at breaking a spell.

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In my last year of residency in New Orleans, my parents called me to update me on Sheryl's health when she was first admitted to the hospital in Peoria. I was standing in my room on the third floor of our home on Magazine Street, where I had moved in the time since her visit. The floor-length windows were open, exposing the upper branches of the cypress out back. She had been admitted to a local hospital and then transferred to a bigger hospital. Was she in an intensive care unit? I knew Sheryl did not want any heroics. She never wanted a heart and lung transplant, even if it would have prolonged her life.

My parents weren't sure which floor she was on. "Do you know what kind of doctor is in charge of her care?" I asked. I assumed it was Cardiology. "She's on the palliative care unit," my mom said, "I think it's intermediate level, I'm not sure though."

I exhaled. I exhaled breath I didn't know I had been holding my entire life.

When you know your loved one is on the short path to death, you carry with you the fear of how their life will end. You worry what your last words to them might be. It stitches itself into the fibers of your fascia, it knits knots into your muscles that throb an unnamed ache.

Once the promise of a death free from violent chest compressions, free from the tubes she never wanted, free from pressure ulcers on a long-term ventilator, was offered, at last, the hope of a good death lingered in the air like a sob.

Unable to reach her by plane, I Facetimed her. Her fiancée Ted was with her. She, forced to wear an oxygen mask that obscured her nose and mouth, blew raspberries into the mask to communicate her distaste for the intervention while I laughed. My mom told me later that she was already confused enough that she had begun to call her nurses by my and my sister's names. I don't know if it hurt more that I wasn't there or less, because she thought I was.

My mom called me in the evening to give me updates from the day, and as we were talking, she paused to say, staring at her vitals monitor, "I think she's going now." I asked if I could stay on the phone, seated on the foot of my bed, staring at the dimly lit exposed brick of my bedroom wall. "She's comfortable," my mom said. I paced the wood-paneled floors of my bedroom. And then, "She's gone." And finally, after a longer beat of silence: "She's already cooling off." My mom, dad, and Ted were with her in the hospital room, a room I only knew by my mind's eye but which I could picture easily. I felt responsible to help somehow, and so, amidst tears, I offered to call my sister and brother to tell them she had died. I wept only briefly in my room that sat eye level to the upper tree branches before collecting myself; the tears I stifled then would come later, without summon.

The morning after Sheryl died was Mardi Gras Day.

The year prior, my roommate and I had woken up early, before sunrise, to drive to the Backstreet Cultural Museum. This, we decided, was how true locals experience Mardi Gras, reveling in the ritual underbelly. The procession was led by the Skull and Bones gang, a community group dressed in homemade skeleton costumes and papier-mache skulls who marched through the streets on stilts and adorned in animal bones. Their role was to "stir the spirits" and bless Mardi Gras before dawn with a ritual reminder of the fragility of life. They chanted lyrics that reminded those who joined the procession that merriment in excess harms the body. There was a time and place for celebration; heed the warning before it was too late.

This symbolic and playful facing of death inspired gratitude for the things we took for granted: our health, our bodies, the time we have left. 'Dis annual wake-up call, we sang.

This year, I was being propelled by something outside myself. Friends urged me to stay home, citing that it was okay to take time to grieve. But how would I grieve a life I barely comprehended I had lost? The weight of it was too heavy to manage all at once. Living in separate cities, I couldn't yet see the multitude of ways I would come to miss her. I imagined myself at home, alone, staring at my hands. It wouldn't do me any good. Instead, we plucked feathers from purple boas and tucked them into our hair, we wore jewelry studded with bones, and we pulled wigs from worn boxes. We left our home in the Garden District and walked toward Esplanade's canopied trees, hand-in-hand, because we could. There were crowds and music and painted faces, and I moved through the joyful parades as a silent observer. From where I hid in the tidy, curated place within my own skull, I witnessed our old city alive with beaded headdresses, ribboned masks, feathered trim, and every pigment of color. I had no stomach for food or drink. I was simply there because I could be. I was simply alive because I could be. I inhaled the scent of magnolias. I think she would have thought it some kind of paradise.