JOURNAL OF FLORIDA STUDIES
AN INTERDISCIPLINARY JOURNAL OF THE IDEA AND PLACE THAT IS FLORIDA

On the Death and Life of My Daughter

Martha McKay Canter

"Life will break you. Nobody can protect you from that, and living alone won't either, for solitude will also break you with its yearning. You have to love. You have to feel. It is the reason you are here on earth. You are here to risk your heart. You are here to be swallowed up. And when it happens that you are broken, or betrayed, or left, or hurt, or death brushes near, let yourself sit by an apple tree and listen to the apples falling all around you in heaps, wasting their sweetness. Tell yourself you tasted as many as you could."
— Louise Erdrich (author; recipient of 2021 Pulitzer Prize)

The Girl Who Died

Six months have passed since my daughter died. I still regularly find myself surprised that she is dead. These surprises sneak up on me in a way similar to that of intoxication. One minute you're fine, the next, you're stumbling drunk. They arrive without warning in the most ordinary moments of any given day. I'll be doing laundry, or preparing a meal, or walking between the kitchen and the bedroom when an event strikes. It's always the same, entering my mind first as a blaze of an erroneous, unformed thought: "Katie's not dead." This prevarication is immediately followed by my inadvertent acknowledgement of the horrible truth: "Oh, God, Katie *is* dead." Every day the reality that my daughter is dead hits me as if it were news. The effects of this tragic news immediately course through my body. I grow dizzy in my attempts to bear the unbearable pain of a mother's grief. I've come to regard these episodes as existential spinning, my mind's attempt to rationalize the most irrational thing imaginable: my child is dead. She was 31.

In 2008, at the age of 19, Katie was diagnosed with Systemic Lupus Erythematosus (SLE), commonly referred to simply as “lupus,” and Antiphospholipid Antibody Syndrome (APS; APLS) when a huge blood clot lodged between her lower vena cava and her heart stopped all blood flowing to her right lung. A cardiologist at Largo Medical Center worked for three hours on a Friday evening, spraying a fine mist of tissue plasminogen activator (tPA), an intravenous medicine that dissolves stroke-causing blood clots, and for three hours more on Saturday morning.

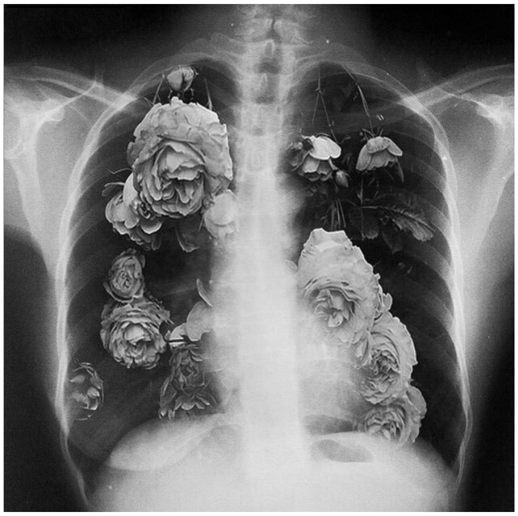
Friday evening as the team wheeled her from the procedure room to her room in the cardiac ICU, she started to bleed from her nose. For a minute or two, the medical team and I stood silent in the hallway just outside the procedure room, watching blood spill from Katie’s nose. The bleeding soon stopped and the weary but worried cardiologist promised to return the next morning at 9:00 to finish the procedure.

Back in her room in the ICU, whose posted rules read “Absolutely NO Overnight Visitors,” the nurse handed me a stack of blankets and pillows. “Your girl is critical,” she said, “you’re staying.” I hadn’t requested an exception.

At 6AM Saturday, I was awakened by the nurse. “The doctor woke up thinking about Katie,” she said. “He’s here, ready to get started now.” I looked at my daughter, knocked out on pain meds, attached to various tubes and monitors, and breathing with the aid of an oxygen mask. “She’s young and strong,” I told myself, “she’ll pull through.” I brushed my teeth in the “Patients Only” bathroom with a hospital toothbrush the nurse gave me and put my bra and shoes back on. When they came to wheel Katie back to the OR, the nurse said, “come on, mama, you’re going with us.”

The cardiologist invited me to look on from the room where a technician monitored my daughter’s physiological responses to the procedure on a series of screens. The room was separated from the operating room by a large plate glass window. Standing far enough behind the technician so as not to disturb him, my eyes shifted between the monitors and my daughter lying on the table behind the glass. If you’ve ever seen a scan of a normally functioning lung, you know that the blood flowing into it resembles a deciduous tree. Imagine you’re lying on the ground under an oak tree budding in spring. You see the major branches and the smaller ones branching off from them. That’s what Katie’s left lung looked like. On the scan, her right lung, which was completely devoid of any blood flow, reminded me of the shoreline at the edge of the Gulf of Mexico a few miles from our home. When the sun shines brightly through the clear water, you can see striations of sand created by the waves, resembling an aerial view of desert dunes. All tissue, no blood. Not a deciduous tree in sight.

By Saturday morning, the clot was completely dissolved and blood flow restored to around 90% of her lung. The cardiologist who saved Katie's life told me she would probably never have 100% function again because scar tissue had formed. Several days into her hospitalization, a young, 30-something rheumatologist, a woman who had been assigned to Katie's case arrived at a diagnosis: Katie had Lupus as a primary autoimmune disease, followed by a secondary one, Antiphospholipid Antibody Syndrome, an autoimmune disease that attacks otherwise healthy blood causing it to thicken and allowing clots to form. Katie would need to be on blood thinners for the rest of her life.



With good medical care and proper medications, Katie remained relatively healthy, suffering lupus flares now and then until 2017 when she was diagnosed with chronic thromboembolic pulmonary hypertension (CTEPH). For the bulk of that year, Katie relied on around-the-clock supplemental oxygen until in late September she underwent a complex surgery at Duke, called Pulmonary Thromboendarterectomy (PTE; see video of John Haney, Duke cardiothoracic surgeon, in link) to remove multiple pulmonary embolisms from her lungs. During the 8-hour surgery, she was put on a heart-lung bypass machine, and her body was cooled to 60 degrees so that the surgeon could stop her heart twice, for 23 and 24 minutes respectively, to remove the clots that had turned to scar tissue. Her lungs were never healthy, but following surgery she was able to live a relatively rich life for a few more years. In the end, despite the surgeries, the frequent hospitalizations, the life-saving blood thinners and numerous additional prescription drugs, and despite regular visits with her rheumatologists, along with a half dozen additional medical specialists Katie saw regularly, lupus and antiphospholipid struck again in 2020, this time with a vengeance that would prove fatal.

**

I am keenly aware that losing my child to a treacherous disease in the year 2021 in no way sets me apart from millions of parents across the world who have lost their minor and adult children to COVID. Anyone alive in 2020 would be hard-pressed not to agree it was the strangest and among the deadliest of years any of us ever lived through. By February the news was grim. By March, it was dire. Having driven from my home in Seminole, Florida to our family's mountain home in Western North Carolina for a spring break visit with my son and daughter, I had only just arrived when the university in Tampa where I taught announced that all courses were to be migrated to an online format for the remainder of the semester, later extended through the academic year. When the lockdown officially began, I stayed in the mountains. My son was there and my immunocompromised daughter lived in Asheville, an easy 30-minute drive from our home in Waynesville. Even though precautions meant we shouldn't visit each other, I wanted to remain close to keep an eye on her health and help her make it safely through the pandemic however I could. Another reason I didn't return to Florida was that my husband, a CPA and senior partner in his firm, would be working all hours of the day and night at least through tax season, and I could teach online from anywhere.

My only reservation about not returning to Florida was that my mom, who had been diagnosed in 2017 with mixed dementia, was living in an assisted living facility in Seminole. At the time of her diagnosis, medical tests further revealed she had been living with a neck fracture that had gone undiagnosed and untreated for years, and which we believe, though cannot confirm, must have occurred 15 years prior during a trip our parents took in their motorhome when Dad had to break fast to avoid a collision, and Mom, who wasn't in her seat, took a tumble and hit her head on the console. Mom, who was in her mid-60s at the time of the accident, was always tough and strong, and occasionally belligerent. She had refused to get an x-ray after the accident, insisting that she was "fine." Her argument when she complained of shoulder pain and weakness in her arms following her fall was "I'll feel fine in a few days with some ibuprofen." With that, they had resumed their trip, unaware that she was traveling with broken C1 and C2 vertebrae at the base of her skull. When her doctor discovered this old, unsteady facture, Mom was transported by ambulance to Tampa General Hospital where a brilliant neurosurgeon repaired her broken neck. Following surgery and a brief stay in a rehab facility in Seminole, we were able to move her to a small, lovely assisted living facility conveniently located right behind my house. By the time the pandemic set in, both my sister and I had been seeing to her needs and overseeing her care. My staying in North Carolina meant that my sister would have to take up the cause on her own, and I wouldn't be able to visit my mom. But when I learned that nursing facilities in Florida were not to allow visitors, my decision to stay near my kids was made easier. In the end, it made more sense for me to stay safe and near our kids in North Carolina where Covid-19 cases were few compared to those at home in Florida.

My mother died peacefully in the early morning hours of September 1, 2020 with a hospice nurse and my sister at her bedside. I was present by the technological affordance of FaceTime to watch her take her last breath, and to grieve with and comfort my sister. It would be only a matter of days later before Katie got word that a branch of her disease called neurolupus was affecting her brain, and only a matter of weeks before her symptoms began rising to a crescendo. The timing of my mom's death and the onset of Katie's catastrophic flare meant that my grief for my mother was necessarily interrupted when my attention naturally turned to my daughter's care. For a time I wondered why my mom's passing hadn't paralyzed me with grief when in the months before she died her impending death had consumed my thoughts. After Katie passed, I learned about anticipatory grief, "an emotional response to an expected and inevitable loss, which begins before it occurs, and allows the necessary readjustments until such time as it occurs" (Pérez-González et al.) I had already been grieving for my mother for three years. Moreover, I knew that she was no longer herself and hadn't been for a long time. I knew she was suffering and wanted that to end. The grief I feel over losing my mother began long ago. When she died, it was replaced with sorrow and relief. We do anticipate the deaths of our elderly loved ones, especially when they have fatal diseases. What's more, we expect to outlive our parents. It's the natural order of life. What is wholly unnatural is to outlive our children. There is nothing natural about my 31-year-old daughter dying before me.

I lost both my mother and daughter in a 7-month span during the pandemic. Notably, neither of them died from COVID, nor did either of them ever contract the disease. As with serious COVID-19 infections, the lupus flare that would take Katie's life began in the spring of 2020 and gained such traction that by late autumn, her entire body was overcome with illness. One mid-September afternoon, Katie called to tell me she'd spoken with her neurologist about a recent brain MRI. The doctor had delivered the awful news that Katie had developed Cerebral Small Vessel Disease, in her case a result of neurolupus. By December, Katie could not physically reach for a cup of water on the table next to the sofa where she lay. Nor could she walk, or bathe herself, or control her bladder or bowels. By this time, she was staying with me at my house so that I could take care of her. Because of COVID restrictions and the fact that Katie's flare was accompanied by fever, often as high as 104°, physicians would not allow her to visit them in person at their offices for fear of the virus. This, despite the fact that she never tested positive for coronavirus, though she was tested regularly to rule it out. One day in January, fearful for Katie's life and at my wits end, I called 911 to take her to the ER in

Asheville where her doctors practiced. The EMT told me that he was not authorized to drive her to Asheville, located in Buncombe County. He had to remain in Haywood County, where we were living, to serve COVID patients who might call in. Feeling regretful, the EMT picked up my daughter in his arms and carried her to my car. I drove her to the ER in Asheville where they gave her a bag of fluids, advised her to see her doctor, and sent her back home with me. They did not have a bed for her. They were prioritizing COVID patients. It wasn't until February 9 that Katie was finally hospitalized. Even then, her rheumatologist had to facilitate the admission, which she did after having seen Katie in person when a drug infusion for a lupus medication necessitated that she be seen in-office. The nurse who took care of Katie grasped the severity of her illness and decline and informed the rheumatologist who then intervened to ensure that a bed was made available for her non-COVID patient. Katie died in that bed 72 days later.

The Girl Who Fought to Live

Katie's final hospitalization began on February 9, 2020 and lasted for 72 days. In all that time, she never believed she was going to die, not even when Catastrophic Antiphospholipid Syndrome (CAPS), a condition that attacks a body in a cascade of simultaneous events, in her case brought on by a tenacious lupus flare, delivered blows, one after another, to her blood, skin, lungs, heart, central nervous system, gastrointestinal tract, and to the demon that would not be defeated, her kidneys, strongly suggesting that the outcome would be otherwise.

Indeed, she survived an entire month longer than some medical experts told us she would, when, in early March, she landed in ICU on a ventilator following a cardiac and pulmonary event she suffered while undergoing hemodialysis. At that time, a surgeon advised our family to stop all treatment, and for about 12 hours, we reluctantly took that advice. But after Katie woke and was extubated, she said in a whisper in the presence of her exceptionally caring night nurse, "I'm not ready to die. I want to live." Katie's words, taken as directive, led to a swift reversal of course, much to the chagrin of anyone who abhors paperwork. But this was *her life*, not something to toy with. I was never so grateful as when she – *not I* – gave the order to reverse the "comfort care" decision. It was right for her to decide. Not me, not some doctor, but Katie. It was her life, her decision.

Two days before she died, Katie was visited by her brother, Jack, who, in cahoots with a couple of empathetic nurses, schemed to sneak Bella into the hospital so that

Katie and Bella could say their final farewells. Jack was, and remains, a loving and supportive brother to Katie. As in all sibling relationships, they didn't always see eye-to-eye, but the love they shared was unique to them. They had their own way of being together, of understanding one another, of overcoming conflicts, and of loving each other. On her final day of life, she was visited by Aaron, who, two days prior, brought her a bouquet of orange ranunculus in celebration of their third anniversary. When he asked a very weak, semi-conscious Katie if she knew what the flowers were for, she whispered, "our anniversary." I cried watching him kiss her on her cheeks and forehead, and again later when, as I stood outside the room leaning against the nurses' station, I watched Aaron feeding her what little food she was able to consume. The charge nurse, Justin, happened to look up then, too. Placing a hand on his chest, he said, "see there. That's the stuff."

On the evening Katie died, her friend Jordan came for his final visit. By the time he arrived, Katie was entirely unconscious. After kissing her forehead, Jordan stayed to talk with Rich and me for several hours, the nurses assuring us that Katie could hear our conversation. "She was too pure for this world, Jordan said, adding, "thank you for giving us an angel."

Later that night, only Rich and I were with her when she passed, which seems fitting. We brought her into the world together, and we were together to ease her passing from it, as best we could, with all the love we have to give our children.

***

I've been journaling about my daughter's illness since she first showed signs of decline. I started writing about her approaching death a few weeks before that fateful night in anticipation of an event I could neither fathom, nor forestall, nor avoid. Writing about the inevitable helped me cope when I had no choice but to accept that I was powerless. I could not prevent my daughter from dying, but I could write about her. I wrote about her illness when it was the only thing in my purview. I wrote about her death when I could not talk about it or think about anything else. For a time, I could barely speak at all. But somewhere along the line, I realized that what I needed to do was to write about her life. And not only to write, but to talk about her life. And not only to talk about her life, but to shout about it from rooftops. I am her mother, her champion, the keeper of her legacy. Yes, Katie died. But for 31 years and eight months, Katie lived. To that end, below is a revised and foreshortened version of the eulogy I wrote and delivered twice, once at her memorial gathering we hosted for friends and family in North Carolina, and once at the memorial we held for family and friends in Florida.

A Mother's Eulogy: The Girl Who Lived

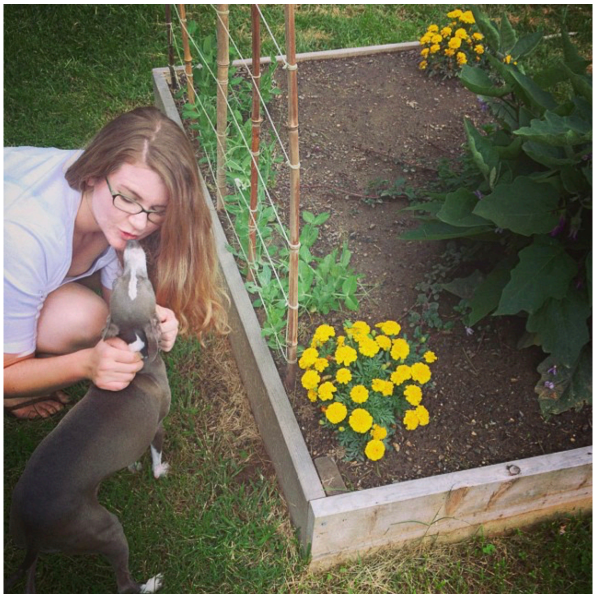
My daughter, Katie Grey Canter, was a lovely human. She was an artist to her core: jewelry maker; photographer; mezzo soprano; gardener; creative thinker and writer. Accordingly, throughout her life, Katie had a contagiously sprightly spirit. When she was little, her imaginary friend, Kindy, traveled with us everywhere we went, often making us late. Similarly, for years we never went anywhere without every one of Katie's stuffed animals. In preschool, she wore the same floral dress, brightly colored striped leggings, mismatched socks and mismatched shoes as often as I let her get away with it. My dad came to visit her on her first day of kindergarten to see how her day had gone. She told him about the friends she'd made, the teacher, the playground. When he said "that's great, Katie! Bet you can't wait for tomorrow," an appalled Katie replied, "tomorrow? I'm not going again tomorrow. That's for the other kids." When my sister was pregnant with her second child some 28 years ago, she asked family and friends for baby name ideas. As the rest of us threw out popular names as suggestions, five-year-old Katie offered "Flower Kadoose."

Katie loved her family and friends fiercely. Her cousins were bonus siblings to her. My sister was her second mother. Throughout the years, Katie remained steadfast in her love for her closest, dearest friend, Dani, with whom she shared her most private secrets and dreams from the day they met as students at Seminole High School. That big love extended to Dani's daughter whose artwork and handwritten cards and notes decorated Katie Grey's refrigerator door.

Katie never met a stranger. She made friends wherever she went simply by reaching out to the people around her to say "hello." She brought home stray dogs and cats to give them a home, and just as often welcomed people to her home who needed a meal and a place to sleep. When Katie was dying, one of her most loyal and loving friends, Jordan, told me that this was the exact way they met at a festival. He was new in the Asheville area and had no plans for accomodations. She invited him to stay with her until he got on his feet, and thus began a long and abiding friendship, which extended to our family, as is true of all of Katie's close friends. In fact, although she made it her practice to reach out to the people around her, Katie was selective about those she called true friends; but if you were counted among that special few, you were her friend for life. Just as she showered love on her friends and family, Katie was a wonderful mother to her English Coonhound, Xero, who died of cancer in February while in Jack's and my care with Katie in the hospital, and her Italian Greyhound, Bella, who died nine weeks to the hour after Katie.

Katie was a keen and quiet observer of life. She paid attention to the small things, and was possessed of an impeccable aesthetic as a result. She adorned her apartment with healthy, thriving house plants, and for a few years when her body was fit and able, she kept a vegetable garden in her backyard. Similarly, Katie enjoyed surrounding herself and those she loved with fresh cut flowers, especially her favorites, orange ranunculus when in season.

At the age of 11, Katie became a fan of Charlotte Church, a girl who, only a few years older than Katie, was propelled to fame for her operatic voice. I remember one evening leaping up the stairs shouting,"turn that thing down," when the volume of an Italian aria reverberating from her shower was so loud I could hear it in the kitchen below. Upon entering the bathroom, I discovered that it was Katie, not Charlotte Church, making that beautiful sound. She started voice lessons the following week, and she competed in vocal competitions and sang in various choirs throughout her school years. Her diagnosis when she was only 19 put her hopes for a professional singing career on hold indefinitely, but a few years ago,



wanting to sing again, she joined a choral group in Asheville. That same year, she joined two other women to compete in a local singing competition. Katie had a gorgeous voice. She was a natural born singer. It was a cruel twist of fate that her illness struck her lungs first, and again repeatedly throughout her life.

When singing professionally proved to be an insurmountable physical challenge for her health, Katie channeled her artistry into jewelry making. She made hundreds of pieces, many of them rings, out of silver and semiprecious stones. She opened an Etsy shop, and had ambitions to do weekend art shows to sell her wares, ambitions which were again thwarted when the fumes from the metal proved dangerous for her lungs.

Despite her compromised condition, Katie remained curious about life, always seeking to learn whatever she could about whatever caught her attention. Her capricious demeanor belied the fact that she had a great appetite for learning about things that mattered to her. While going through her things recently, we discovered notes she'd taken in her study of philosophy and Greek mythology, not for a class but for the knowledge she'd gain by the endeavor. Katie was a graduate of Florida State University where she earned her Bachelor of Science degree in Criminology, much of it online; equally, much of it undertaken from various hospital beds. Aspiring to be a "blood spatter expert," thanks in part to Showtime's Dexter, Katie took an internship with the Asheville PD, only to quickly realize that to rise in the ranks on a police force, one must start out as a beat cop, something she had no desire to undertake. She had no interest whatsoever in carrying a gun or arresting people, or any of the things cops do on a daily basis. Rather, the features of the job that affected her most deeply, events she shared with me in her time as a rookie police officer in the making, were of the humane variety. She told me, "the cop I'm riding with is really kind, Mom. He showed me how to look out for the sex workers. He doesn't arrest them but he watches out for them to make sure they're safe." Similarly, she was moved to learn that many of the cops on the Asheville force take in homeless folks on cold nights. Again, she explained, "they take them in, but they don't complete paperwork. They just give them a hot meal, a warm shower, and a place to sleep for the night, then release them come morning." Katie's gentle heart would never have tolerated being a cop, but at least in her brief stint with the force she witnessed kindness where she least expected to find it.

Kindness, above all else, was the human trait Katie most valued in others, and tried always to offer, even as her illness, with its recurrent demand for courses of steroids sometimes threatened to put civility just beyond her reach. But even then, *she would apologize, saying "it's the steroids. I'm sorry," when she snapped. Still, it would be disingenuous not to acknowledge that Katie could be difficult, sometimes even when not on steroids, and often to the chagrin of the people closest to her. She wanted things how she wanted them, she paid little attention to schedules, sometimes breaking appointments at the last minute. Her rheumatologist assured us that Katie was not alone in this behavior. "All of my lupus patients are like that," she said. I was relieved to hear it, but then again, we mustn't forget that years before her lupus and antiphospholipid antibody syndrome diagnosis, we were often late for events when Katie was little because the imaginary Kindy couldn't find her shoes. Katie lived on Katie time. It was part of who she was, but certainly not all of it.*

In fact, I'll go out on a limb to assert that Katie was the most organized person any of us has ever known. This was something I knew about my daughter for a long time. She once started a business she called "Katie's Clutter Control" where she would go to people's homes to help them get their ducks in a row. But the extent of her organizational skills was driven home when, after she died, we went to her apartment to begin the painstaking task of sorting her worldly goods to give to her closest friends and loved ones. This is when I realized that her insistence on arranging every single thing she owned, and folding every item of clothing just so was no joke.

This is also when I discovered the full extent of Katie's appreciation for cosmetics and all things beauty related. Who knew she had her very own Sephora store housed in her Asheville apartment? I certainly did not. But now I have my own abridged version, something of a Sephora Light. It must be noted too that her cosmetics were all natural, no animal byproducts, vegan wherever possible, like her diet.

As with her penchant for all things cosmetic, Katie's generosity for gift-giving knew no bounds. Every year at Christmas our family would make what always proved to be a flimsy pact to go light. "Let's make this Christmas more about spending time together," we'd say. "Let's only give each other one or two small gifts," we'd say. We'd say this knowing full well that Katie Grey was going to go nuts with presents, and she never disappointed. Her generosity was matched only by her talent for selecting ideal, personal, thoughtful gifts for those she loved.

The list of those she loved was made brighter and more vibrant three years ago when she fell in love with Aaron. In her 31 years and eight months on planet Earth, I never saw my daughter happier, more content, more herself than she was with Aaron. The love they shared was a thing to behold. The way they spoke to one another, gently, kindly, respectfully; the way they worked together to resolve issues; the way they loved each other made my mother-heart sing, and I know the same is true for Rich and for Aaron's parents, too. They were a beautiful couple in every way. It quickly became clear to anyone observing them together that they had created their own little world. It's not that they became antisocial, but that they were content together, with or without anyone else. In the months before she got so sick, they began shopping for a house to buy, one with a yard for the dogs to run, where they were to share their life. He would start his own computer shop; she would make jewelry and do crafts shows on weekends during the season. He would cook – someone would have to cook – and she would keep things clean and organized to a fault. They spent countless hours building a simulation of this life playing Animal Crossing. I can't tell you how many pics of their little world she texted to me, gushing "look at this adorable town we built, Mom!" Or "look at that cute hutch I just got for our kitchen" or whatever it was she was so thrilled to have procured. Even though I was fairly immune to the charms of Animal Crossing, I knew enough to know that in playing the game together, Katie and Aaron were planning their future. What I do know is that the last three years of Katie's life, those she spent with Aaron, were her happiest….

The Mother Who Endures

I recall very few details of the weeks and months following my daughter's death. I know that there were phone calls to be made and that I made some of them. To whom, I recall only in very few cases. What was said during those conversations I can only guess. No doubt there was love sent from afar. No doubt there were offers of "if there's anything we can do, anything at all," and platitudes, "she's in a better place now, no longer suffering," and "I can't even imagine."

But we can imagine, can't we? And we do. We often imagine, when we are parents, how we would respond to the worst possible news any parent could ever receive. When our children are infants, we worry about their growth and their health. When they are teenagers, we lie awake nights worrying, hoping they are safe, hoping those sirens we hear in the near distance are not responding to a wreck they've been in or a house party they're attending gone wrong. We worry throughout their lives that they will be able to avoid danger. From the moment we know we're going to become parents, we are struck by a recognition, of which we had been previously, blissfully unaware, that there will never be another day in our lives when we do not worry about our childrens' wellbeing. And when one of our children dies, we worry if we did enough to keep them safe and healthy and well. We worry whether we were good enough parents to our deceased child while they lived, as they lived, and as they died. Even if we know we were and are good parents, generally, we may be left to face the fact that we may not have always been the parent they needed when they needed something other than what we had to give. The last is a worry that has stuck with me even until now, 10 months and six days, as of this writing, since she passed.

I know that after Katie died there were details to be sorted with the funeral home and that I recall that I helped to sort them. I remember going with Rich and Aaron to the crematory where we selected two pink Himalayan salt urns, one for us and one for Aaron, each of which would hold half of Katie's ashes. I remember eating tacos afterwards at the Taco Temple two blocks from Katie's apartment, then backing into a pole in the parking lot as we were leaving to go begin the heartbreaking task of clearing out Katie's home, sorting through her worldly goods that told stories of her life. "What was that?" I asked my husband when my car connected with the pole. "You hit a pole," Rich replied. I put the car in drive and started to pull out. "Don't you want to see if there's any damage?" he asked. "No," I said, and proceeded to drive the two blocks up Baird Street to my daughter's apartment.

It took a month to clear out Katie's apartment. Some days I couldn't bring myself to go. Others, I recall being there, sorting, taking my time, looking at things, deciding which items should go to which of Katie's friends, making piles, and sometimes trying on her clothes. A week or two before she died, Katie said, "Mom, if I die, promise me you'll wear my clothes, because I have a bangin' wardrobe!" The request is the closest thing I have to any indication that she was contemplating the possibility of her own death. Believing that she would recover, and rejecting the alternative, I told her that I would. Later, after she died, I recalled the promise I had made to her that day in the hospital. I selected several items from her closets to keep before giving the rest to friends, and donating one box to a local charity. In keeping with my promise I made to her that day, I do wear her clothes. I wore one of Katie's dresses to deliver her eulogy at the second memorial gathering we offered, this one in July 2021 for friends and family in Florida who could not join us for a small, intimate gathering we hosted in her memory in North Carolina in May. I wear her Pink Floyd t-shirt around the house and to run errands. I wear her scarves, sweaters, jeans, and skirts, and most days I wear her jewelry, pieces she made by hand when her hands worked, and when her lungs were comparably strong. Even with all the many pieces I kept for myself, Katie's bangin' wardrobe proved to be so sprawling that it begged to be dispersed among friends. I spent the entire month of May doing exactly that, along with giving away Katie's furniture and household and personal possessions to friends and loved ones whom I knew loved her and would take care with her belongings. Beginning in early May, I invited my daughter's closest friends to come to her apartment, one at a time and by appointment because I needed to pace myself, to look through her clothes and personal belongings and select items they wished to keep. This exercise proved cathartic for me at the precise time in my life when I was at my most fragile, most distraught, and least capable of functioning in any of the normal or usual ways. Although I only recall *that* Katie's friends answered my invitations to come over, my memories of particular moments spent with them reminiscing are mostly obscured by my grief in the immediate aftermath of her extended, traumatic hospital stay and eventual death. I am grateful to each and every one of them for the time they spent with me then, and for the love they showed my daughter throughout her life.

It would be a full two months after Katie's death that I was able to muster the courage to undertake the necessary work of looking at my daughter's life in the digital realm, attempting as I went to see her life through her eyes. In late June I embarked on the emotionally grueling task of going through Katie's phone with the two-pronged objective of finding and preserving photos she took and stored in the cloud, along with other important personal notes and items I wanted to keep and preserve, and deleting her digital history to help ensure her legacy would be protected. Because such a task takes a heavy emotional toll, it's still a job that remains unfinished. I must prepare myself to be devastated all over again each time I open one of her devices in search of additional evidence of my daughter having lived, created, and loved.

One evening, I found a video of Katie singing “Once Upon a Dream” on her phone. That night, grief plunged me to my lowest point in the eight weeks since her death. Whether it was rock bottom remains to be seen. By late that evening my thoughts were of the *I don't want to live like this anymore/ I don't want to feel this pain anymore/ I cannot survive this any longer* variety, while simultaneously my intellect told me the "no more" option was untenable and that I needed to gather myself and stop this train of thought in its tracks. To be clear, my thoughts that evening were not about suicide or how I might go about ending my life. They were centered solely on putting an end to my intolerable grief. Given my agonized state of mind that evening, I’d have paid the ultimate price not to feel the pain. But of course I knew there was no escaping my grief, and that I had to continue to endure it for however long it takes until I might feel something comparable to whole again. As a stop-gap solution, I took some melatonin and went to sleep.

The following morning and most mornings since, I was not similarly distressed. As a result of my abrupt shift in perspective upon waking the next day, I thought about how incredible the human central nervous system must be to house a built-in mechanism which is triggered to protect us from experiencing the full weight of ongoing traumatic grief, perhaps a neurological switch which, when flipped by some innate biological process, offers us a mitigating degree of reprieve. Perhaps this mechanism I'm imagining exists to provide a steady drip of mollifying trauma shock by which we are emotionally numbed and protected, not unlike a steady drip of intravenous pain medication administered to protect a patient from experiencing physical pain to its fullest extent. A bit of research, even a basic Google search might confirm my hypothesis. I don't presume to be discovering a new phenomenon. I do know that the shock of a devastating event can be re-triggered by external stimuli. But what I’m experiencing is the polar opposite of that. It’s as if my brain prevents me from experiencing the worst of my grief indefinitely. On days when I’m offered this reprieve, when a gathering storm in my mind threatens to torment me, some mechanism, real or imaginary, prevents it from building.

This is not denial in any conventional sense because I am aware that it is happening even if I don’t feel the full force of grief. Nor do I actively choose not to think about the events and emotions threatening my erasure. I am not deliberately rejecting the thoughts. It’s that even after I’ve acknowledged their presence, they simply refuse to build to a crescendo. Because on these days of reprieve I remain cognizant of the internal storm’s attempt to brew and rain a world of pain on me, although the anxiety relaxes and wanes, there is never a moment when I do *not* feel as though I'm standing at the edge of a precipice, and that a slight breeze or wayward feather could catapult me over the edge into the dark abyss. These intermittent respites are tenuous at best.

It has been difficult for me to locate information about grieving the loss of a 31-year-old adult child whose death was not the result of an accident, substance abuse, or suicide. When I’ve run Google searches using variations of the terms “death of an adult child,” nearly all of the sources returned center on these three types of deaths. Those that do address deaths of adult children by illnesses tend to offer advice predicated on traditional social and cultural relationships as they customarily evolve by the time a person reaches their thirties. Articles offer advice about how a grieving parent might deal with their feelings about their relationships with their child’s spouse and with their grandchildren. My daughter was not married, though I do love and have maintained a close relationship with her boyfriend of three years, who is, to me, my son-in-law regardless of legal marital status. They had no children, so I am not seeking advice about relationships with grandchildren. My husband, son, and I involved Katie’s boyfriend in every plan we made for her cremation, her belongings (he got first dibs on anything he wanted, and we gave him the money from the sale of her two-year-old car), and her memorials, so we have not experienced conflicts described in the articles I’ve read. The articles returned in my searches invariably offer further advice to elderly parents whose deceased adult child had been acting as a caregiver or source of financial support to the grieving parent before death. The prevailing presumption is generally that the parent is an octogenarian who has lost a child in their 50s. Again, none of these scenarios describe our situation. My husband and I knew years ago that we would always support Katie financially, and that we, along with her boyfriend, would always be her caregivers when her illness flared. In the months since Katie’s death, I have not located any article offering information or advice for people like us. One New York Times article from 2017 at least offers statistical insights, reporting that a study out of the University of Texas at Austin, which relies on “data from the federal Health and Retirement Study from 1992 to 2014, [reported] that 11.5 percent of people over age 50 have lost a child" (NYT). The same report revealed that in the case of "child deaths after parents have turned 50, the figure grows from 2.8 percent by age 70 to 3.4 percent by age 80" (NYT). While helpful to know, the primary example the article relies on is still that of an 80-year-old widow whose 51-year-old son had died of a heart condition.

Though always regrettable, heart conditions among middle-aged men are not rare, certainly not nearly as rare as the complex disease that killed Katie. According to the Lupus Foundation of America, approximately 1.5 million Americans have lupus, 70% of which are SLE patients, and 90% of which are women (Lupus.org). One third of all lupus patients develop multiple autoimmune diseases (Lupus.org). Antiphospholipid antibody syndrome (APS; APLS), Katie's secondary autoimmune disease, occurs in less than 1% of the general population, and less than 1% of APS patients experience catastrophic antiphospholipid syndrome (CAPS), the disease that ultimately took Katie's life. Considering the extreme rarity of Katie's diseases and her cause of death, it therefore stands to reason that there is very little information available for a 50-something mother whose 30-something daughter suffered from and died of rare diseases, diseases so mysterious that their causes continue to elude researchers. Trained grief counselors and therapists -- as well as many nurses and some medical doctors -- tend not to know about or have ever even heard of the diseases that killed my daughter. To that end, I am on my own to a degree, researching independently, and working my way through grief. I will seek therapy at some point, but even finding a therapist who is a good fit requires energy I haven't yet summoned. It also requires that I explain Katie's diseases to any therapist I might turn to, which in turn requires me to muster energy to tell that tale, possibly more than once, until I find the right therapist.

The psychological tasks I'm now confronted with require me to reconcile the loss of my daughter and the life she led, tormented always by illness, and punctuated by the slow but resolute march toward death she endured in the end. I'm forced to reckon my experiences as her mom throughout her life with events I witnessed her having to endure in her last months while acting as her caregiver and patient advocate. Doubtless I suffer from what I've learned experts call "complicated bereavement." I'm grappling with the trauma surrounding the way she died and my having been beside her, my body on high alert throughout that prolonged experience, while being also burdened with a mother's grief of having lost her daughter and all that entails. In truth, I think what I must continue to do is separate these events to face them individually before I'll be able to achieve an honest articulation of peace framed by any single narrative of her life and death.

One result of this complicated emotional state is that I’m experiencing a low-grade agoraphobia, "fear of the marketplace," a term I'm applying to the situation only because I don't know the proper term for *distaste for and disinterest in the marketplace*. I harbor no desire to go anywhere, see anyone, or talk with even my closest friends and relatives. For a time I felt lucky to have Bella's old age and abandonment insecurities to fall back on while Rich ran every errand because I am not ready for primetime, and because there are some sociocultural expectations that demand excuses for my reluctance to participate in the circumscribed understanding of established social order. It can be exhausting and frustrating to conjure acceptable excuses to counter the insistence that it's high time I rejoined consumer culture and the world in general. “It’s been months,” goes the reasoning, “it would do you good to get out!” I can’t predict when I will be ready to step back out into the world of people without feeling like a fish out of water. Until that time comes, small doses of time spent with trusted friends are manageable as long as they are spaced few and far between.

Life has moved differently for me since my daughter died. I have become quieter in thought, speech, and action. Some days I pass in reflective contemplation, simply existing, quietly, reticent, at times even taciturn and indifferent. I am cautiously starting to let in the light again and testing the waters of the living. In August 2021, after I’d been home in Florida for two months, Rich and I started taking morning walks on Indian Rocks Beach. I have found dipping my toes into the warm Gulf waters therapeutic. I keep in touch with Aaron, though not so frequently as to interfere with his need to carry on with his life, which he has to balance with his grief, just as I must. And he is doing that beautifully. I’ll see him in the coming weeks for lunch and hugs, and probably a selfie or two. He’ll catch me up on his studies and goals, and I will cheer him on, as I always do, and tell him I’m proud of him, as I always am. I’m starting to take better care of myself, too. I’ve dropped the weight I gained over the pandemic, and I joined a yoga studio in Largo near my home to resume my 25-year yoga practice that I’d neglected for the better part of two years.

After spending some time at home in Florida, I returned to the mountains in September to start the process of getting the house in shape to sell. I made a list of things that needed to be done: weed the overgrown garden; have a load of gravel delivered for the driveway; order new kitchen countertops and sink; fix the leaky ceiling in Katie’s old bedroom; find someone to repaint the lower kitchen cabinets which have taken their share of abuse over the past 22 years. It was in the midst of doing this work -- and realizing that I *could* do the work -- that I noticed a shift in my grief and in myself. Much like the morning in June when I woke feeling infinitesimally liberated from the violent grief I'd felt the night before, I recognized that the physical labor I was performing -- shoveling gravel, yanking out well established shrubbery, clearing away debris we've collected over the decades, cleaning, scrubbing, repairing my mountain home, all the while reflecting on the love my family has shared there -- had begun to clear away the debris that has been collecting in my head too. We built the mountain house in 2001 on land we purchased in 1999 next door to the cabin we rented many times when our children were small. Our mountain house has been a vacation getaway, a home for our kids at different junctures in their lives, and a home base for us all through life changes and illnesses. As long as Katie lived in Asheville, the house in Waynesville was important and necessary to our family. The house has served us well. Now, with Jack moving on and Katie gone, I've realized it no longer makes sense for us to keep it. Similarly, my husband and I are preparing to sell our big family home in Florida and are looking for a new, smaller place to live as we begin to live again.

Coda

Four months have passed since I wrote this essay. Only now am I emotionally and intellectually prepared to pick it up again with the intent to revise it. In that time, as one might expect, my grief has passed through phases, as grief is wont to do. Recently, a very close friend in whom I confide, one well acquainted with the grief of losing someone dear, offered a piece of advice that I have since put into practice as a methodology by which to live in the wake of Katie's death. By this practice, there has been a marked change in the nature of my grief. The advice my friend offered was prefaced on his belief that "the organism is hell-bent on wellbeing." Our bodies, our minds, in other words, want to be well. When we suffer a profound loss, it is necessary that we grieve as we do; but when we continue to torment ourselves, to tell ourselves stories about what we might have or should have done differently to have intervened or helped more/better/differently, how we might have changed our ways, how we might have listened more carefully – *all of that* – we are fighting our own nature which wants above all else to be well. To that end, my friend offered,

> …it is OK to let the whole damned world die with Katie. Let the whole thing go up in flames and with it, the stories, and the questions, and the theories and objectives, and meaning, literally the whole [thing]. Basically, set alight

> anything that makes your grief unbearable. The stories that make your grief unbearable, stories of guilt and responsibility, stories of duty, honour, the good, purpose, what a family is, what a life, what it should be, the 'what I ought to have done' and 'what I did' narratives of every stripe, the various nuanced perspectives that time and education affords, and, frankly, any story whatsoever that in any way undermines the cherished and by definition infallible thing that is your love for your daughter and your daughter's love for you. That is the epistemic center of your grief. Everything else is [noise]. You loved your daughter. You raised her with care and affection. You shared her life and her passions. You treated her when she was sick. You raised her up when she was well. And you laid her to rest when it was her time….

My friend's thoughts on grief changed the nature of my grief because upon hearing it, I gave myself permission to *be well*. Not *whole*. That will never happen. Nor *back to normal*, whatever that is. But to *be well* when I feel well. To feel well when I *want* to feel well! That shift is what enables me to sit here now and revise this essay that I started writing four months ago. I can now, finally, look at photos of my daughter, or listen to her voice recordings, or go through old messages she sent me without always breaking down as before. That doesn't mean I am *better* or *healed*. Sometimes I still break down. That is to be expected. We don't *recover* from the loss of a child. What we do is *endure*. The best we can do for ourselves, and for the memory of the child we lost, is to pay attention to the shifts in our grief, and give ourselves permission to live again, however incrementally, when we sense a shift is afoot. We must allow ourselves to be well when what we want most, aside from the impossible – the rebirth of our beloved child, healthy and able – is simply to feel well.

I will grieve for my daughter for the rest of my life. This much I know for sure. But I'm learning every day that grief does change, even as it changes us. Being dead with the dead grows untenable and exhausting, and I've come to think that it may very well be the exhaustion that reanimates us after such a profound, incalculable loss. So I have begun practicing being alive again, feeling well again. I've begun to take to heart Louise Erdrich's words in the epigraph with which this piece opens. She's right. No matter what tragedies we face, we still have to let ourselves love. We have to feel love, just as we have to feel grief. These are the reasons -- the true reasons -- we are here on earth. So I've started allowing myself to be alive again, to sit by apple trees and listen to the apples falling all around me in heaps, wasting their sweetness. I will taste as many as I can in whatever time remains for me in this life.

Bibliography

"Antiphospholipid Antibody Syndrome." National Heart Lung and Blood Institute. U.S. Department of Health and Human Services. Accessed October 30, 2021. https://www.nhlbi.nih.gov/health-topics/antiphospholipid-antibody-syndrome.

"Antiphospholipid Syndrome (APS)." Hospital for Special Surgery. Accessed October 30, 2021. https://www.hss.edu/condition-list_antiphospholipid-syndrome.asp.

Canter, Katie G. *Selfie with Moonstone.* Photograph. Asheville, 2016.

---. *Selfie with Mom*. Photograph. New York, July 2017

---. *Lungs and Roses.* Photograph. Durham, Sept. 1, 2017.

---. *In the Garden with Bella.* Photograph. Clyde, May 2013.

"Duke Chronic Thromboembolic Pulmonary Hypertension Program." medicine.duke.edu. Accessed October 30, 2021. https://medicine.duke.edu/divisions/pulmonary-allergy-and-critical-care-medicine/about/division-programs/duke-chronic.

Erdrich, Louise. *The Painted Drum*. New York, New York: Harper Perennial, 2019.

Erkan, Dr. Doruk. "The Abcs of Antiphospholipid Syndrome (APS)." HSS Playbook Blog, August 20, 2020. https://www.hss.edu/playbook/the-abcs-of-antiphospholipid-syndrome-aps/.

"John C. Haney, MD." Duke Health. Accessed October 30, 2021. https://www.dukehealth.org/find-doctors-physicians/john-c-haney-md.

"Lupus Facts and Statistics." Lupus Foundation of America. Accessed October 30, 2021. https://www.lupus.org/resources/lupus-facts-and-statistics.

"Mixed Dementia - Alzheimer's Association," February 2020. https://alz.org/media/Documents/alzheimers-dementia-mixed-dementia-ts.pdf.

Nayer, Ali, and Luis M Ortega. "Catastrophic Antiphospholipid Syndrome: A Clinical Review." Journal of nephropathology. Society of Diabetic Nephropathy Prevention, January 2014. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3956908/.

The New York Times. "Florida Coronavirus Map and Case Count." The New York Times. The New York Times, April 1, 2020. https://www.nytimes.com/interactive/2021/us/florida-covid-cases.html.

The New York Times. "North Carolina Coronavirus Map and Case Count." The New York Times. The New York Times, April 1, 2020. https://www.nytimes.com/interactive/2021/us/north-carolina-covid-cases.html.

Pérez-González, Alba, Josep Vilajoana-Celaya, and Joan Guàrdia-Olmos. "Alzheimer's Disease Caregiver Characteristics and Their Relationship with Anticipatory Grief." MDPI. Multidisciplinary Digital Publishing Institute, August 22, 2021. https://www.mdpi.com/1660-4601/18/16/8838/htm.

Shear, M Katherine. "Grief and Mourning Gone Awry: Pathway and Course of Complicated Grief." Dialogues in clinical neuroscience. Les Laboratoires Servier, June 2012. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3384440/.

Span, Paula. "A Child's Death Brings 'Trauma That Doesn't Go Away'." The New York Times. The New York Times, September 29, 2017. https://www.nytimes.com/2017/09/29/health/children-death-elderly-grief.html.

Wiseman, Stewart J, Mark E Bastin, Charlotte L Jardine, Gayle Barclay, Iona F Hamilton, Elaine Sandeman, David Hunt, et al. "Cerebral Small Vessel Disease Burden Is Increased in Systemic Lupus Erythematosus." Stroke.

Lippincott Williams & Wilkins, November 2016.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5079231/.