THE UNSHUTTERED HEART:

A MEMOIR OF LOVE, LOSS, AND RECLAMATION

by

KIMBERLY WILLIAMS

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Written under the direction of

Paul Lisicky

And approved by

Paul Lisicky

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THEESIS ABSTRACT

The Unshuttered Heart: A Memoir

by KIMBERLY WILLIAMS

Thesis Director:

Paul Lisicky

_The Unshuttered Heart_ is a personal memoir written in essays of varying lengths. It tells the story of a sheltered young woman who grows up lonely and feeling out of place. She finally meets another young woman who is also attracted to women and the two begin a passionate relationship. They are happy together, despite her partner’s chronic illness, and Kimberly’s giving up her writing. Kimberly eventually takes on the role of caretaker and sole breadwinner, and is devasted when Erin dies of a colon infection. She tries to navigate her grief in a world that does not recognize lesbian widows. Eventually, with much heartache and work, she refocuses on her dreams.
UNSHUTTERED HEART

I believe that we are all born with our hearts wide open, for what do we know of the world but love? Only later do we learn about pain, how others can inflict harm, how we should protect ourselves. Erin kept her heart open her entire life. That’s why she attracted so many people. That’s why I loved her at once.

My heart was unshuttered at first. All I knew was the love of two new parents who were excited just to have a child. I wasn’t a first grandchild, but I was still cherished. I had cousins and aunts and uncles to spoil me. I was too young to know the ache of grief that shadowed our little family: that my mom, a Daddy’s girl, had lost her father when I was one. That possible siblings were lost twice between my mother’s legs. That her frustrations would arise in threats “if you don’t behave maybe I’ll go away. Maybe I’ll go away and never come back”.

I believed her.

I began to look at myself as a disappointment. I was no longer the bright girl who could recite all her nursery rhymes. I was the girl who couldn’t keep her room clean and didn’t deserve her toys. The negative voices became much louder than the positive ones. I know I was still loved, but I began to feel as though I wasn’t earning that love fully. My voice became quieter and softer, so you had bend close to hear it. I discovered that I could put shutters around my heart so it didn’t hurt so much when I didn’t feel loved.
For the next twenty years, I nailed shutters across my heart. I thought I was keeping out the pain. But I was keeping out the love that was waiting for me, and it was not until I met Erin was I ready to let someone pry away those boards. For our precious thirteen years together I was loved completely, lavishly, until her last moment. My challenge has been what to do with a heart that has been opened but no longer has someone to love it. How to keep it open? How to rebuild it without resorting to protection I have always erected?
THE FRAGILITY OF IT ALL

When you find the love of your life, you heart doesn’t care what defects they possess. Crazy family, usually. A propensity for addiction, maybe a flawed gene or two that will result in monster offspring. But some people come already broken, damaged, or sick. Rarely are these ills fatal. Many Americans live with some form of chronic illness. Odds are, your new love will suffer from some chronic ailment.

I met the love of my life at the Barnes & Noble where I’d worked for a month. Her name was Erin Bridget Charles. She was a striking Irish-Italian beauty, with black hair and sparkling brown eyes. She could make a room crackle with warmth and energy. Erin talked easily with anyone, from the most erudite professional to the pizza cashier. Her joy and laughter was infectious. Her presence was like an upbeat song that could always cheer you and change your mood with just a few bars of music. She was the song I’d been waiting to hear all my life.

Erin worked as an Adjunct English Professor, but she also had her own acting troupe. At first, I found her a little too outgoing, too loud. I had no idea that she, too, was secretly attracted to women but hadn’t acted on it. But then a casual dinner out turned into a date, which turned into a night together. We watched The Adventures of Priscilla, Queen of the Desert. She dragged me up to dance through the up-tempo songs, and asked me to hold her while we sat together on the couch. The next morning we lay in her bed.
and planned our future. My heart leapt up and told me: *this is your mate. Don’t ever let go.*

Erin suffered from adult-onset asthma. She had been diagnosed a few years before, a genetic curse from her mother’s side. She carried bright yellow inhalers that she misplaced everywhere. The first attack I witnessed was terrifying; she became breathless, dizzy, and actually blacked out for a moment, her head down on the breakroom table. I called her name urgently. After an anxious moment, she opened her eyes, and told me she needed to get a rescue inhaler from her mother’s house. The ER was out of the question: she had no health insurance yet.

The drive was a frantic ride through wooded roads. I kept urging her to drink the coffee she clutched (caffeine helps open the airways). It was my first official meeting with her mother, who rushed out and guided Erin to a chair, helped administer several puffs of the inhaler, then told me to leave her house. Erin called me back in. The drama of it all bewildered me. But I followed her anyway. So was my initiation to life with a partner who has a life-threatening illness.

Chronic illnesses are incurable, but not terminal. Depending on the ability to control the disease and the worst of its symptoms, one can live a perfectly long life. For me, and for millions, there is no backing out, even after you’ve seen the worst of it. It simply became a part of our lives. I became an expert in my partner’s illness. After a few months, I knew every drug that Erin took, what might trigger an attack, and how to handle one if it happened. I could tell by the sound of her breathing that she would wake
with an attack. I projected outward calm, trying to slow her labored breathing, as I simultaneously tore the plastic top off of a vial of liquid albuterol with my teeth, then shoved the mouthpiece of the nebulizer between her lips. I would wipe the saline from my mouth while I encouraged her treatment and kept one hand on the phone, ready to dial 911.

I accepted the fear, the uncertainty, and we built a life together, ignoring the fragility of it all. Maybe the possibility of impending doom made our time together a little more precious. I never looked back.

We found a home. We spent time decorating it; she painted the walls, and I chose and arranged the furniture and knick-knacks. We filled it with love. We didn’t fill it with children. For a lesbian couple, children are an expensive, difficult acquisition. And besides, we were young enough that we could worry about it later. Instead, we had dogs. An Akita puppy was our first Valentine’s Day present to each other. Erin named her Margo Channing, after a spirited Bette Davis character. Eight years later, Erin also named her parents’ puppy Molly; she would become ours within two years.

Erin’s siblings gave us five nephews, and one niece. We found we loved being aunties, and then giving them back. We hosted elaborate murder mystery dinners, cocktail parties, and casual nights with friends. We both liked big band music, and danced whenever a song came on during a movie, or a commercial, or just cause. Seduction nights eventually turned from flowers and fancy dinners to a few lit candles and a certain CD on the stereo. Our home was small but warm with laughter and love. We could make each other laugh no matter what was going on, and that became an everyday goal for both of us.
Ten years in, I couldn’t imagine my life any other way. Sure, there were bouts of extended illness for Erin: pneumonia that took months to shake off, whopping cough contracted from a student, and an eventual diagnosis of chronic bronchitis. We relied heavily on my salary, as I became a part of the bookstore’s management team. Most of the possibly hazardous house chores fell to me: dusting, cleaning, etc. Erin was the laundry queen. I was the main cook, because I loved it. It was a respite for me, a chance to use the creativity that festered unused. But this was just a temporary phase, I told myself. I never considered myself as an optimist, but thread-bare hope will make you see bright corners around every turn.

As a lesbian couple, we were lucky to live in New Jersey. In 2004, same-sex couples could enter into a Domestic Partnership. This gave us the right to be considered next-of-kin in medical situations. I would be allowed in the ICU if Erin was hospitalized, and could make decisions if she was incapacitated. We got our license on an ordinary week day, when Erin went to renew our dogs’ licenses at City Hall. She called me to come meet her, and we signed our license in front of the City Clerk. Nothing particularly romantic, but it didn’t matter to us. We wore matching gold bands with a Claddagh design bought on a family trip to Ireland. We needed no formal ceremony, until the ceremony meant a true marriage – that wouldn’t come until 2012 in New Jersey, 2015 throughout the country. We could wait. We were married in our hearts from that first night.
By 2007, Erin was often breathless, and suffered from constant fevers. She saw one male pulmonologist after the other, heads of their departments at various hospitals. They shrugged at her symptoms and said her fevers might be psychosomatic. Finally, a young female doctor took her seriously enough to order more comprehensive tests, and proposed a lung biopsy to examine the scary spots the c-scans showed. It was major surgery, requiring a thoracic surgeon (a matter-of-fact Indian man, who was terrified of Erin’s large boobs), a chest tube, and several days in the hospital. But it was the only way to discover what was actually going on.

Erin made it through the surgery well, but spent the next three days in the ICU with a lung that collapsed twice. Erin’s family: her sister Tara in Maryland, her brother Sean in Houston, and parents who were now in Gettysburg, had always left me to tend to her. They considered Erin a bit of a drama queen who exaggerated her health problems. This surgery they took seriously, with her sister visiting her in the hospital, and her mother planning a stay for several days after Erin’s release from the hospital. This relieved a little of the pressure from me, but this was to be an anomaly.

The biopsy finally gave us answers. Erin had a granulomas tumor removed, along with a small piece of lung so scarred by asthma and pneumonia it no longer functioned. We finally had a name to put to all her symptoms: sarcoidosis. Sarcoidosis is an inflammatory autoimmune disease. It can affect various organs, but most often affects the lungs and lymph nodes. It can result in granulomas, organ damage, arrhythmia, intense pain, heart failure, and in 5% of patients, death. But only 5%. It could be treated (but not cured) with increasing amounts of steroids.
The cause was unclear, but family history (her grandfathers and uncles had it) can be a factor, and exposure to talc and silica can cause granulomas. Erin loved her powder, and silica was found in detergents, make-up, toothpaste, and more. It was something I discovered in a mad crusade to rid the house of anything harmful. It was also a by-product of construction. The house we rented had bad pipes in the bathroom, which meant our kitchen ceiling below it had been torn out and replaced twice. The work was done by a skinny alcoholic friend of our landlord. He smoked cigarettes on the back steps, and had carelessly dry-sanded the ceiling both times, which had covered the kitchen and dining room in silica-rich dust.

With her bad lungs and sarcoidosis, Erin was forbidden to work. We went through the arduous task of applying for Social Security Disability, debating the answers to the 30 page questionnaire. We turned it over to her doctor to complete the medical part, and crossed our fingers. We’d heard nightmares about friends and family who were truly disabled, but still had waited for months or more, applying and appealing, for checks. Erin got a call from Social Security two weeks after her doctor sent the completed application in. She was approved. Not only was she approved, but she was considered disabled months before, and would be receiving some much-needed back pay. We felt a rush of relief, but I wondered exactly what had been in the pulmonologist’s report.

Erin joined the 9.9% of working-age Americans who are officially considered disabled. We received a small stipend each month, a bit of help to defray the price of health insurance and spiraling prescription costs. In 2008, the Great Recession hit. Barnes & Noble decided to freeze the salaries of its managers, while the booksellers still received nominal yearly raises. Luckily, B&N covered insurance for domestic partners,
but at a steep price – 11% of my weekly salary. After two years, Erin would be eligible for Medicare, but we knew it wouldn’t cover half of the tests, doctor visits, and medications that she needed. I had to keep my position at B&N for the insurance and the money, despite the frozen salary and problems that had begun to crop up with the other managers.

Debilitating chronic illness claims at least two victims: the one who is ill, and the well spouse. I was lucky that I didn’t need to take care of Erin physically: she could wash, dress, and feed herself. But I was her emotional support. I was her lifeline to the outside world, especially after her car’s muffler broke and we decided it was not worth the cost to repair and insure her car. There is little support out there for young caregivers; most caregiving groups focus on adult children caring for their aging parents, or retirees caring for their Alzheimer-suffering spouses. I was lucky to come across Maggie Strong’s *Mainstay: For the Well Spouse of the Chronically Ill* on the shelf at Barnes & Noble. I read it during my breaks. It was a beautiful, illuminating book. She wrote about looking up divorce lawyers the day her husband told her it was too much for his heart condition to mail a letter. *So true.* It let me know I was not the only one who experienced the overwhelming burdens, frustrations, or guilt of dealing with an ill spouse.

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We started to live our lives in crisis mode. Erin careened from one health disaster to the next. I was breadwinner and caretaker, and along with the sarcoidosis, she also began to suffer from chronic pancreatitis at bi-annual intervals. She had three more surgical procedures in as many years. While I used my vacation time for planned procedures, unexpected hospitalizations held their own problems. A day in my life went
like this: wake up, take care of the dogs, visit Erin in the hospital, go to work for eight and half hours, and come back to visit her (while a near-by relative feeds the dogs dinner), stumble home and walk the dogs at midnight. Set the alarm and repeat.

Crisis-living left me exhausted and somewhat bitter, but I told myself she would do the same for me. Every month brought another illness: Erin had diarrhea and a slight fever for two days. Just a stomach bug, I told myself. I loaded her up with Immodium and Gatorade while I went to work my monthly 10 hour split shift — a two hour manager’s meeting in the morning and then a return at 3:30 to close the store. I arrived home near midnight. Luckily, she was asleep.

The next day, Erin continued with the mysterious intestinal problems. I cautiously asked her if she thought it was another bout of pancreatitis, but the pain wasn’t the same. I slept late the next day, debating what to do. Only another caregiver would understand my reluctance to go to the hospital, again. I whispered to God, to the air: Not again, not again, I just can’t do this anymore. But the illness continued, and I had to deal with it, however much I tried to convince myself it was nothing. By Wednesday morning Erin was dehydrated and actually confused me for her mother. No choice. We’d have to go to hospital. Again.

I thought this was going to be like any other visit; I grabbed a bag with essentials, left unpacked from her last hospitalization. I filled out the paperwork and answered all questions. I knew her medications and previous surgeries better than she did. Erin was slightly incoherent. The medical staff took me at my word. The medical insurance was in my name, after all.
I’ve never been a pushy patient-advocate, but I knew something was wrong when her fingers started to turn purple. I waved her nurse over. The term cyanotic got added to my vast medical terminology. It meant that not enough oxygen was reaching her extremities. When admitted, blood was taken to be tested, but no one could get an IV started. My precious gal had always been a hard stick, in the best of times. Suddenly the doctor returned with confusingly dire news: Erin was in renal failure. They needed to put in a central line. When the doctor asked Erin, “How are you feeling?” it solicited her whisper I’m scared. Then she closed her eyes and went silent.

The fragile existence I’d held together for so long shattered. We’d played the odds and we’d finally lost.

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I was thankful that my mother lived only ten minutes from the hospital; she arrived as I tried to understand what was happening. I didn’t realize how poorly I’d dressed for the overly air-conditioned ER until she put a sheet around my shoulders. Another doctor came to talk to me, while several staff members worked on Erin. Dr. Rosegarten was kind and soft-spoken, and had the face of a grade-school teacher in a neatly pressed lab coat. “Do you have any children?” she asked. I shook my head. “Any other family? Does she have family?” Yes, her mother lived over three hours away in Gettysburg. Her father had passed away the year before. Her sister Tara was an hour’s ride away, her brother Sean a 3-hour plane ride away.

“They need to be informed. She might not make it through the day.”
A torrent of tears choked back during every other crisis started to spill down my face. Dr. Rosegarten must have had years’ experience delivering this type of news. She smiled at me sadly, but with a little encouragement. She seemed to read my mind: my regrets, my fears. “You got her where she needs to be. And you can do this. I know you can.”

Before calling Erin’s family, I needed a practice call. My practice call was to my boss. It was my day off, but I knew I wouldn’t be in the next day, or for the foreseeable future. My boss was a cool, stoic woman, a few years older than me. She hated absences, especially among her senior managers. She startled me with her gentle tone, genuine surprise, and promise of prayers.

Business done, I called her mother. Yes, Erin was in the hospital again. Yes, it was serious. Yes, she should come. I couldn’t quite repeat the phrase might not make it through the day. My mother-in-law got lost going to the grocery store. I didn’t want her to be an emotional wreck – or more of an emotional wreck than she might normally be — for the 2 hour ride to my sister-in-law’s house. I just told her: the sooner, the better. I called her sister’s cell number and work voicemail, leaving the same message on both, Erin in the hospital, very serious, call me ASAP.

Transfer from the ER to the ICU happened much more quickly than movement to a usual hospital room. By the time I’d moved my car to the permanent parking lot and retrieved a sweatshirt, there was a bed for her. Our home for the next few days would be ICU, Room 1. There were a dozen decisions for me to make, each posed as necessary for her continued survival. Respirator for now, yes. Surgery that would give her a 50% chance, yes.
My sister-in-law Tara arrived in time to hear the surgeon’s pitch. They suspected Clostridium difficile colitis, an infection that lies in wait and attacks the lining of the intestines. They would do what they could to remove the infection, up to possibly removing her colon and giving her a colostomy. She would then have a bag attached to her for the rest of her life. But that was preferable to death, of course. Tara and I joked about Erin with a colostomy bag. *Honey, time to change your bag.* Oh God. But I’d have done anything for her. Anything.

Though I’d never heard of *C diff*, as the professionals call it, the disease has become one of the “most common microbial cause of healthcare-associated infections in US hospitals” according to the CDC. It has caused nearly 500,000 infections in a single year, and with the strain being particularly resistant to treatment, about 29,000 of those patients die within 30 days of their diagnosis. So statistical chances were 6% that Erin would not live through this. But the infection had been active for weeks, probably attacking after Erin had taken antibiotics to get rid of an upper respiratory infection. It was likely Erin had been exposed to the infection during her last hospitalization, a few months before. She had also been exposed to MRSA in the ICU after a surgery to repair her hiatal hernia three years prior, but luckily that had never become active. I hadn’t considered the risk of all her hospital stays; at the time, they were each necessary to fix her whatever was ailing her at the time.

Tara and I watched them wheel her off to surgery and we waited in the ICU waiting room. Tara confided in me that her GPS had taken her through the “hood” of Camden. She had reason to be afraid, though she always carried herself with a toughness that contrasted with her Nordic good looks, her platinum blonde hair and blue eyes. Her
husband, Andrew, would drive my mother-in-law to the hospital — both of us worried that Mom would become hopelessly lost in the deep, murderous heart of the city if she drove herself.

Mom C arrived as we waited for Erin to make it through surgery. She looked startled and worried, a petite woman without her armor of perfectly coifed hair and make-up to protect her. We hugged and talked about Erin’s condition. Several weeks later, my mother-in-law would also come down with c diff, and would suffer illness, recovery, and relapse for months. For now, she sat quietly with us and tried to make small talk.

Erin returned from surgery and we sat impatiently as the nurses settled her into her room. The surgeon explained that yes, Erin had c. diff. They had flushed out what they could of the infection and had left her abdomen open in case they needed to go back in to remove more. She was given the standard treatment, strong IV antibiotics, and was covered with a cooling blanket to reduce her fever. We three, the women closest to her, finally entered her room. The respirator puffed oxygen to her in rhythmic pulses, the central line bloomed out into several tubes delivering IV fluids and medicine. Her abdomen was covered in something akin to blue duct tape, protecting the surgical wound. A whitish nitroglycerin cream was smeared on her purple hands, trying to encourage more circulation. Automated surgical stockings expanded and deflated around her calves, discouraging blood clots. Luckily, the drugs kept Erin in a sedated twilight.

She was, the ICU intern told me, the sickest patient in the ICU. She would remain their sickest patient for the next four days. I stayed until after midnight. The staff was lenient about visiting hours, and I was allowed to be there at any time, day or night.
My mother returned after making sure our dog, Molly, had been retrieved from our house, fed, and walked. I would spend the small amount of time I was not at the hospital at my parents’ house, which was closer to the hospital than ours. I slept in my sister’s childhood bedroom, with Molly curled in the hollow of my stomach, or by my knees. Our first dog, Margo, had died at home, 10 ½ years old, in 2009. Molly, a Jack Russell-Pug mix, worried over me, the only part of her pack left in her sight. She didn’t have to be told that her other mommy was very sick. She sniffed my shirt and recognized the antiseptic hospital smell, and burrowed closer to me.

My cell phone went off at 5:15 AM. Erin had not had a good night, and the surgery staff wanted to go back in. I gave my oral consent to a nurse anesthetist who listed all the dangers and possible complications of the surgery. I changed into clothes borrowed from my sister’s drawers, and let Tara’s house know what was going on.

I stopped in the chapel of the hospital before going upstairs. This was Lady of Lourdes, a place I had visited several times to see my Mommom when I was a child. The surprisingly large room was a full-on Catholic chapel, filled with dark pews, gold angels looking down, glowing candles and glittering stained glass. I knelt in a pew, my Catholic upbringing kicking in as I reflexively crossed myself. I did not pray for Erin’s recovery. I knew miracles happened, because we had been brought together, two lonely souls afraid to admit we both liked women. I didn’t ask for another miracle. I didn’t want to ask for something I might not receive. I prayed for the strength to endure whatever was to come.

Morning turned into afternoon which turned into evening. Erin made it through surgery, but more of her colon had been removed. Tara and her mother came to sit with me, and my mother came as well, bringing her parish priest to administer the “Anointing
of the Sick”. When I was young, it had been called “Last Rites”, but I guess the change in language was meant to be more hopeful. Erin’s family was also Catholic, and her mother appreciated the ritual. We kept a bedside vigil, watching as her legs also began to turn purple in large blotches. Tara told me that Erin’s brother, Sean, was flying in that night. One of his greatest regrets had been not coming up when their father had suffered his fifth heart attack, and passed away a week later. Tara realized how grave the situation was, while Mom C asked one of the doctors if he thought Erin was out of the woods after her second surgery. He looked at her with a little befuddlement but told her softly, “No. I’d say we’re still in the forest.”

Sean arrived late that night, and I felt the pain of his shock when he looked down at his big sister, unconscious and tethered to half a dozen wires and tubes. He hugged me hard. The new night nurse was strict, and allowed him only a few minutes, as it was past visiting hours. I stayed the night in a recliner next to Erin’s bed, dozing a little in between the interruptions of the nurses, interns, and respiratory therapists. At least she didn’t need any new surgeries.

More things began to go wrong. Erin’s lungs were now dependent on the respirator, and they would likely remain that way forever. The MRSA which had lain dormant now started an infection in those delicate lungs. Erin’s hands turned a blackish mulberry color, and the nurses no longer checked her lower legs for poileal (by the knees) or dosalis pedis (by the ankle) pulses. She would lose the use of her legs as well as her hands. The hardest part was not being able to hold her hand and feel any response. Instead, I sat close and caressed the delicate skin of her inner wrist.
Once the MRSA was active, we had to don gowns and gloves in order to enter her room. More people came: Erin’s Aunt Sharon, Mom C’s sister, came to support her. Erin’s cousin and her college roommate came, as well as my Dad and then my sister, who spent her workweek in Ocean County, and her weekends at my parents’. The staff didn’t mind who came, as long as they were gowned and gloved, and the room wasn’t too crowded.

Thanks to my Mom’s diligence, Erin was “Anointed” each day. She received three operations in four days; the last one completely removed her colon. Her brother, prompted by his wife in Texas, tried to wish me a happy birthday every day. Soon, not yet. I posted updates on Facebook to friends and relatives near and far. Thousands of prayers were said. In the end, there was no saving her. Though the staff tried everything they could, Erin died by inches, a little each day, according to her death certificate: it listed three causes of death over four days. Sarcoidosis was listed as a contributing factor.

When the nurse brought me the DNR papers, there was no question of whether or not to sign them. The only question was when to remove the extraordinary measures, and I knew it needed to be soon. Her family and I had a short meeting in the conference room at the end of the hall. The doctor laid out the stark truth: had Erin been any older, her heart would have given out already. They have been adding more medicine to regulate her heart rate. Her hands would needed to be amputated, and possibly part of her legs. She would forever be dependent on a respirator and a feeding tube. They couldn’t measure her brain function.

There was really no reason to continue things. Everyone was crying, and Sean whispered, “Now we know why Dad went when he did.” But the final decision was mine,
and it was my birthday. Her family didn’t want me to decide right away. But I knew my sweetheart. Ever the people-pleaser, she would hang on as long as she could, just to spare us pain. And that was no way to leave this world, desperate and fighting. I told the doctor to transition to palliative care right away.

Once I’d decided, I became impatient; I hated the gown and gloves meant to protect me from the deadly infections that would soon claim her. I wanted to remove all plastic barriers and crawl into the bed with her. To whisper her to sleep.

But while it had felt like it had been just the two of us for so long, there was a whole host of family members to consider. Erin’s mother, of course, wanted to be with her until the end; she’d brought her into the world. Tara, too, wanted to be with her sister. Her brother couldn’t. Her Aunt Sharon wanted to be there for her sister, my mother-in-law. And my sister wanted to be there for me. The intimate farewell I’d imagined became a crowded affair. Thankfully, my parents had kissed Erin goodbye, and gone home to wait. I’d return to them when all this was over, to the house where I was raised, where Molly, the last of my little family, waited for me.

The hospital staff was supportive, and understanding. Mercifully, they turned off the alarms that would signal death. They removed all other machines and tubes one by one. It took an entire 35 minutes to disconnect everything. Finally, the respirator tube was removed. It was thick with muddy brown gunk that had been clogging her lungs. Finally, she was free of everything but oxygen tubes in her nose and the wire that measured her arterial pulse. I stood on one side of the bed, her family on the other. The numbers on the heart monitor silently plummeted. I’d brushed her hair to hide the small white streak in her bangs, wiped away the goo the monitor tabs and bite block had left on her cheeks and
forehead. She laid there dark-haired and pale, beautiful beyond belief. I leaned over and whispered, *it's ok. You can let go now.* I felt her heart’s final beat pulse beneath my gloved finger. And then it was over. Nearly fourteen years together, and then, no more.

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I sobbed but didn’t scream. I was too numb to break down all at once. It happened in pieces. I was suddenly a widow. I’d wear that label not just for the next few months, but forever after. Whatever else I was, I was a broken half. I could tell people exactly how long I’d been a widow. Grief math is second-nature and precise: it’s been 6 years, 7 months, and one day.

Only 1.1% of women are widowed before age 39. I was a member of an exclusive club I never wanted to join. There are very few support groups out there, and while others might have lost their spouses, they would not quite understand. I had an incredible love for a maddeningly brief amount of time. Erin was my first, and I thought she would be my forever.

Our fragile existence together had ended. Life had been hellish at times, but we’d endured it, because we couldn’t imagine life without the other. Complications arose like weeds. As caretaker, I didn’t question the garden, I didn’t question my ability to pull out the worst and go on. That was my life. I simply took my hoe, and rooted out whatever was harming my beloved. While the garden bloomed, it was Eden. And any time in paradise is worth the price, however brief.
It was the last day of fifth grade. I stepped out into the early morning humidity, squinting into the yellow haze. My backpack was light; only a library book, notebook, and jar of jam for my teacher were inside. I was dressed up in a cast-off Easter dress of my cousin’s; it was a creamy ivory polyester, with grown-up spaghetti straps. I had done my best to tighten the bright orange belt around my chest and waist, but it still sagged loosely. I was wearing a badge pinned above where my left breast would hopefully grow in. It looked like a play sheriff’s badge, but it actually read: Safety Patrol. This was my first official day as a safety.

Mom pulled the door closed behind me, urging me to “have a good day.” I walked the four leafy blocks to reach my assigned post. In our crime-free, suburban South Jersey town, sixth graders were given the job of being “safeties”. For this day and next year, I would be covering the post in the middle of the long, empty block that led to the school. There would be no streets to help cross, stretching my arms up like birds’ wings, holding back the eager youngsters from harm. My only job would be telling the students not to run, or to make sure no one cut through the gulley that ran along the ravine behind me.

I arrived at my post, placing my backpack against the telephone post in the middle of the block. Tall yellowed grass rose up past my knees, ready to swallow me. Across the
street stood a grove of peach trees, hunched and knotted like old crones, reaching green
arms to the cloudless sky. My recent reading had been more fantastical than usual, tales
of Camelot and the like. I liked to think of scenes in romantic terms. I pulled up a long
shoot of grass and wrapped it around my index finger, dry fibers separating to stand out
at odd points, like a little crown.

I’d have at least ten minutes before the other children would venture past in little
groups. I searched the ravine behind for wildflowers, but saw nothing but Queen Anne’s
lace, and some flowering weeds. When we first learned about the Underground Railroad,
I’d imagined that the ravine had been a part of it, with runaway slaves sneaking through it
at night. Our town was north enough that a few black families had settled here, just
beyond the school. They had built a church and a few houses in the 1850’s. Their great-
and great-great grandchildren still lived along the two streets on the other side of the
school. Three of them attended school; one was in my class.

Byron was also shy, a nice boy with beautiful fudgy skin and long lashes. We
didn’t talk much, but sometimes we shared lunch. He wore his otherness on his skin,
while I wore my otherness on the inside. It was something I couldn’t name back then, just
a feeling of not fitting in. He once sat on the school curb for a whole hour with me when
my grandmother had mixed up the time she was supposed to pick me up from a class trip.
Our fourth-grade teacher had debated about whether or not to stay with me, or make a
call, but I had insisted, with a rising heat in my face, that my Gram would be there soon.
Byron stood by me and promised he’d wait with me. He knew a lot about cars, and he
talked about different kinds until Grammy had pulled up, in her beige Pinto.
I leaned against the telephone pole, feeling sweat bead and drip down the back of my neck. I tried to imagine the peach grove across the street into a medieval forest, but my hair had grown tired of its knot, and my curls began to unravel down my back. I’d begged Mom to let me to put my hair up for this last day. I said it would be cooler, but I really just wanted to look older. I’d learned to twist it up myself, so I undid the grass ring from around my finger, and caught at the falling waves of copper.

My hands were full of curls when the car pulled up. It was red, with cracked leather seats, and a box full of papers in the back. The driver smiled at me and leant toward the passenger window so he wouldn’t have to shout.

“You look pretty,” he drawled, slower than most people. He pushed dirty-blonde bangs out of his eyes.

“Will you show me your underpants?”

They’d talked about this in safety patrol preparation, but I couldn’t remember what to do. I let my hair drop against my back. The sweat dried in crystals immediately. I was compelled to remember the sight of my underwear that morning, rosebuds on cotton. One of a set of three, each a different color. Suddenly, I couldn’t remember what color I was wearing.

“No,” I breathed in sharply, “no.”

He tossed his hair back, his lips widened in a show of acceptance.

“All right, then. Just watch this.”
He unzipped his jeans, unsheathed a man’s part larger than any I’d seen. I tried to feel the grooves of the scarred wood of the pole with my hands, pressed my back hard into it, my heart hammering. But I couldn’t help the way I stared, how my mouth dropped open. He’d rubbed his thick tail with both hands, blue eyes enlarging to hold mine. His movements became a rhythm, a humming that didn’t need words. But it took too long; disgust began to wash through me, and I turned my head away, like I should have at the start.

He finished. I could tell when I heard his zipper pulled up against its metal teeth. I glanced back at him. He gripped the wheel and tried another smile, this one less certain.

“Well, see ya,” he mumbled.

The car took off and bumped down the road to the corner, his right flasher half-blinking. I could report this, of course. That’s what you were supposed to do. I could describe him well. And the car, like Byron had pointed out to me that one day. It was a Pinto.

The first children started to walk by, the youngest. They walked in twos and threes, giggling, excited about the last day of school. Some carried presents for their teachers, or cards dripping with glitter and glue. I found my voice again and told the eager ones not to run. Blue. That’s what color rosebuds I was wearing. I started to gather my hair again, twisting it into another knot, leaning against the pole for balance.

Shame silenced me. I never did tell anyone. I don’t know if I felt complicit or not. I don’t know if seeing that unwelcome penis turned into a lifelong revulsion. I just know it was one of the things that I let mark me as different and damaged for far too long.
THE LONELIEST SIXTH GRADER

Throughout elementary school, I had a core group of neighborhood friends: Ann, Allison, and Gina. Ann lived directly behind my house and Allison lived next to her. I always hopped the fence, or later, used the gate that my dad had installed. Allison had lived there first and had been my best friend, but when Ann moved in the knew they were fated to BFFs. It was hard to feel so betrayed at five years old. Gina lived a few houses up from them. She was a nice enough girl who, like me, existed on the outskirts of Ann and Allison’s relationship. They were the bosses, and we orbited around them, trying desperately for that third place.

Of course there were other girls in school with whom I was friendly, but I was painfully shy. My great conversation starters were “Could you pass me a piece of paper?” or “What page are we on?” There were girls I knew through softball (where I stood in the outfield and prayed that no balls would come to me), through music (I played violin) and through Girl Scouts. But I knew I would never be one of the popular girls, the pretty and self-assured ones who wore designer clothes, which had just come into fashion. I was lucky if Mom could afford to get me a pair of Jordache jeans from Clover for the first day of school.
I’d always turned to my books and my schoolwork to distract me from my shaky social standing. I read any time we weren’t working on other subjects. I had gone through nearly the entire “extra reading cart” for advanced readers. I was quite proud of the fact that I always tested at several reading grade levels when assessed at the end of the year – I could barely ask for a pencil, so I certainly couldn’t work in a humble brag about having a 10th grade reading level in 5th grade.

The foursome of Ann, Allison, Gina, and I began to crack and crumble. Growing older we all wanted more, we wanted to have our voices heard. Though the logical solution may have looked like Gina and I banding together, I was too jealous of the times she had been the “next in line”.

Sixth grade seemed to be the time everyone was beginning to flex their judgmental muscles, readying them for seventh grade, when we’d go to the junior-senior high school and meet students from all over our small district. The girls were practicing their new styles, their bored faces, their excited exclamations. I watched them as I wrote a gothic tale called “The Dark Rose”, illustrations included. Maryellen, who was an uber-popular blonde with long lashes, glanced at it. She sat next to me in the afternoons. She flipped through its pages. I could tell she was practicing her patronizing smile when she returned it to me, “How sweet.”

While the popular girls were practicing their adolescent ways, I was feeling more and more out of place. I wasn’t boy crazy, or girl crazy (I didn’t even know that was possible). I was book crazy, and I was also looking forward to maybe finding some new friends in 7th grade. By the spring of sixth grade, with the warm weather and our hormones starting buzzing and firing off at unpredictable times, the girls were all a bit
moody. I don’t remember how I gotten into an argument with Lynn, a brunette who was one of the bus kids, but her final retort was “Nobody likes you.”

It hung in the air like a terrible taunt.

“Ann likes me,” I countered.

“No she doesn’t,” she said, “she just plays with you because her mother makes her.”

I stared at her. Lynn’s blue eyes sparkled with the mean certainty of truth.

She was right. But she couldn’t be. I couldn’t be completely friendless.

I turned to the girl behind me in line.

“You like me don’t you?”

“Sure.”

I went down the line asking each girl in my class, the heat rising in my cheeks, my eyes starting to water. I asked more and more desperately.

“You like me, don’t you?”

Each girl said yes with little enthusiasm, barely looking at me, only half paying attention, as the truth became clearer and clearer. Everyone was lying. I had known it for a long time. It just took someone bold enough to point it out to me. I stood at the end of the line and did my best not to full-out cry.

It would be another 13 years until I met Erin and she would make me forget all of those lonely days. In fact, had I known her then, she would have been in 10th grade, busy
with theater and band, a boyfriend, and plenty of friends of her own. If she’d seen me on that day, she would have let me cry the tears I sniffed back, made me laugh for the rest of the afternoon and promised me, “It will get better. I promise.”

ALTERNATE JOURNEY

Philadelphia, 1997

I was a suburbs type of girl. There was no denying that. I was brought up in a modest but loving home – I had two doting parents, and a bedroom of my own filled with toys and books. We had a front yard and a back garden, a dog, and eventually, I had a sister. My mother had been a teacher but she’d been forced to stay at home with me. She sublimated her boundless energy into baking, keeping the house clean, and molding me to be the perfect little girl. I loved the baking, hated the cleaning, and failed miserably at the perfection part.

Damian was definitely a North Philly kind of guy. Now settled with his dad and stepmother, he had lived in a variety of places with his Mom and brother during a tumultuous childhood, acerbated by his Mom’s mental illness and his parents’ divorce. Sometimes the lights went out, sometimes there wasn’t much to eat. He thought a friend whose family had frozen French fries was rich. Surviving his upbringing with a sense of humor had been difficult, and usually the darker side of music and films were his escape. His prom-king looks might have brought him admiring glances from the girls, but he’d
felt like such an outsider, there would be no camaraderie with anyone but the other outsiders.

We met in the bookstore I was assigned to in Northeast Philly. I had worked my way from part-time bookseller to Store Manager in a mere 8 months. It was more by luck than by ambition, but I happily accepted the promotions, one after the other. When my own location closed, I was transferred to the new Frankford Mills store, which had just lost both the Assistant Manager and Store Manager. I didn’t mind the extra drive, and this store was going to be big something big, something to rival the new Barnes & Noble stores opening up in our area.

Damian and I were a mismatched pair, visually and otherwise. He was a foot taller, standing at 6’3”, and when he wasn’t at work, he wore concert shirts and jeans. Damian’s blonde hair reached his shoulders, he had gray-blue eyes behind his wire-rimmed glasses, and one of the first tattoos I’d seen up close (other than my uncle’s unfortunate “Rose” tattoo – he married my Aunt Mary). I looked like I’d stepped out of a Pre-Raphaelite painting with my curls and long, floral dresses. When I wasn’t working I usually wore all black in the New Yorker-style of all black, not the Goth style. Any outsider would have paired the new Assistant Manager up with anyone else.

My first impression of Damian was Damn, he’s handsome, and he probably knows it. I didn’t expect to have anything in common with him. I prided myself on my eclectic taste in art, literature and music. Okay, maybe I was classically eclectic. But certainly we wouldn’t have anything to discuss outside of the book business. But like anyone who is forced to work alongside others, especially when that supervisor is also painfully shy, I grasped for things to talk about. Damian had worked in the mailroom of a
local company for a few years after high school, but was now attending community college. He was taking a literature class. *The Scarlet Letter* was the first book he needed to write a paper about, and I offered my editing skills. I considered myself a decent editor and writer.

We worked on the paper and then watched *The Simpsons*. I loved to laugh, and he loved to hear my laugh. Damian’s first floor room was like a cave: the bedspread was dark brown, and dark shades covered the windows. Damian was still nursing a broken heart from a long-term relationship. He talked about all his relationships, his love of movies, his need to know more about books. He showed me a short movie he’d made, of his first girlfriend placing donuts on gravestones in a cemetery. I could tell he was nervous, but a minute or two in, I started laughing. I couldn’t stop. He was delighted. Never underestimate the dark humor that can lie within even the most unlikely form.

We were soon a kind of “uncouple”. We loved being in each other’s company. It was like being with a friend and lover all at once. I cooked for him, and he declared, “if you cook like that every night, I’ll marry you and just sleep with prostitutes.” I was raised a Catholic, and belonged to a non-denominational Christian group. Damian was my rebellion, he was my acknowledgement of my otherness. He knew about what I called my Catholic wish never to have sex until marriage – though it was actually more of a sentimental wish to remain a virgin until I knew I was in love. Damian was not only an atheist, he was an antagonistic enemy of religion. He believed it all was a sham, something people had made up to console themselves and he wished to wake them up. He talked to me about religion, but he was never disrespectful, just curious. His true disdain for it came later.
After returning several late nights to my parents’ house, they recommended I stay over at Damian’s house after late nights. Damian didn’t mind sharing the bed, and we snuggled and watched TV and movies and listened to music – he introduced me to Tori Amos and Ani Difranco. We went to concerts and museums and I introduced him to Klimt and Rodin and Camille Claudel. We loved introducing each other to new things, opening up worlds neither knew existed.

We were caught up in the language of the Brontës, of Hawthorne, of Shakespeare, as Damian encountered these for the first time. A recovering Romantic, I was happy to share some of my favorites with him. It was also the year of romantic movies: The English Patient, Baz Luhrman’s Romeo + Juliet, Hamlet. I shared some of my own journals and poetry with Damian, and he gushed over my work in terms all writers would die for. Our store’s computer system had a rudimentary email system, and we left each other ridiculously flowery messages. We’d write to each other whether or not we were working a shift together or not. If one was without the other, there could be a back log of twenty some notes for the next day. I recently found some:

(Damian’s initials were DJP, mine are KSW)

From: DJP       To: KSW       7/12/96
I miss you like angel like Timothy Leary misses LSD, I miss you like Burt Reynolds misses hair, I miss you like Liz Taylor misses youth, but most of all dearest Kymberly, I miss you like all artists who long to be with their muse. Strange to think of you like so, but you so inspire me so me guesses you fall under that category.

We shared stories of our childhood that we could now laugh at. Like how I cried when I was measured as the shortest kid in second grade, or how he thought he had broken his dick the first time he masturbated when a shower of semen sprayed across the bed. No doubt, he had the better stories.

And why just a friendship instead of a romance, you ask? Because I had already broken several hearts in my years between high school and college, unwittingly giving hope to boys who would later horrify me by declaring their love. I’d had no high school romances, and as the pattern continued in college, I’d decided it was safer to dedicate myself to writing. I believed myself incapable of anything other than unrequited love. I was a very late bloomer in terms of seeing myself as a sexual creature. In my adolescence I’d lived only in my head, and had controlled my body very strictly as a gymnast. I’d been seduced by chaste love stories, and had never felt a curious throbbing between my thighs. It wasn’t until I was eighteen that I felt that there was actual life below my waist.

EUROPE, 1997

I planned our trip to hit the highlights of art and literature: London, Amsterdam, Florence, and Paris. We would visit the Moors of the Bronte sisters, the Tate and the National Gallery. Amsterdam would be part cultural, part art: Van Gogh and the Rijkmuseum, plus the Red Light District and “coffee” houses. In Florence we would visit
the more religious art: the Duomo and the Uffizi museum. There would be no escaping the churches, though I hoped Damian would be more interested in the architecture than repulsed by the sacred.

And finally, Paris. I had been to Paris as a seventeen-year-old; I still spoke rudimentary French. We’d visit the Rodin Museum, and I’d finally see Camille Claudel’s work up close. We’d visit the Louvre, and take the train out to Vernon, where a former professor had recommended seeing the gardens and house of Monet. There was the Notre Dame, the Sacre Couer, the winding hillside of MonteMarte. I would show off my skills at navigating a complicated but well organized Metro system.

From: DJP To: KSW 11/15/96

You are beautiful, Kymberly. More beautiful than any woman I know. You have won my heart tenfold and that is why I play the fool of ignorance. You are the sweetest breath my neck has ever known. I do not give into you because I fear you. I do not know as of yet if I wish to be destroyed, again.

There is a certain satisfaction in introducing others to the things you are passionate about. The trip was my Christmas present to him. I hoped it would bring us back to the early days of our relationship. He had started to want more, like all men do, but not necessarily from me. He wanted to keep our friendship and have a girlfriend at the same time, but it was tricky. I felt things shifting around the holidays. I was sick the entire month of December, but had to work through it, and I was less of a ray of sunshine. Damian missed his exes at Christmas. I didn’t realize how lonely it could be without someone when you’re used to it.
For New Year’s, we went to a casual restaurant with his family. I loved the veggie burgers and Spanish fries which we’d enjoyed on several other occasions. I foolishly tried to keep up drinking margaritas with the others. I didn’t feel anything until we all stood up, and the black wooden floor tilted. Damian steered me to the door. I hoped the walk down to the waterfront would refresh me. Maybe just a little.

The fireworks were dazzling bits of dizziness. I leaned back against Damian. I knew he would hold me up if I needed it, but I didn’t want to be that girl. I stared down at the pavement and tried to will the world to stop swirling. But after a while, the shrieking stars fizzled. I walked along with everyone until I just couldn’t keep it in. I might have mumble something, and then stopped. The contents of my stomach splattered on the cobblestones. Damian probably asked if I was okay, which was at once the stupidest and sweetest thing to ask at that time. No. I heaved again. I had the decency to feel bad for whoever’s stoop I was befouling. I wretched for several minutes while Damian’s brother sat with me. Damian returned with a bag and some paper towels he’d gotten from one of the closing restaurants. Think you’re OK to get up? Damian asked. I cautiously nodded.

I spent the next 20 minutes holding the bag and getting sick as we rode in the backseat of the van. I didn’t think there was anything left inside me. Damian rubbed my shoulders, and I handed the bag to him as we got to the condo. I sought out the little bathroom off of his bedroom, and laid my head on the plastic seat. Though he was solicitous, Damian seized this opportunity to take some candid shots like his idol, Diane Arbus. I turned my head the other way.

Bastard.
Love you.

I finally splashed some water on my face and laid down on the bed. Not only did I feel like shit, I had to work the next day. I really think I began to lose my appetite that night.

Growing up, I had never been really skinny, just petite. Once puberty hit, I had curves to go along with my svelte body. Throughout junior high and high school, I was a gymnast. I was fit and curvy. One of my guy friends had told me that I was “built like a shit brick-house”. Even if I wasn’t conventionally pretty, I had a great body. I gained a few pounds during college, but not much.

Food was suddenly repellant to me. I don’t know why, but I began to worry about the calories I consumed. Working at a bookstore, it was easy for me to look up the calorie count of anything in the diet section. I’d been a vegetarian since college, so it was easy for me to eat just vegetables. If I ate too much, I could easily make myself throw up.

I don’t know what had suddenly triggered me. Work had become more stressful. My new boss was temperamental, and a visiting VP had developed a dislike for me. She never tried to hide it. Damian was working at a photo shop in a near-by mall. Though I’d gotten him into an empty Assistant Manager spot, he left when he realized the heavy retail holiday schedule would conflict with his school schedule. He’d dramatically walked out one day by leaving a brief note and his keys in the manager’s office. I didn’t get to see him as often, or write or receive notes through our rudimentary email system each time I logged on to a computer.
What we’d had was the closest thing I’d had to a little romance. Romance as friendship, because we only talked about it in those terms, even if one or both of us had felt differently. So the beginning, the good parts, were the honeymoon phase. The middle where I was trying to hold on to something that couldn’t last – I couldn’t have a best friend I wouldn’t have sex with, while denying him other kinds of love. And with my eating disorder, I was putting my anguish and madness on display – don’t you love me enough to want to save me? But having him admit he couldn’t handle going forward gave me the courage to see what I was doing to myself, to realize I didn’t want to waste away.

For me, not eating was a challenge, a puzzle. How long could I go without eating anything? All right, just a few nuts for me. It was winter, so I wore layers, but didn’t anyone notice? I was proud of the way my hip bones were rising to meet the surface of my skin. It was Damian’s brother, of all people who noticed how much weight I’d lost. After that disastrous New Year’s Eve, I hadn’t seen him for a few months, until Damian was recovering from a burst appendix. He asked Damian if I was dieting. “Not sure” he related to me,” and then Danny said you looked like you’d lost a lot of weight.”

“Are you trying to?”

“I’m just not hungry anymore.”

“But that’s a problem, champ. (Instead of love and angel I’d been reduced to champ and sport).

“You need to go the doctor’s. I don’t want you wasting away.”

“Ok.”

Without my consent the disorder had taken control, wormed its way in to my bones. If I ate what might be considered a normal portion of something, I would then
escape to the bathroom and induce vomiting. I’d transfer my great-grandmother’s engagement ring from my right to my left hand, insert two fingers and hit the right spot. I had a responsive gag reflex, and I wouldn’t take long in the bathroom, just long enough for the first thing I ate (what some call a marker) to come back up.

I went to my family doctor, whose staff was supportive and positive. The doctor suggested Prozac, which was just in its initial heyday of a panacea to all ills. I went for blood work and other tests. On my next visit, my doctor read me my results: my body had turned carnivorous, consuming the protein that was stored in my calves, thighs, arms. That explained the night aches. I told all this to Damian in a phone call. He’d said, well maybe you should try the Prozac. Some people need something extra to get them through certain things. I was talking to Kate about it the other day.

Kate was a new friend from school. He’d shown me pictures he’d taken of her. She was cool, low maintenance. The way he used to take pictures of me and call me cool. I felt more than a pang of jealousy. It bubbled up in my empty stomach and made vomiting easier.

LONDON, 1997

As we boarded the plane, I was optimistic. Damian was excited, and I thought this could perhaps work. We found our seats and we watched a flight attendant trying to help an older passenger with his seatbelt. “It seems stuck down there,” the man complained.
“You’re right, “the attendant assented, “let me get a torch and see if we can find it.”

I smiled at Damian’s stricken look. A torch is the British term for flashlight. He still needed me. The cultural intelligence which I had once happily shared with him, in the end I wielded like a weapon. He kept close to me as we de-planed and took to the Tube to our stop. When we rode up in the tiny elevator, he said nothing about the tight quarters. Until we got to our room. I unlocked the door to our room, a double. The travel agent who had booked the trip had been a Catholic neighbor, and I hadn’t realized that she’d booked double rooms with twin beds.

“Woah, champ, this room is small.”

I actually liked the room, with its pale blue walls and French doors opening onto a small balcony.

“Most European hotel rooms are tiny, especially in the cities.”

Damian took that in silently. It’s hard to complain when your trip is being paid for.

Before we got to Europe we hadn’t eaten together for several weeks. On the first day, I got by on a coffee and later, we ended up at a TGIFridays. I didn’t expect London to be so much like Manhattan; I still pictured streets out of Shakespeare or Dickens’ London. While Damian had a meal, I ate what could be optimistically called a sixth of an oversized baked potato. The server who collected our plates looked as though she was going to get in trouble.
“Did you not like it? Could I get you something else?”

No, I assured her, I wasn’t hungry, that was all.

I wasn’t so far gone from shame that I could ignore the dismayed looks of servers and even cooks who came to check on why I’d barely touched my meals. I tried to order what looked like the smallest item, or a dish that I could foist off untouched portions on Damian, although he was resisting this.

From: DJP To: KSW 7/19/96

We all need our hunger, Luv. Your just more focused and dedicated to yours than most. The rest of us satisfy it, then find another to burn for. Like me wanting you to be mine, cmon.

ALTERNATIVE JOURNEY

If I was a smoker, I’d be smoking right now. I shifted slightly in the twin bed to stare at the clock: 4:40 AM. Damian hadn’t returned from the night before. He’d gone out after dinner, seeking some entertainment, while I’d returned to the hotel to wretch up the majority of our Indian banquet. The food had actually been quite tasty, and it would have stayed put, if my spiraling eating disorder hadn’t taken over. I’d been tired after spending most of the day at the Tate. I’d soaked in the beauty of the Pre-Raphaelite Brotherhood, sitting in that red room after Damian had called me an emotional vampire.
“You stand next to me and you try to steal my pleasure of seeing this art. You’re like some type of emotional vampire.”

I’d stalked away because part of that was true. Part of the reason for this trip was my joy in sharing new experiences with him; it was how our relationship had begun. We had discovered artists and musicians together. There was a symbolic irony that the Waterhouse paintings that we’d both so longed to see were on tour back in the U. S.

We hadn’t spoken much through dinner, except to ask what dishes we were being offered. I’d paid the bill, just like I paid all the bills. This trip was my treat, and it was beginning to rankle me. I needed rest and Damian wanted to explore the London nightlife. Well, he could do so if he wanted.

“Goodnight. See you later.”

“Don’t forget our Tube stop.”

Maybe Damian had decided this trip wasn’t going to work, and he’d gone home. Or maybe he’d met some emotionally stable, lovely lady, and was sleeping off a night of pleasure in her flat. Maybe he’d waltz in around breakfast, perfectly rumpled and happy with himself.

What if he didn’t? What if he’d gone down the wrong street, wandered into the wrong neighborhood, been accosted and chased down by punk thugs with cockney accents? I supposed the hotel desk could point me to the nearest police station. I surreptitiously checked his daypack – his camera and new lenses were there, along with
the black travel journal I’d given him. I was sure it was blank – they’d barely been apart. But I still wanted to check its pages. The only thing that seemed to be missing was his wallet. How would I describe him? As my traveling companion? My friend? Boyfriend? Casual friend with benefits? None of the above?

5:30 AM. The hotel breakfast room didn’t open until 7, so no coffee ‘til then. I just needed some coffee to dissolve away my appetite. Of course there was only a hot water heater and teabags on the dresser. That was the British answer to everything – here, darling, have a cup of tea. Depressed? Cup of tea? In the midst of an eating disorder? Sip that tea with some honey, perhaps.

As was my habit, I reached out for the book I’d left on my bedside table. The only thing I could concentrate on were short essays. My attention span had shrunk along with my appetite. I re-read pages two, three times over. Sometimes a phrase or two would stick out at me, but not often. Where the hell was he?

We were actually supposed to travel up to the wild moors of Haworth, in Brontë country via train that day. He could sleep for the several-hour ride. If he still wanted to go. If he showed up. This was the only free day left before we rode the Chunnel and paused in Brussels on our way to Amsterdam. I’d called about the train schedule from King’s Cross Station: an 8:30 departure. When I planned this trip, it was supposed to be an arts-and-literature best hits tour of Europe: London, Yorkshire, Amsterdam, Florence, and Paris. The Masters, the Impressionists, Van Gogh, Rodin, etc.

Pretty postcards and beautiful cities. Standing in front of paintings I’d admired for so long, and hoping to find inspiration in the same places that some of my favorite writers
had written. That was my ambition, my reason for being. I burned with words on some nights, and I believed that my talent was what had won Damian over. I was a genius! I expected to flame out early and die young, but maybe I didn’t have to do it alone.

I heard a key in the door, and Damian came in, looking exhausted, and more than a bit abashed. I raised my eyebrows and blew out a breath.

“Hey, I’m sorry if I worried you.”

I fought the impulse to shriek at him. I was too tired for that.

“What happened?”

“I didn’t realize that the Tube closed, I thought it ran all night.”

“Oh?”

“I asked some people, and they told me the buses still ran, but I couldn’t understand the schedule. I didn’t have a watch, and the schedule said things like twenty-two oh four. So, I just hung around until the tube started back up. It was cold.”

“Well, I’m glad you’re alive.”

He kicked off his shoes and fell onto the other bed. I sighed.

“Oh, Damian, the Brits use military time. After twelve noon, add hours and minutes. So, say, 6PM would actually be 18:00.”

He ran a hand through his blonde bangs. He’d recently cut his longish hair short, and I admitted, he was stunningly handsome, even if I currently wanted to kill him. I
liked standing next to him, to have eyes on me, have others wonder what he saw in me. It used to be that we shared literature and art and movies. That was no longer enough.

“Um, so are you up for our trip to Yorkshire? It’s a 3 hour plus ride. You can sleep on the way.”

He rolled over to squint at me.

“I forgot about that. I’m so tired, I can’t do anything today. Don’t we have a lot of places to visit still? You can go on your own, right?”

Oh course. *Wuthering Heights* was one of the first books we had bonded over; Damian had to read it for a community college course, and I was the college grad. He reminded me of Heathcliff, a passionate and complicated character. I wouldn’t be able to read parts of the novel to him on the way up, or remind Damian of the discussions it had sparked for us. All my plans for this trip were unraveling one by one.

“I’ll be fine alone. Just rest and don’t get lost. I’ll be back for a late dinner.”

Luke came down to breakfast with me. We both had coffee, and he piled his plate with eggs, sausage, potatoes, and some pastries, eating quickly. He looked across the table at me, as I sipped her coffee.

“Are you going to eat anything?”

I was a vegetarian who hated eggs, and that had already limited my food choices before I had decided to restrict myself to 500 calories a day. I picked at a triangle of toast and scraped a little jam across it. I was pleased that Damian watched my calorie
consumption. He’d been the one to point out how much weight she’d lost during the winter.

Please go to the doctor. I don’t want you to waste away, he’d implored. But that was months ago. More and more, I’d felt him pulling away, shutting down to me. And today was just another example. I’d imagine this trip would re-ignite our intimacy, our understanding. I wanted to recapture that sweet feeling when we met that we’d known each other from another life, when we enjoyed talking about everything and nothing. But we’d been in London for three days, and Damian wasn’t warming back up to me.

I said goodbye in the hotel lobby, receiving a half-armed hug. So I’d being going to Haworth alone. It was only fitting, to journey to Brontë country alone, the sisters’ house. I never regarded Branwell as much more than a self-absorbed twit. The sisters both worked and wrote. Each was brilliant in her own way, but I was especially drawn to Emily. I joined the throng of London commuters and got off at King’s Cross, making my train in plenty of time. I found a window seat and tried to give off the attitude of don’t sit next to me, don’t talk to me. It seemed to work.

I changed trains twice, once at York, and then at Leeds, then took a bus the few remaining miles to Haworth. The Parsonage was up-hill. It was spring and I paused in the garden first, taking in the well-groomed greens and delicate blossoms. On one side of the wall was the graveyard, the other side, the house. Outside death, inside life, in the house, both life and death. There were only a few visitors coming in as I entered. A mother and daughter preceded me from room to room, pointing out reverently there was her desk, there was a painting she made, there’s a sketch. Oh, there’s one of her notebooks, open to an unfinished page. All the sisters had sketched and painted, as well as written. Except
of course the two oldest, who died young and whose clothes or drawings wouldn’t have been preserved, but refitted into dresses and canvases for the others. That’s what poor families did.

The sisters’ bedroom was tiny. Three beds, so small and close together they could have held hands in their sleep. Branwell’s room was larger, so it held a display. Behind glass there was a brass collar with KEEPER etched on it. I had always wanted a large dog. The description of Emily’s mastiff, Keeper, following his owner’s coffin to the graveyard tore at my heart. I just want someone to follow me all the way. If it was just a dog, so be it.

I was conscious of my limited time, so I could make my trains back to London. But I wanted to walk past the graveyard, and up to moors. Damian liked graveyards, a Goth teen still locked in that tall body. I looked in at the graves and took some pictures. It is a rough journey, and a sad heart to travel it ...if I dare you now, will you venture? No, I was venturing alone. Maybe this would be our breaking point. I stood and looked out at the moors, the wind lifting the clumps of heather, whispering alone, alone.

I made it back to London. I had enjoyed a lovely day without Damian. Maybe that was the point. Maybe I could pour my passion into my writing and if love came along, it came along. I could live like one of the Brontë sisters. I scribbled away in my travel journal, uninterested in the darkening scenery. Why was I so attracted to brilliant, consumptive women?

Oh, right, because that’s who she was actually attracted to.
When I first started hanging out Damian, we kept to one or two, then two or three late nights. We stayed in his bedroom and watched movies, laying together on his bed. We’d become more physically comfortable with each other, and eventually, as a lone body will reach out for another body, we enjoyed a chaste closeness. Most nights we simply just slept, but at certain times there were embraces, make-out sessions, and exploring each other’s skin, knowing the thrumming of the heart beneath. He stroked the inside of my forearm, amazed at my skin’s silkiness.

Later we needed more than just warmth from each other. He was a singularly feminine guy for all his straightness. He loved the writings of Anais Nin, and we watched “Henry and June”. I’d seen it alone when it had first come out, and the love scenes between June and Anais had excited and confused me. A slow pulsing had begun between my legs, but I fought it down.

Damian knew me so well I couldn’t hide my reaction from him.

“Is that what you like, my sweet, another girl?”

I buried my face in my pillow. He spoke to my neck.

“I’d bring other girls to bed for you.”

But I wasn’t ready.

Our intimacy had progressed to a stage at which there was almost no going back. I began to realize that men have needs, and by taking Damian so closely to sex, I needed to let him achieve release. Since I didn’t want to go all the way, not yet, I had to let him
finish things off for himself. Maybe part of the strain in our relationship stemmed from
the fact that I’d had let him go so far with me, but no more.

Damian was still in our hotel room when I returned. We got a take-away pizza
and a bottle of wine. I was a cheap date now, just one glass of wine and I was buzzed, no
need for anything else. I ate the cheese off my slice of pizza, left the crust on my napkin.
Damian shook his head at me.

“Sometimes you’re really gross, you know.”

I knew. Most things had lost their taste, so I just allowed myself a bit of the foods
that still held flavor. I was looking forward to getting to Paris for some pain au chocolate.
I wondered if I’d keep it down. Damian was asking me something as I washed my hands
in the bathroom.

“So did you enjoy your day? Was it as romantic and tragic as you hoped?”

“Yes.”

“You’re gone for a whole day, and all you have to say is yes? I thought you’d at
least have some stories to tell.”

I remained silent.

“Sometimes it’s like being with a ghost, Kym. You spook me.”

“And sometimes it’s like being with a vampire?”

“Yes. I suppose I should expect a werewolf next.”
In the morning, I felt an ache in my lower abdomen. I ignored it as she hurried Damian along and got ready. When it persisted, I went to the bathroom. There was a bit of menstrual blood spotting my panties. *Shit.* One of the aspects of being a successful anorexic was that you didn’t get your period anymore. I was a failed anorexic, just like everything else.

I hurriedly explained to Luke that check-out was in five minutes. I just had to do something in the bathroom and I’d be down. I gave him my purse; I had made a local call about the trains, and I probably owed something for it.

“Can you go down, please, Damian. I’ll meet you in a minute or two, I promise.”

“What are you going to do?”

I was going to shove a tampon up my twat, but he didn’t need to know that. He didn’t need to know that I’d failed, that I’d been eating too much, that the skinny image was just a façade. He looked worried for the first time in weeks.

“Seriously, what are you doing?”

“I just have to go, I promise, and I don’t want to be charged for another day. Go check out and I’ll meet you.”

He did as I said, shutting the door behind him, the concern in his eyes something I had coveted for days.

The train ride was *long.* I was not impressed by the fact that they were traveling beneath an ocean, nor was I scared. Few things scared me. Though Damian and I started
out sitting together, the car was practically empty, so he moved to another seat, across the aisle and a few rows ahead. He took out his travel journal and began to write feverishly. That black journal I’d special ordered for Christmas, the one with the Hieronymus Bosch painting on the cover.

I had introduced him to Bosch, when Damian was stuck on Giger and Escher. I’d opened a whole new world to him, and now he was pulling away? I had to see what he’d written. I just had to see.

Amsterdam was beautiful and confusing and cool. I accompanied Damian to a “café” where he selected a variety of weed and rolled it into a joint. He smoked part of it, and offered me some. Unlike Damian, I’d never had any weed. If I had a reaction, I no longer trusted him to be around to help me through it. He took the rest with him and we walked through the red light district.

We got separated at some point, and I’d given him the address of the hotel so I knew he wouldn’t (hopefully) get lost again. They were meeting at the Van Gogh Museum at 2pm, or 14:00. I wrote it on his hand in ink and it was the most intimate thing I’d done to him in god knows how long.

The women in the red light district stood in their plate glass windows, offering themselves. I didn’t judge them. I once thought, maybe being a prostitute would be easy money. That was back when I went to college near Manhattan and before I’d really fooled around with anyone. I didn’t know about the messiness of sex, the way a man could actually repel me.

Girls instead of guys? Was that what I really wanted?
The Van Gogh Museum was a revelation for me, a disappointment for Damian. He’d brought his camera, but pictures weren’t allowed. He’d taken it back to their hotel, just two blocks away, and I started the Museum without him. I got the audio tour and discovered the development of Van Gogh’s style, from his early work to his last. A wonderful, mad genius.

*Alone, like me, alone.*

I returned to the hotel for a nap. I lay in another lone bed, my body exhausted, my mind racing. Starving artists and starving, starving. I’d had nothing but a miniature wheel of cheese for breakfast. I rolled away from the window, and saw Damian’s backpack on his bed. The journal was in it. The journal with writing. Thoughts that had poured out of him, thoughts he had hidden from me, purposely moving to another seat.

I had to know. It was wrong, but I had to know. I flipped the pages. Of course, he had skipped several pages and started one-third in:

*I don’t know what to do with Miss Stark anymore. She bores into me with those eyes, and she asks too much. How can I help her when she’s the one who needs to decide whether or not to eat, whether or not to live? I can’t force her. I am done with crazy ladies. After this trip, I will have much less to do with her.*

He’d given me a biography of Zelda Fitzgerald a few weeks prior. He’d said that he was done with crazy women, and I could have it.

He’d soon been done with me.
And yet, he’d come on this trip. He took my money each day, as I paid for meals only he ate. He couldn’t, wouldn’t, help me.

Selfish bastard.

He’d made me feel guilty for trying to share in his enjoyment of this trip. I started shaking, no longer able to rest, or even sit still. I took my bag and walked out of the hotel. I stared walking through neighborhoods away from the tourist attractions, walking over canal after canal. She’s the one who needs to decide whether or not to eat, whether or not to live. There was no way to get him to care, to change his heart. He was going to leave me as soon as we de-planed in the States. We’d go days without speaking, then weeks. Did I need him? And did I really want to die?

As she passed by a flower shop, I gazed at the beautiful blooms. There were buckets of tulips in every color—lavender, coral, fuchsia, and blush. Wasn’t that worth living for? The shop owner stood in the doorway and called to her:

“You are beautiful, angel. Take care of yourself.”

I was worth saving. On the next block, there was a small café. I ordered a tea and an apple strudel. I tasted every part of that strudel. The fragrant, ripe, sweet apple. The crispy and buttery flakiness of the strudel dough. I sat there until the waitress told me the café was closing for the day. I headed back to the hotel.

Was I afraid to be alone? Not really. Maybe that was my fate.

But I was damned if I’d continue on with this farce of a trip, continue paying and hoping for something that would never happen. I’d tell him tonight. I’d take him to a nice
restaurant, and then tell him when they got back. They were supposed to be leaving for Florence tomorrow, but I would enjoy Florence alone.

I took a shower, washed my hair. Let it air dry into those Pre-Raphaelite curls. I’d wear the one long dress I brought, a black dress with a floral pattern and ties that laced up the back, accentuating my slenderness. I waited for Damian to return from wherever he had wondered to that afternoon.

He sensed something was off as soon as he walked in the room. My smile was stony.

“What’s up?”

“Nothing, I found a nice place for us to go to dinner.” Actually, the hotel had made reservations for her.

“Um, Okay, you’re really dressed up.”

“I just wanted to look pretty.”

When was the last time he’d called her pretty, beautiful? She couldn’t remember. It didn’t matter.

“I’m getting a weird vibe from you.”

“Because I want to go out?”

“No, it’s something else. You’ve decided something.”

“We can talk about it later.”

“I couldn’t eat not knowing.”
He couldn’t eat.

“I read your journal.”

“You what? How could you? How could … I wouldn’t expect that of an enemy, let alone a friend. How could you?’

“I’m sorry, I wanted to know.”

“I would never have expected you to … you don’t own all of me, you know, despite the fact you’re paying for this trip.”

“So you’ll have little to do with me once we get home?”

“I don’t know, you’re really messed up, and I can’t help you, and I don’t want to watch…”

“You don’t want to help?”

“Lucy, if I couldn’t help my Mom with her drug problems, what makes you think I could help you?”

“You could just stand by me. But it doesn’t matter. You can’t do it, and I don’t need you.”

Our conversation went round and round. Finally, he realized that I was sending him home. He called his parents while I went down to the hotel bar. I ordered a glass of white wine, and a plate of fruit and cheese. We never went out that night. I found that I couldn’t muster the tears I thought I’d shed at our parting. As an apricot dawn rose, we wished each other good luck like people who had barely known each other. We were both hurting in our own ways, but we kept those wounds carefully stitched and covered.
Florence and Paris awaited me. I had a glorious time as a lone traveler, meeting other people that I never would have encountered had I still been traveling with Damian. It was not so easy to say I would eat normally and suddenly do it. I prowled restaurants until the time felt exactly right to ask for a slice of pizza, a baguette. Sometimes, I still wretched them up, the baguette combined with red wine turning into a purple mush.

I spent as much time as I wished in the churches Damian would have mocked: the Duomo, Santé Croce, Notre Dame, and a smaller Cathedral with a Saint Rita statue covered in paper. I hadn’t learned about Saint Rita in my Catholic upbringing, but from what I understood of the writing, she was the Patron Saint of Marriages. There was room on the paper skirt, and no one to see, so I wrote in her high school French:

*If it pleases God, let me find someone to love.*
This is a love story.

Whatever you believe, whatever your politics or opinions; whether you read this as a survivor’s story, or a second chance story, know this: this will always be a love story.

I am the only one left to tell our love story so I will tell it slant, missing large pieces of what it was. But it was a great love story, a passionate one, the kind that doesn’t fade, that doesn’t get diluted by time or retelling.

We met at the Barnes & Noble. It was my third store since I’d graduated from college, three years previously. I had worked at a Community College, another chain bookstore company for the holiday season, been unemployed for a month, and then joined a small bookstore chain. At the chain I rocketed from part-time worker to Store Manager. I was not hugely ambitious, but I knew a lot about books, and many of the senior chain-store workers were fleeing to Barnes & Noble. It would eventually put many of the chains out of business.

I’d met a young man I’d had an intense and soul-shaking relationship with just the year before. We’d been best friends, then near lovers, then I’d taken him to Europe and sent him home early, alone. I was depressed and suffering from a combination of anorexia and bulimia, what the DSM-IV categorizes as a non-specific eating disorder. I’d starved myself down to a waif to see if he would want me. He didn’t.

Sometimes you have to see you own bones to realize you want to live.
When I returned, I began seeing a therapist. I should have visited one years prior because I suffered from bouts of depression, most particularly Seasonal Affective Disorder. But my family was always the buck up, it’ll get better, cheer up, nothing’s wrong-type. I hid my dark moods with silence and a black wardrobe. They could understand broken legs but not broken hearts. I had to destroy myself physically in order for them to realize something was wrong with me mentally.

The first time I met Erin, I thought she was loud. She was elegant, well-spoken and beautifully put together. But she was loud, her voice laced with a slight Buffalo accent, carrying across the store. It was poetic irony that I, who was chronically silent, should be drawn to such a sounding bell. At first, I wasn’t. She was too put together. She had ebony hair pulled tightly back in a ponytail, and perfectly painted red lips and nails. Not the cuddliest looking person, yet there was a warmth in her eyes that let you know she was looking only at you, she was listening only to you. It worked on everyone from the crankiest customer to the fussiest child.

I’d been hired as a 30-hour bookseller, intent on going back and getting my graduate degree in creative writing. But with a new store opening, the person who handled special orders was transferring. I was offered the regular, day shift position away from customers. I had the expertise, and I very happily took the job. So my official meeting with Erin was in the small office I shared with the community relations manager. I was sitting at my desk, back turned.

“Wow” she said dramatically, “you’ve got some head of hair.”
I went to turn myself around for a proper handshake, but she’d impulsively reached for a copper curl, as if to test its softness or elasticity. She held it a moment, than another. She shook my hand steadily, and smiled a goodbye as the Asst. Manager pressed on with their tour.

I saw her again at lunch. She was introducing herself to others, in a way I never had the courage to. I flipped through the weeklies I’d brought back to read, but she began to interrogate me. I even remember what I was reading: a Time Magazine review of the film *A Thousand Acres*. Erin realized that it wasn’t talking that I disliked, it was disinterest. Erin took an interest in everyone she talked to. Complete strangers would feel like they had made a fast friend after just a short conversation. She oozed sincerity.

We shared several passions. Literature, of course: we were both readers and writers. She had an MA in English, and taught at a local college. We also loved theatre: she was an actress and a playwright with her own small acting troupe. My senior year, I had worked in the literary department of a well-known Off-Broadway Company, and one of my projects had been a musical called *Don Juan, Loveless* for which I’d written the concept, lyrics and book. Her MA writing project had been a play called *Sisterly Love*. Talking to her was like talking to a college friend who shared your passions and loved to talk more about your class after it was done. It sparked an inkling of joy in me that I hadn’t felt in so long.
The next day was a Friday. I addressed postcards to customers whose special orders had come in, fed them through the stamp machine, and thought about Erin. She was working the day shift, too. Because she covered the register, she had a set lunch. I knew she was there before I saw her, as I inhaled a sweet cloud of her perfume on my way to the bathroom. Each station had its own extension. I dialed the registers. “Hello?” Erin answered, a co-worker laughing in the background.

“Um, when’s your lunch today?” I asked.

“Oh, Kymberly, Hi sweetie, Hi, my lunch? It’s at 12:30. Why?”

“That’s when I’ll take mine,” I told her,” see you later.”

I saw her an hour later, when I pushed up my V-cart with special orders to be shelved behind the counter. We both dressed up in those days: I was wearing tights, mules, and a short skirt. I might have stumble a little on the uneven rug. She was wearing a white top and some patterned slacks with high-heeled shoes that winked in black patent. Erin’s face broke into a wide, ruby grin.

“So you didn’t mind me asking you all those questions yesterday?”

“No,” I smiled as I sorted my books away.

She talked until a customer showed up in line. She pulled me in for a half-hug, and I squeezed her back. “See you at lunch.”

Conversation flowed easily between us. I felt safe, comfortable, as if I’d known her for a long time. I really didn’t have any of those relationships now, except with my younger sister. My other friends were more casual, some from high school, some new
friends who I’d met through a non-denominational Christian group run out of my Dad’s church.

Throughout the afternoon, I thought about spending more time with Erin. I had moved into my own apartment 2 months prior, at the urging of my psychologist. You’re 25, you need to start to put some separation between yourself and your family. I had no one to go home to, no one to report to. I could ask Erin over for pizza and wine. I kept that thought while I called tiny publishers on the west coast, seeing if they could send me obscure special orders.

My extension buzzed. Sometimes orders were on their way, and customers would call to check on their status. “Yes?”

“Hey Kymberly, it’s Erin. Are you doing anything tonight after your shift?”

“No… (ask her, ask her)

“Would you like to go out somewhere to eat? I really like the Mexican Food Factory. Is that okay?”

“Sure”

“Great! Great.” I could almost hear her smiling into the receiver.

I’d never eaten at the restaurant we were going to, but I liked Mexican-American food. Aside from recovering from an eating disorder, I was also a lacto-ovo vegetarian. I could always get cheese enchiladas. I hadn’t realized how strange my eating looked until my European trip with Damian, when several servers had asked if “I hadn’t liked?” or if
it “didn’t taste good?” One of the chefs even came out from her small kitchen, to my
great embarrassment.

“I’m sorry,” I’d told her. “I just wasn’t hungry. It was a very good dish.”

Erin had only seen me eat lunches, which were understandably small. Would she
notice something off about me right away? They served drinks, there, didn’t they? I used
to joke to Damian that I was a cheap date: one glass of wine, and I was buzzed. That
would help, wouldn’t it? And I could always excuse myself to use the bathroom…

We both left work at about the same time; she had to stop at the bank with her
check.

“I’ll meet you there,” she grinned, pressing my hand.

I drove out to the highway dotted with strip malls and restaurants. I turned left,
and started looking for the restaurant. It was painted a greyish-purple for some reason. It
was really close, but I went from light to light, unable to find it. Eventually, I knew I’d
driven this wasn’t the way: I reached an old traffic circle that had been changed into a
complicated intersection. Oh shit! I’d gone too far!

I turned around at the next possible light. I called 411; I didn’t have a speaker
feature, so I held my cell to my ear, steering with one hand, scanning the strip malls,
negotiating the rush-hour traffic. The person on the other end couldn’t find the address of
the restaurant. I sped down the highway. Would Erin leave the restaurant, disgruntled,
thinking I had stood her up? Had I lost a good friend before I even made one?
Finally, I saw the restaurant. I parked quickly, relieved that her distinctive plum-colored Saturn was still there. I entered the darkened lobby, and Erin sprang from a bar seat.

“Oh, thank God! I thought you changed your mind.”

“No, I just turned the wrong way and didn’t realize it.”

She grabbed a partially-drunken margarita from the bar and sipped it, then offered it to me.

“You want one?”

“No thanks. I’ll have wine with dinner.”

The hostess ushered us into the dining room, and offered us a booth. We were early for two twenty-somethings on a Friday night. When suggesting the meal, Erin asked if I minded eating early, and we discovered that both our families tended to eat around the same time. We smiled at the similarities we kept on finding, while reproductions of Frida Kahlo and Diego Rivera paintings beamed down at us.

We ordered our meals, and I sipped my wine while she finished her margarita, then had some red wine with dinner. I don’t remember what either of us had, but I remember how the conversation never stopped. I told her that I couldn’t stand margaritas because I’d had too many on New Year’s Eve with Damian’s family, and had ended vomiting all over a cobbled side street in Philadelphia. I also told her how I took him to Europe, then sent him home early, finishing the trip alone.

“Whoa,” she breathed, “brave.”
She told me about her various boyfriends, some of them long-term, but none of them the one.

“They’re so difficult. Actually, I think I really just want to be with a woman at this point.”

I tried to find her foot beneath the table to kick it. I laughed in joyous relief and smiled.

Me too. Oh my God, me too.

I’d felt different ever since I could remember. Alone. Closed off. I thought it was my artistic side, my extreme sensitivity. That’s why I was always the quiet student, even when I knew the answers. That’s why my few friends weren’t the popular girls, the outgoing girls. My friends were the left-overs. I’d gotten my first kiss from a boy in Kindergarten (a quick peck as he covered my head with his Spiderman jacket), and my first unwanted boyfriend in first grade. His name was Lee. He had shaggy brown hair and gave me a tiny red ring so he could say we were engaged. He loved me and I didn’t love him. These one-sided crushes subsisted for many years, until high school. I never did date anyone. I had male friends, but I didn’t want to lead anyone on. Truth is, I didn’t know why I always felt different. I was a girly-girl who loved to read and write. I found love matches in literature: Rochester, Darcy, and Sydney Carton. But not in real life.

My first exposure to lesbian culture was when I was seventeen. That year, I saw both Henry and June and Oranges Are Not the Only Fruit. I was intrigued, and for the first time I felt moved by what I saw, not just emotionally, but down there. I was a very late bloomer. The next year, I went to Sarah Lawrence, which is full of beautiful, strong
lesbians. I admired them from afar but was too afraid to seek them out. I had been raised Catholic after all, and while I championed their right to live however they pleased, I didn’t think that applied to me.

I’d told Damian about my being intrigued by lesbians, and he showed me some amateur film he’d shot which actually made me horny. So, this was part of me: being attracted to women. He encouraged it. I did love staying over at night with him, sharing a bed to feel his weight against my back, or his arms the few times we had snuggled, just like any body needs to be held, cradled, cherished. But we never went further than making out. I kept to my Christian principles, newly reinforced by my participation in a Christian group.

I’d talked to my psychologist about perhaps dating, but I’d never told her about it maybe it being a girl. I reached for Erin’s hand across the table.

“I’m so glad we decided to go out.”

Our plates cleared away, Erin suggested drinks out at another place, and made sure I knew exactly where it was.

“I don’t want the night to end just yet,” she said, and her strong voice was a little wistful.

*  

We had another round of drinks, and I became more animated with the alcohol. She told me to pretend we were married friends, away from our husband for the night. I
even invented an imaginary son named Wills, like the prince. The ringing laughter that Damian had once said was beautiful bubbled up from me, and Erin did her best to elicit it every minute. I hadn’t had so much fun in ages. Really, ever.

She looked at her watch and noticed the time. She had to go to her parents’ house in Shamong to take care of the family dog. Her parents were away and the house was empty. There were four bedrooms and she had twin beds in her room. We could watch a movie, do whatever we wanted. It was just a 20 minute ride through the back woods. I paused a second, no more.

“Sure.”

I was a bit buzzed, but it was a happy buzz. I followed her coupe down the highway, and then we drove further and further out into the pines. There was a nearly-full moon in the magical darkness that lay before us, beckoning. I kept Erin’s car always in my sight. Traffic lights disappeared, and the length between stop signs stretched longer and longer. It didn’t matter. With the moon ahead to guide us, I realized I would follow Erin anywhere.

And I did.
EARLY YEARS

Erin and I spent most of that first weekend together. I followed her to her apartment and we slept in her double bed. She brought me cereal and coffee in bed; only later would I realize how uncharacteristic this was for her. We were reverential with each other’s bodies, taking the time to know each other slowly through fingertips and lips. She found out I was ticklish and delighted in making me giggle.

Erin turned me into someone else. Since I’d been a teen, I had been the sad girl. Even though I tried to deny it, I had always felt alone, left out. I was a forgotten wallflower, and Erin invited me into the garden. Love with Erin was so easy. It flowed from me effortlessly, and I accepted her love gratefully. There was no tortured drama. That’s when I realized that all relationships had led me here. To her.

She loved old movies and quirky comedies: she was a devotee of Bette Davis, and adored Mel Brooks and introduced me to Ab Fab, the Brit comedy. We always had good food and good entertainment. Erin’s mother was Irish-Italian, so she’d taught Erin how to cook, though Erin praised my cooking, telling me “you must have been Italian in another life.” It was odd to be praised for things that came naturally: cooking, decorating, and entertaining. I guess I had absorbed something from working alongside my mother all those years.

Erin liked to dance, and so did I. We preferred swing music. She’d hold out a manicured hand to me and lead me through a not-quite-choreographed, giggly dance. Being basically the same height and body type, we fit together perfectly: hip to hip,
breast to breast, hand in hand. Though it took us a little while, within a few weeks we knew each other even more intimately. Before we settled in the sheets, Erin whispered.

“I never make any noise.”

Oh, she made noise.

We moved into our first official home together after two months. It was a two bedroom condo in Cherry Hill, very close to the Barnes & Noble we both worked at. It was a typically cookie cutter condo: a sliding glass door with vertical blinds that looked out onto the parking lot, a front room, dining area, and a small galley kitchen. It did have a washer and dryer, and two bathrooms to go with the two bedrooms. We tried to paint some character into condo: mint green and purple for the bathrooms, a light peach for the bedroom. Erin and I were both femmes; no one at a first glance would guess that we were a couple. Of course, the first couple months we couldn’t keep our hands off each other, so it was no secret at the bookstore. Eventually, of course, we became less demonstrative. Our neighbors first got to know us as “the girls”. Once they realized we were a couple, they usually like us enough for ourselves that our lesbianism was never an issue.

For our first Christmas, we had to spend half of the day separated with our own families. But first, we had our own Christmas celebration. I had my first fake Christmas tree because Erin was allergic to real ones. We brought with us some of our own ornaments and collected others. Our first ornament was a sand dollar with two Victorian angels painted on it – one with short black hair, and one with red curls. Our names are scripted on it. It is still the first ornament on the tree each year.
We’d promised each other engagement rings for Christmas. I asked for a garnet, and Erin asked for an emerald. I had spent a day searching through the jewelry stores of Haddonfield for the perfect ring. It was hard to find an emerald – most engagement rings were diamonds. I finally found a vintage cocktail ring – a beautiful emerald surrounded by small diamonds. I couldn’t wait to give it to her. After all the presents were opened, I retrieved it from the bedroom. I knelt down and started trembling. She held me by my shoulders, “Honey, you don’t have to be nervous.”

I wasn’t nervous. I was awestruck with the importance of the moment. I was asking to seal myself to her forever. She was my fate, and I was accepting that. I don’t even remember the words I said. Erin loved the ring. It was too big; she had the tiniest feet and hands. She wore it proudly the first few years, and then only when dressing up after we had gotten our wedding rings. When she was forbidden to get manicures she didn’t want to bring attention to her hands. Now it lays in our jewelry box on a chain with her wedding band. I wear them when I want to feel her close.

Our first Valentine’s Day together was a bust. Erin had to work. I was going to get her a bottle of her perfume – Pleasures – the scent of it now can still bring tears of longing. I was also going to cook dinner. I had a blinding migraine, probably the worst since we’d met. Erin came home to find me crying on the couch. “What’s wrong?” she asked. I sobbed about how I hadn’t gotten her a present or dinner made and my head hurt so badly. She kissed me and told me it was okay and was there anything to do to help my headache? I was not used to being treated with compassion instead of disappointment. *Really it can’t hurt that much.* We had some take out Chinese and I had a doctor’s appointment the next week to deal with my migraines.
The next weekend, we picked out our real present, an Akita puppy. Erin had seen an ad in the paper for puppies. Her parents had an Akita, Samantha. She was a large, protective dog. Sweet, but shy. I’d always wanted a large dog. My parents had owned medium sized dogs: a fox terrier, and a spaniel mix. I thought about Emily Brontë’s Mastiff, Keeper. An Akita would surely be big enough, and Erin knew how to raise one. She made me promise to let her name it Margo Channing, after the Bette Davis character in *All About Eve*. We drove down to Paulsboro and found the small bungalow advertised.

Dog song answered our knock. We were greeted by a fluffy pack of excited puppies. We’d been advised there were only two girls left. The woman pointed out one to Erin as I simply sank to my knees and let the little noses sniff my face, the tongues taste my ears.

“This one we call Speck ’cause of the little spot on her neck,” the woman pointed out. Erin handled Speck, then put her in my arms. She was sweet-faced, unafraid, and she gave me a kiss. “This one?” Erin grinned at me. I grinned stupidly back. By the end of the night, Speck had been re-christened Margo Channing. She would grow from her beginning weight of a few pounds to one hundred and twenty-five pounds.

I thought Erin would be the Alpha Mom. She had lived with an Akita, after all. But she ended up being the more indulgent parent, so I had to be the disciplinarian.

When her parents’ dog, Samantha, stayed with us, she sensed the power shift and looked to me for meals, walks, and permission to go outside. Though Erin came off as such a forceful personality in public, I was surprised at how laid back she could be at home. Sure, she was a neat freak at times, but only at times.

We might have stayed in Cherry Hill despite the rising rent, but the condo board sent us a letter that dogs over 35 pounds were not allowed. Margo was close to a hundred
pounds by her first birthday. There was no way we were going to live without her; she was our child. We started looking for places to live, and Erin found a house for rent near her college roommate. We saw it on a snowy day. It was small, but there was a yard for Margo, and the rent was much more affordable. It was close to 295 so the commute wouldn’t be five minutes, but it would be a manageable 15.

We moved to Gloucester City that winter. If Haddonfield, where my parents still lived, was old money, and Cherry Hill had been new money, then Gloucester City was no money. We lived on the outskirts of the city itself, on a quiet street. Our landlord thought his sparkle popcorn ceilings were the epitome of elegance; the man still wore a mullet in 2001. But he was nice enough; he always got things fixed eventually – by one of his buddies – he was a sheet metal worker. We tore the outdated wallpaper from the wall and painted them a bright magnolia white. This house seemed even more like a home. Margo loved her yard, and she made friends with all the neighbors who were brave enough to approach her. We were accepted without question.

Our house became the place for birthday parties, cocktail parties, and elaborate murder mysteries. I’d plan out a full menu, decorate according to time period and location, include music, and Erin and I would dress up as our characters. We always made sure everyone enjoyed themselves. Erin would drag me out of the kitchen to join the rest of the party.

Our best days were there. Despite the occasional flares of asthma. Despite the bouts of pneumonia. We were living there when Erin’s parents had gotten a puppy to replace Samantha. Her mom had asked for name suggestions, and Erin chose Molly. Molly was a bit rambunctious, and Dad C’s health had begun to fail. They had no fenced
yard, and it was difficult for them to take care of the young Molly. She came to us before her second Christmas. While we had never felt lacking before, suddenly we felt like a complete family.

So this was what happiness was. I had never known the sweet peace of joy, the constant delight of love. Erin adored me. She was fascinated by everything I did. I turned a part of the back yard into a garden. Erin was enchanted by our home grown tomatoes, cucumbers, peppers, zucchini, and herbs. She marveled at the homemade pesto and roasted peppers I made. Erin bragged to anyone who came over about my prowess in the garden.

A garden was more important than a few dark poems, wasn’t it? Loving Erin was a better life than that of a lone writer. I had never felt so complete. So I told myself.
SACRIFICES

On a random drive to the drug store Erin told me, “The doctor thinks it would be very dangerous for me to try to become pregnant.” *Fuck Yeah.* She’d been on disability for two years, and we hadn’t been talking about having kids at all.

“Oh course it would be too dangerous, honey. Don’t you think the two of us and Molly are enough? And all your nephews and Kaitlyn? I know you love being an Auntie.” She was quiet for a few uncomfortable moments.

“I always imagined being a mother. I gave that up for you. Don’t say I never sacrificed anything for you.”

I didn’t answer. What could I say, thank you, you delusional woman? Becoming pregnant would have been dangerous for her regardless of who she was with. The fact that I didn’t want kids was something I never hid from her. Dogs were enough for me. I thought they were enough for her.

Did she want to talk about sacrifices? I sacrificed my chance to get my MFA in creative writing to work at Barnes & Noble so I’d have a steady job with benefits for us both. I went into management despite my reluctance so I could earn more money. Eventually I became the sole breadwinner and her caretaker. I put my writing away and spent hours watching reruns on TV because that’s what she wanted to do. I did the dusting, the dishes, the cooking, the cleaning, the vacuuming, the gardening, the laundry, and of course I worked eight and half hours a shift at the bookstore. Busy nights meant I got home around midnight. Erin would already be in bed with Molly, but when she was alive Margo waited for me. I’d see her the silhouette of her head on the window sill, the
undulation of her tail curling and uncurling in greeting. She was my girl until the end.

Her happy greeting made up for some of the exhaustion, some of the bad days.
THE KINGDOM OF ILLNESS

“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” – Susan Sontag

2016

My sister told me it took six people to hold me down.

“I told them you were a stubborn redhead who needed more anesthesia than the usual person,” my sister said matter-of-factly. She described for me the dinner I didn’t remember having, the migraine pain which I did remember, and my odd actions, such as taking off my shoes in the restaurant.

” And that was the last bit of sense you made.”

Jennifer told it all dispassionately, as if recounting some neutral scene between strangers or vague acquaintances, not sisters who had once been best friends. She had the discretion not to tell me that I had lost control of my bowels; she practiced discretion that bordered on taciturnity.

I had planned on taking her to see a 30th Anniversary showing of Labyrinth, a movie I’d loved as a young teen. It had turned my sister into a David Bowie fan at eight years old. Back then, we’d gone everywhere together. Now, we saw each other mostly on
weekends, which she spent in manic activity involving the Catholic Church we’d both been raised in.

I had just lost the past eight hours of my life to the surreal nightmare of a seizure. It was my first. I was hooked to a telemetry meter, a plastic monitor hung around my neck in a long baggie, plastic wires running to five different spots on my body. My right arm was pierced with an IV that dripped a solution of God-knows-what. My entire right arm had been encased in marigold yellow tape, from fingers to upper arm, over-wrapped painfully. I was naked except for my underwear and a hospital gown that wasn’t properly tied in the back.

Just an hour ago, a nurse? A tech? Had cut away some of the tightest of the bands of yellow tape. My glasses were missing, so all I could hear was her kind voice, see a bob of black hair. “You were very combative when you come in. Maybe that’s why they tied this so tight. You won’t fight me now, right?”

I smiled and thanked her. How could she be so clear and the rest of the night such a blur? Fighting with hospital staff? Pulling out IVs? I didn’t even remember the paramedic staff arriving, being wheeled into an ambulance past a restaurant full of gluten-intolerant families. Did they put the sirens on? Did they ask me if I had overdosed on something? Did they just turn the lights on and flash them through the Sunday night, blue red blue red blue red …

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I begin to remember small parts of the night. Living my life through books, I have always identified with certain characters. As I’ve grown older and examined those
characters, I find the qualities we had in common have changed or I have outgrown them. I loved *Jane Eyre*’s quiet, fiercely moral character. But it ends up I am not the silent observer, the girl forgotten in corner.

I am Rochester’s first wife, the madwoman in the attack. Apparently, my true essence is the fighting woman. No one tells me that I screamed, but I cannot imagine that much fight without vocal accompaniment. I have always been a screamer. If I am generous with myself, I can say my latent essence is screaming warrior, not quiet observer.

Still in semi-consciousness, I shift in the hospital bed. A stern voice chastises me, “Kymberly, don’t move. We have to do a procedure.”

The same voice softens, and turns away from me, “We’re doing a lumbar puncture. To check for meningitis or an infection like that.” My mother’s voice murmurs assent. She must have arrived at the hospital at some point. To my rational brain, the procedure seems reasonable, but I know what I am in for: more pain.

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2009

Years before, I woke up from a dream of pain to the reality of pain. This wasn’t unusual. I had been a gymnast in my teens, and was used to the aches of an abused body. But the intensity of the pain I felt was overwhelming. It felt like someone had taken a sledgehammer in the night and shattered my knees. They pulsed and throbbed, a little swollen and tender to the touch. I couldn’t stand the weight of one swollen knee on top of the other. I am usually a side-sleeper. I knew pain, but this was beyond anything else,
even the shoulder muscles I’d torn that had me waking up Erin in my sleep, begging for something to stop the ache.

Luckily, Erin was currently in the hospital. A procedure to widen her pancreatic ducts had resulted in pancreatitis, of course (she was the queen of bad odds – the odds were 90% that she would not develop the disease). For me, her absence was a relief. One less thing to worry about. I’d acted as care-taker for years. For me, there was no calling out of work today — I was a bookstore manager working a skeleton shift. It was summer, and most of the other managers took off alternating weeks. With no money for vacations and no planned excursions past visiting my in-laws’ house in Gettysburg, I used my 4 weeks of vacation time taking care of Erin.

So the morning I woke in crippling pain, I had unwillingly made a solo entrance to the Kingdom of Illness. I didn’t know my diagnosis at the time. It felt like guards were sent to drag me from my bed; I still had to get up that humid morning. I didn’t know how much the world would change for me. I already believed myself a card-carrying member of the Kingdom of Illness, as Susan Sontag called it.

It was ironic that it was my Scandinavian Viking genes that betrayed me. For the past four years, I have been the “stronger partner”. Erin’s constant lung disease progressed to chronic bronchitis, and she was often sick long before we were handed the diagnosis of sarcoidosis. I say “we” because that was our certain and irrevocable entry into the Kingdom of Illness. I would never let her go alone; chronic illness claims both the diseased partner and the well spouse, just as surely as addiction claims the addicted and the enabler.
Joint pain and swelling were symptoms of so many diseases, some of them acute, some of them chronic. I was tested for Lyme disease, lupus, rheumatoid arthritis, and other diseases. My general practitioner couldn’t find anything definitive, so I limped along on double-doses of Aleve to a rheumatologist.

Adrienne Hollander was a petite, sharp-eyed doctor with a strong hand shake. She tested my strength and reflexes, asked about the timing and scale of my pain. Then she ordered another battery of tests: more blood work, and a chest x-ray. That’s weird, Erin and I said to each other. The bloodwork I did the next day, because it was fasting, and I was working the 3:30-Close shift at the bookstore. The chest scan we scheduled for my day off. It didn’t take long, and when we returned from the scan, there was a message to call Dr. Hollander’s office. We scheduled an appointment the next afternoon, but wouldn’t be given any answers until the next day.

Dr. Hollander walked in three minutes past our scheduled appointment time. She pulled up a chair to us.

“Well, we’ve got our answers,” she smiled. “You have Lofgrën’s Syndrome.” She leaned back and anticipated our questions. “First: we don’t know how you got it. It’s a rare, but acute, form of sarcoidosis. It mostly occurs to women in their thirties, of Irish or Scandinavian descent. I guess from your red hair, that’s in your ancestry. We treat it with steroids and pain medicine. It should resolve itself in a couple of months.”

What started as Lofgrën’s Syndrome never did resolve. In fact, months later I was using a cane at work. Methotrexate was added to my prescriptions. It’s an all-purpose immunosuppressant, but it is known widely for being a chemotherapy drug. I had once
been able to walk five miles in an eight and half hour shift, but I began to gain weight, both from the prednisone and my diminished mobility. Searing pain hobbled me again, but a bronchoscopy biopsy showed normal sarcoid levels in my lungs. Dr. Hollander re-examined me. “What you’re describing to me, the lethargy, the migrating pain, sounds more like fibromyalgia.”

My mother-in-law suffered from fibromyalgia, so I knew what to anticipate. A silent disease that injured your body in different ways each day, that interrupted your sleep and left you exhausted. The exhausted part I had down already. Mom C was on disability herself, relying on the income of her husband’s retirement fund to keep them comfortable until she reached sixty-five. What could I do now? I still had to be the strong one. Erin was on complete medical disability, a paltry thousand dollar check that just covered our rent. My salary covered most of the rest, though our expenses, especially medical, were escalating. I couldn’t take a leave from my stable, twelve year career at the bookstore that had brought us together. I had four weeks of vacation, and healthcare that covered both of us.

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1997

When Erin and I met, we were both working at the bookstore. We were in our twenties, and both recent escapees from the Kingdom of Illness: she was a recovering codeine addict, and I was a recovering anorexic/bulimic. Both our afflictions were fueled by our depression. We lived our lives to please others; we couldn’t admit who we really
we were. To admit we were later-in-life lesbians. Our love seemed to heal our wounds, and we grew together. At least, we felt healed then.

If I was a lithe Merida with strawberry curls and curves I couldn’t starve away, Erin was a cheerful but bold Snow White. I have a picture of her from right before our time together. She had one of those smiles that people describe as “lighting up a room”. As a writer, I am not a peddler of clichés, but she warmed cells I didn’t even know I had. She could speak to anyone, separate them from a crowd and make them feel like she came just to talk to them. I imagined a future growing old together, growing fat or thin, cranky or sweet alongside the other.

It was cruel that she was exiled from the Kingdom of the Well so early, and that her last years were spent trapped in that colder Kingdom. I was her lifeline to the outside world, and some days I was a poor one at that.

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2016

“All right, Kymberly, let’s try the swallow test again. When you came in, you failed it.”

I hope I’m not going to be asked to remember any one’s names. Heather (the 7am nurse) spoons something white and cool into my mouth. It had a tiny spoon like the kind you get for ice cream samples. It is at once soothing and tasteless.

“Good, let’s try the water.”
It is only in the kingdom of illness where swallowing water is seen as a victory.

I can swallow water.

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There is a portion of the Kingdom reserved for those with Invisible Illnesses. We have an electric fence like the kind dogs do. We wear collars that look like necklaces, and you will not know where our Kingdom ends and the real world begins. But we do. I tried to work like usual. I swallowed medication after medication in order to keep going. I told the Store Manager about my condition, the times I needed to take off for various doctor visits. She was a stern blonde whose desk-top heater blew even in summer, but it never quite melted her icy exterior.

Finally, one manager’s meeting, one of the Department Manager was talking about the need to replace a café worker. She has a real injury, not some made up disease like fibromyalgia. He was a young man whose mother had died of heart disease the year prior. There was a brief silence, and then the manager moved on to a new topic. I sat at that misshapen breakroom table in stunned silence. The manager knew. We’d talked about it for more than a year. Maybe that was how she felt, too. Something made up. An excuse. It was certainly how the other Assistant Manager viewed it, complaining about his merchandising duties while scurrying away from customers because he didn’t know any authors beyond Grisham, and he couldn’t even spell Antigone, or realize it was required summer reading.
I called the Company’s “We Listen” Hotline. They listened when I talked about not being taken seriously, about feeling belittled, about being left defenseless and unsupported. Yes, the District Manager could call me at home. She never did. I don’t know what her view on invisible illness was. But for a hard-selling Texan, I assume the term meant *imaginary*. I talked to the company’s vast HR department. I was allowed to go on partial disability, that is, down to a 30 hour, 4 day week. I could keep my status and benefits and get paid for that extra day off. I could work a set schedule, though I made light of my demands: I’d open on Sundays to do payroll, close on Friday nights (the busiest night of the weekend), still do the split shift, Manager’s Meeting 7am Monday/close shift. But I needed two days off in a row, and a set schedule. When I had Dr. Hollander write the note for me, she asked *you don’t have a set schedule?* Retail sucks.

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The neurologist walks in to assess me. She is blonde and a little plump, has a calm nature probably cultivated from therapy sessions or perhaps anti-depressants. She smiles at me, and asks me questions that I think I were probably asked hours ago, but now I can give intelligible answers.

“You’ve never had a seizure?”

“No.”

“Not as a child, with a fever? Not after a night of drinking?”

“No.”
“And you’re feeling better?

Despite my sore arms, my pulsating back, my fogginess. “Yes.”

“Well, the tests didn’t show anything, but after a seizure they often don’t. We’ll call this your first seizure.”

“First?”

She purses her lips, and launches into a much-told warning, as if it is a gift. “You get one freebie. If you have another seizure, we must report it and your driver’s license will be taken away for six months. The time you’re most likely to have another seizure is right after you’ve had your first.”

My mother has walked in with her hospital volunteer badge on. She is a petite blonde woman addicted to capris. She has brought a faded navy bag of clothes for me – mine needed washing she explained, before leaving for a little while. I must have dozed in between. The neurologist looks at her, probably observing the same curve to our lips, though I look more like my father. “This is …?”

“My mother.”

“Judy Williams,” my mom shakes the doctor’s hand. “I volunteer here, but I’m Kym’s mom.”

“I can speak freely?” the neurologist asks. I nod.

“What I want to do is put you on anti-seizure medicine right away. This might also help with your migraines. Do you live alone?”

“Yes” I answer, “I have my own apartment.”
“Can someone stay with you?’

“She’ll stay with us,” my mother declares.

“We don’t want you to do anything dangerous the first week. No driving. No baths when alone in the house. That kind of thing.”

*Oh shit. Really, a whole week. Shit. Fuck. Bloody Hell.* I have just started my second year of graduate school, and completed my first week of teaching two classes at the local community college. Since the seizure happened on a Sunday night, I remember my mom asking “Who should I call at the college?”

I didn’t know. I missed one class with my students having no idea what was going on. In addition, I have six tutoring students.

My mother smiles. “Oh, we’ll take care of her, doctor.”

“Good,” the neurologist stands up and shakes my mother’s hand, “I’ll have the nurse start a Depakote drip.”

My mom whips outs a mini-notebook from her faded Vera Bradley purse.

“What’s that for?”

“It’s anti-seizure medication, Mom,” I tell her.

Invariably, she asks. “How do you spell that?” Neither of my parents are strong spellers.

The doctor smiles at us, “now take care of yourself. If another seizure is going to happen, it usually does pretty quickly after the first.”
My mom’s manic energy made her a wonderful first grade teacher, but it has finally mellowed in the eight years of her retirement. She pulls up the chair next to the bed.

“We’ll make this work, honey. You just need to worry about feeling better.”

“But my classes. And my teaching.”

“We’ll figure it out.”

Tasked with the challenge of describing fibromyalgia, imagine a smashed piano left on a windy beach. Then imagine the cover ripped off the piano. It is buffeted by waves that come from nowhere, at odd intervals. Then imagine someone is still trying to make music with it. Someone sadistically picks out a tune on the bare strings. Because, do not forget, that the piano is a stringed instrument. Feel the pain travel slowly from the struck key to the end of the wire, calling out a sad note. Sometimes, the player keeps striking the same note, so the wire doesn’t stop trying to make music; it pulses on and off, music and silence, music and silence.

2016

My parents still live in the first house they bought, the house I was raised in. My old bedroom is an office, and nearly every wall that was once wall-papered is now painted. But I need to spend the week in my parents’ house. I sleep in my sister’s room,
which is technically a “guest room”, though Jennifer sleeps there every weekend unless she is traveling.

The trees that loom in the backyard are taller, but they cast the same shadows that they did when I was little. I loved growing up here. But now I feel trapped. Every time my parents ask how I am, tell me how much they love me, I feel obligated to say, fine, *love you too*. At night, the clock I bought them as an anniversary gift chimes each sleepless hour. With my new medications and limitations, I’m afraid to take anything extra to make me sleep. *Midnight, one, two.* Please let me sleep.

The most disconcerting effect of the seizure is a mild aphasia. I can see the word dangling there, I can spell out the first three letters, but I can’t retrieve it until it no longer matters. I talk to my students about using precise, concise language. And yet I can’t always do it myself. I can always pull out the word aphasia, but not other words. My spelling is also atrocious. Thank God for auto-correct.

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2005

Once, during a particularly difficult spring that sent Erin’s asthma flaring up to an attack-a-day levels, she came back from the doctor in tears. He was, typically, male and white. *I should be ashamed to be complaining. But I can’t help it. My lungs hurt so much. But he has patients on oxygen. I should consider myself lucky that I can still work.*

Therein lies the shame of the chronically ill. Joan Didion explains that it is assumed “if I take a certain combination of drugs, at certain intervals, I may avoid the
headache”. So you begin to think if I do this, and that, and avoid these things, and never enjoy blank again, I can get this under control.

For so many decades, the Kingdom of Illness was seen to be the province of the weak. We aren’t even good at keeping ourselves alive properly.

We learn quickly to say that we are “fine”. When I first began to suffer from fibro on top of the Lofgrën’s, I was sometimes in so much pain I needed a cane. But my duties were not modified and I did not ask them to be. My mother would ask me during every phone call how I was feeling. I would say “achy” when I couldn’t move and couldn’t wear my rings because the slender gold bands hurt too much. Don’t say achy, Erin would hiss, tell her you’re in pain.

* * * * * * * * *

2016

I have finally begun to see Erin’s … frustrations. I loved her best, and she loved me, but I was also her jailor. I encouraged self-care, then hovered over her, repeating superstitious patterns. If we treat it like this, or she takes that, maybe it won’t be so bad. She didn’t need advice, more medication, more nagging. She needed distraction from the pain. She needed understanding. She needed love.
FUNERAL PLANS

The funeral I never wanted to happen must be planned. The church must be visited, readings and songs chosen. Then the funeral home will be opened for us on a Sunday, so we can make the arrangements for her body. Now, I have the task of deciding how to celebrate her soul and dispose of her body.

By my mother’s and my sister’s good standing, the church I grew up in will host her funeral. Or as the Catholic Church now positively calls it, Erin’s *Resurrection Mass*. We will not be celebrating a Lazarus-like resurrection, but the passing on of her soul to paradise. No one at the church says anything about her being a lesbian, and I am allowed to write her eulogy, which will be delivered before the mass begins. Her family and I chose readings, some of them used for her father’s funeral the year before. Her mother insists on having the final song be “You Lift Me Up”, a secular song made popular by Josh Groban. Her mother always wanted that sung at her own funeral.

“You’re letting Erin have the song first?” I ask her.

“Yes. She should be pleased.”

I don’t tell Mom C that Erin always thought the song melodramatic and sentimental. Funerals are not for the dead. They are for the living.

The funeral home is a beautiful Victorian house by a park. It is appropriately hushed and somber with its Cherrywood floors and paneled walls. Mom had called the owner, and he has arranged to meet us that afternoon. He’d handled my Great Aunt Bea’s
memorial a year or two before. She had lived to be 101 and died peacefully in her sleep. My mother doesn’t come; it is only Mom C, Tara, Sean, and me. The owner is kind and solicitous after a lifetime of dealing with grieving families. Choices have to be made: viewing, funeral, burial? Or something simpler. We decide to have Erin cremated like her father had been a year earlier. Like one of her idols, Frida Kahlo when I die promise me you’ll burn this Judas of a body. That way, her ashes can be divided between her mother and I. We avoid an argument over where she should be buried. And no viewing. Erin had been self-conscious about her appearance for years, after her weight had ballooned on prednisone. She’d lost the weight after she’d had her second bout of pancreatitis, but she wasn’t her beautiful, vibrant self. Erin was vain, a trait passed down directly from her mother and grandmother, who never went out of the house without being properly coiffed and shellacked. She wouldn’t want people to remember her the way she looked now.

Little details: what kind of Mass cards, what kind of box to hold her cremains during the mass, when would everything be? He would write the obituary, but I insisted I could do it. He would proof it and submit it to the local paper. For the death certificate, he asked her mother for details. Birth date, place, etc. Her mother would be listed as next of kin.

“But what about me?” I asked.

“Because you weren’t legally married, you’d have to get the domestic partnership papers and it takes longer. This way it’s just quicker and easier. Believe me, I’ve done this for other couples and it’s been a hassle each time.” No judgement in his tone. This is just logistics. Not homophobia, not discrimination. Logistics. I’ll still be the first survivor mentioned in the obituary first.
What could I say? Sean had come from Texas, and his wife and kids had just arrived. Did I want to hold them hostage over paperwork? Besides, I wasn’t paying for the funeral. Sean was a successful oil executive, and would be footing the bill. We had lived paycheck to paycheck, and Mom C had been left with only the proceeds of their house when my father-in-law had died. OK. Nearly fourteen years together, and I was still not officially the next of kin. Fucking logistics.

Tara and I flipped through the sample Mass cards in an album with plastic sleeves. We have to pick text for one side, and two pictures for the other. I find an appropriate text, something not too religious of flowery.

“What about donations in lieu of flowers?”

“Oh, yes, yes,” Her mother concurred, “I don’t know where to. Maybe the American Lung Association?”

“I know that is a great cause, but I thought since Erin loved our pets so much, how about the Animal Welfare Association?” I suggested softly, so as not to contradict.

“Oh that’s perfect!” Score one for the not-really next of kin.

We have arranged the funeral details, her family and I. No viewing, just visitation and Mass at the church. We have picked out the Mass cards. Chosen the wooden box her ashes will be displayed in. Her sister Tara is enlarging a picture of Erin from her wedding. We’d only met and begun to date a month or so before the wedding. Erin had her hair long, for once, pulled back in an ebony knot at the back of her head, tiny pearls
pinned into the bun. She looked youthful, slim, healthy. Happy. No one at that time realized HOW happy. We’d signed the lease for our first place together after the rehearsal dinner. We’d taken two or three boards from the funeral home to decorate with pictures, writing, etc. My family would be responsible for the flowers.

White roses. Those were her favorites. I’d get her white roses for six-month anniversaries and other unexpected days. White roses, and irises. Irises were my favorite, something she had a hard time finding for me, but occasionally would surprise me with.

I’d told these choices to my mother as I started to put Erin’s Resurrection Mass program together. For the front, I was cropping a picture of Erin from my Aunt Bea’s 95th birthday party. She looked happy, maybe a little a pale, but with a smile that had me smiling back at her image despite myself.

“Can the florist put some other flowers in? Another color?” My mom calls from the other room.

“Yes, yellow is fine. Other flowers are fine. Just remember the one white rose with a green ribbon for the table with her box.”

The funeral director had suggested a single flower to stand next to the box of her cremains.

“What was her favorite flower?” He had asked us.

“White roses,” I answered quickly,” a white rose, with a green ribbon.”

“Oh that sounds perfect,” Mom C agreed.
She was *my* wife. Don’t you think I ever gave her flowers?

My sister and I were at my house picking up some things when finally, after trying to reach Erin’s best friend for five days, she was calling back. Maria was a bubbly, whip-smart blonde who actually made a living as an actress.

“What’s up?” she sounded appropriately alarmed, “I’ve gotten all these messages from you, call ASAP, 911, Erin very sick. I was out of the country. I’ve just gotten through customs. So what’s wrong?”

For a second, I thought absurdly of the story you tell about the cat climbing up on the roof, then falling off, etc … Erin climbed up onto the roof …

“Sweetie, Erin got a really bad colon infection. She was in the ICU for days. She had 3 surgeries. The doctors tried everything they could and she fought so hard, she really did,”

The tears had crept into Maria’s voice, “what are you saying?”

“She didn’t make it. She tried so hard, she really did.”

“Oh my God, Oh my God, Oh my God.”

I got to handle those kind of phone calls.
I was trying to work on Erin’s eulogy and talking to my favorite cousin, Susan, when the obituary came through. I am not afraid to name Susan my favorite cousin because she always has been; we have the bond of best friends who can pick up no matter how much time has passed. When I was five, my aunt and uncle took her and my cousin Paul out to live in Colorado. From then, we would see each other on a three to five year basis, and write in between. Susan was an entertainer; she was going to sing at the funeral for Erin; she shared Erin’s ebullient spirit and her kindness. She was now living down in Orlando with her second husband. Susan had been “Belle” at Walt Disney World, and still sang for Disney on certain occasions. I thanked her for coming up. I didn’t necessarily need her to sing. I just wanted the comfort of her presence.

The funeral director was probably surprised by the ease with which I’d written Erin’s obituary. I was a good writer, and years of caretaking had taught me to multitask through the grief. He’d kept my original with a few important changes: where I had named myself wife, he had written partner. And instead of in-laws he listed my parents as Kymberly’s parents. No technically, I was no wife. Technically, I was no widow.
EULOGY

Kindness, Mischief, and Song

Erin was the family eulogist. So to stand here, trying to say something poignant and witty and graceful about her is like trying to sub for her: is utterly impossible. There never was, nor will there ever be anyone else like Erin. I perused our combined 1000 or so books, searching for one passage, one quote that might define her. But I was unsuccessful. Then I came across a partial poem that seemed to personify her:

“I believe in kindness.

Also in mischief.

Also in singing, when singing is not necessarily prescribed.”

- Mary Oliver

Erin was an early singer, and an early miracle-maker: she whistled tunes in her crib, where she was confined in a hip cast, because she had been born without hipbones. The doctors didn’t think she would ever walk. She would prove them wrong time and time again.

While she always believed in kindness, she was an early convert to mischief; as the oldest of three children, she ruled their games and their make-believe. Her peculiar obsession with nuns started early; along with house and school, they also played church. While Sean got to participate in these imagined worlds, Tara was relegated to single neighbor on sled, and altar-boy (there were no alter-girls yet). Erin would serve potato
chip Eucharist’s and have Tara use a Patten made of a paper plate glued to a Popsicle stick.

In childhood beauty contests, Erin was always Miss Western Hemisphere. I have no doubt that she won most contests. She loved Tara and Sean so much she included them in her mischief; I doubt any of them will forget the time she took them on a joy-ride on a wagon hitched to their riding lawn-mower until they encountered Mom and Dad riding home the opposite way on their dirt road. I’m sure Erin did not sit comfortably for a long while after that. She always wanted the best for Tara and Sean, or what she deemed the best. Her extensive imagination would elevate a game of Clue into impromptu theatre: notes were given: go to the dining room, where blue water in cordial glasses would symbolize poison; an axe in Tara’s bedroom, and the last clue, where a wrench would be found in the mailbox. This, perhaps, was her attempt to toughen up Tara. We all know how well that did work.

She also wanted Sean to achieve all he could. On his seventeenth birthday, he received an official letter, stating that he had been drafted into the Marines. Sean proudly proclaimed his enrollment to anyone who would listen; it was not till some time later that the letter was exposed as a fraud, concocted by Erin. But he did feel like a Marine for several hours, didn’t he? I will pause in my family reminiscences lest the nephews and niece get some more ideas.

I will now mention Erin’s great love of Dickens’s “A Christmas Carol”. The George C Scott version would run on a constant loop from Thanksgiving until January 1st; she adored the story of the old miser receiving “Reclamation”, and learning to keep Christmas in his heart always. But Erin needed no reclamation; perhaps it was her job on
earth to make sure we sought our own reclamation, for she always had the kindest heart, much more like Scrooge’s nephew, Fred, who believed in a time when “men and women open up their shuttered hearts, and regarded others as fellow travelers to the grave.” Erin’s heart was never shuttered, nor did it need opening; like the ghost of Christmas Past, her light might have blinded us. She gave herself to everyone she met, no matter how lowly or troubled, no matter what it took from her.

She called “Aunt” her most honored and beloved title. And though she leaves us early, I hope you keep in your hearts, how much she loved you, her nephews and niece, how much she loved all of us. She helped me to open my shuttered up heart. She loved generously, lavishly, fully. That, beyond her teaching, is her greatest legacy. She loved without judgment; she had a tremendous talent for love, and for giving. Her greatest joy was in making others happy; a perfect gift to someone else, who would glow with joy when they opened it, was much better than a gift to her.

Erin’s spirit was so much greater and brighter than her body could take. She was one of those people who lit up a room, who made friends with every stranger. She changed many lives, not only through her teaching, where she entertained, slyly cajoled, and permanently influenced her students. The limits of her body, when she was forced to give up teaching, slightly dimmed her glow. But it was always there, for anyone who looked closely, or listened deeply. A trip to pick up a pizza would take her 45 minutes, not just because of the Charles’ infamous disregard for time, but also because she had just made life-long friends with the cashier. And life-long-friends were family to her; sisters and brothers, nieces and nephews whom she’d chosen as her family.
What I can guarantee to you all is that she loved you so much more than you can imagine. She prized her role as devoted daughter, sister, niece, cousin, friend and co-worker. Each cross word, each missed call is forgiven completely. She is so far beyond the worries that consumed her each day, resting in the arms of her father, John, and her Eternal Father, God.

For me, Erin was the answer to a prayer I never dared pray. I was a lonely 25 year-old when we met. I blossomed in her reflected glow, and my shuttered-up heart opened, forever. I knew from the start, having witnessed her health scares that she was a blessing on loan from God, and was never mine to keep. Let me share one of our favorite poems:

“I did not live until this time crowned my felicity, when I could say without a crime,
I am not thine, but thee. This carcass breathed, and walked, and slept, So that the world believed, there was a soul the motions kept, but they were all deceived.
Which now inspires, cures and supplies, and guides my darkened breast;
For thou art all that I can prize: my joy, my life, my rest,
No one’s mirth to mine compared can be: They have but pieces of the earth;
I’ve all the earth in thee. “

- Katherine Phillips
TWO BROKEN HALVES

When we met, we were two broken halves who had finally found our other half. We felt complete together. The world finally made sense. All those lonely, messy, difficult years were over. They were our testing ground, the precursor to this time of bliss. We both came with wounds and issues that we weren’t afraid to show each other, and just being together healed some of those. I no longer wanted to starve myself into nothingness. She no longer wanted to escape into codeine’s nauseous oblivion. We wanted to be right where we were. We wanted to build a life together, and we needed nothing beyond each other.

You are not supposed to seek healing for your wounds in someone else. Their presence can’t fix everything. And when their presence is taken away, you are left even more wounded, even more broken than when you were before.

Our last few years together were still happy, but there were cracks in the blissfulness of our initial time together. Money troubles, constant health problems, worry about her health, worry about money, worry about issues at work strained my new optimism. I became less of a partner, and more of a caretaker. Her chronic illness drained her of her liveliness. I would sit in the room with her and feel lonely, missing the woman she used to be. Chronic illness is a country no one wants to visit, a dark and rocky one that some couples do not survive. The only hope is some form of remission; no cure is possible. Still, I would hope against hope that her symptoms would decrease and stabilize, that the good days would outnumber the terrible ones.
ANXIETY


The sun can kill you. The light can kill you. Pollution can kill you. Traffic can kill you. A trip down the stairs. The demon that sits beside you and tells you “life really isn’t worth it anymore.” The pills that you take for pain, migraines, high blood pressure, they call out to you like the drinks and food in Alice do. They may as well have carefully lettered notes around their necks: eat me, take me, take all of me. Enough would surely stop everything.

Really, will you ever be happy again? Will anything ever give you joy again? Before, having lived alone, lonely, without love and far removed from joy, you accepted the shadow life. But now that you’ve seen the other side, how can you go back?

She was your mirror. In her eyes, you were beautiful, brilliant, brave and kind. Without her to reflect those aspects of you, haven’t you lost them? You think, who will ever find me beautiful now? After two years of steroids and pain meds, you have ballooned far beyond beautiful. You are not curvy, sexy. You are fat. You are ugly. No one will ever look into your green eyes, and say wow, I’ve never seen anything so amazing.

And if I go on, aren’t I just wasting this life? What was I saved for? Yes, I know time is precious. The knowledge brings its own fear: am I doing enough? Is it okay to take today to heal? For Erin, I could fight armies, I could chase away legions of ghosts. Alone, I let them keep me cowering beneath my comforter.
THE CURIOUSLY PRECISE ARITHMETIC OF GRIEF

Even if usually you don’t know the date, or what day of the week today is or yesterday was, you know the exact day and date that you lost your beloved. If you were there, or if there was a particularly traumatic phone call alerting you, you will also know the time. For me, it was 11:40 pm, on Saturday, June the 25th. At least, that precise time was the doctor’s call. She was gone perhaps 3 minutes before, but I was too blinded by tears to look at a clock. I’ve heard her mother say it was a quarter to midnight, but my memory is clear and correct.

For at least three weeks to a month afterwards, you count the time in days. She’s been gone for nineteen days. Two and a half weeks seems too vague, dishonoring the time. Later, you will count the time in weeks. 8 weeks. 9 weeks. 11 weeks. You count time from Saturday to Saturday. You may wake or be unable to sleep until you have marked the time, 11:40. This time 17 days ago you left this world. You left me and stepped into Paradise.

For me, it took a good 3 months until I could count the time in chunks, in anything beyond weeks. It was very difficult for me to generalize to my new boss, who was blissfully ignorant of my loss (and remained so for the few months I knew him) and say I was a “new widow”. At that time, “new” meant 2 months and 5 days. But with some people, you soften the blow (why?) of breaking the news to them. You side-step the obligatory sympathy that they’ll have to express, that will never, ever be enough. My friend recently wrote of the 4-month anniversary of losing her father. And my late wife’s
cousin marked the 17th year anniversary of her own father’s death. Loss leaves us so good at counting time, at remembering precise dates like never before.

Even for me, when asked how long it has been, I told my grief therapist that it would be 2 and a half years on Christmas, exactly. Before, my birthday was special not only for it being my own day to celebrate, but for being exactly 6 months to Christmas. Some people do know, and others don’t, that I lost my wife (what else could I call her?) on my birthday. So that day now is a day both of celebration and sorrow. The two sides of life: bitter and sweet, life and death. I thought that at the time, I was sparing her extra hours of pain, and sealing her life to mine. My beginning date would be her end date. A symmetry of dates. I didn’t know then, that it didn’t really matter, not in the short run. Maybe for some, dates will eventually go hazy, the years go uncounted. But now I know, there is no stopping the automatic arithmetic of grief. You’ve been gone for two years, 5 months, and 8 days. Well, not exactly – it’s not 11:40 yet.
There are two ways of spreading light: to be the candle or the mirror that reflects it.”

- Edith Wharton

For too long, Erin was the candle and I was her mirror. When we met, her flame was so bright it warmed everyone around her. It illuminated the darkest parts of me, and banished some of them. My own candle was a poor, stubby little thing. Or maybe it was just a slender stick, easily broken. Either way, I was glad to be the reflection.

I spent all my energy trying to keep Erin’s candle lit; when it sputtered, weakened by illness, I kept on heaping more fire on it. Adding extra wax, trimming the wick. I should have been attending to my own candle, illuminating the darkness for us both. At times, I did. But I thought my own light such a poor substitute for Erin’s that I kept on polishing my mirror instead.

So it is no wonder that when she died, the mirror shattered and the darkness was complete. I told myself I would never be the submissive wife or sublimate myself to my partner. But that was before I ever fell in love, when I still thought marriage would be to a man to whom I would never surrender most parts of myself. When I met Erin, I was bewildered by love, and if I was the quieter partner, it was okay: I was the woman behind the woman.

It is no wonder that the perfectionist, the little girl who thought that her parents’ love was conditional on being the best at everything, would fall into a codependent relationship with the first person who said she loved me, all of me, even my flaws and failings. I thought I had left behind my perfectionism, my need to not
disappoint my parents. I had left behind my punishing need to not be a
disappointment my parents. I had rebelled in the most irrevocable way: by
becoming something they never wanted me to be, by choosing a fate they would
never have chosen for me. There was no coming back from my coming out; I was
never going to be the golden girl that they were proud of again.

I would lie in my bed at seven, eight, nine, awake with anxiety about school.
Had I done all my homework? (yes, always) Was I going to get an A on the test the
next day? (I almost always did.) Each assignment, each test and quiz was not a
chance to prove my knowledge; it was another chance to fail. And I felt that love
was conditional on straight A’s, good behavior, and properly done chores.

As an avowed feminist, I devoured books like A Room of One’s Own. If I
ever married, I thought, I would never sublimate my dreams or ambitions to a man.
But being a lesbian feminist is something much more complex and confusing.
Usually, there is a dominant partner, and it was not me for a very long time. I didn’t
know if I could really call myself a writer any more, even my daily journal had been
abandoned. My poetic attempts were nothing more than scribbles on cards. The
well had run dry, and I had let it, and I hadn’t cared at the time. I was loved. If love
meant the world would go on with one less mediocre book, where was the loss?
LETTER TO THE LOST

You’ve ruined my life.

I tell her as she smiles out from the posed picture, make-uped in all her youthful glory.

So happy then. So happy. That was just the start of our lives together, and I should have paid attention to all that had happened then. Her mother’s erratic behavior. Her roommate’s curious jealousy. The dramatic health issues. All those would be repeated again and again throughout our life together.

You’ve ruined my life, babe. You showed me great love and then took it away. I am not the person you changed me into—I am neither open, nor fierce, nor fearless.

I thought life now would be different. That there would be more of a community. That I would feel more at home. I have made a home for myself but you took away all the squishy warm feelings with you. I wake up and the sun is a sliver of just another chance to ruin this day, love.

I want to do a ritual purging, Christmas is coming on soon, and the tree is still in the same corner I messily packed it into last March. I adapted your habit of leaving up the decorations far too long, putting too much store in the glimmer of tinsel and lit Dickens houses. If anyone has turned into Scrooge it is me, but I already had the visitations, I already know the ending, I just don’t have the heart to behave the way I should; the un-shuttered heart that you broke open lies pretty useless.

You’ve ruined my life bitch.
Maybe I won’t put up our ornaments this year. Maybe it’ll be a generic tree, one with angels and drums and nameless things that sparkle.

You’ve ruined Christmas. Of course you did. It was our holiday, tree-trimming on Thanksgiving, George C Scott on a continuous loop since barely after Halloween. Most nights, he’d barely get past his first journey for reclamation before you fell asleep.

To love is to ruin and to heal all at once, and I’m awed at how well you did it, so well, I never felt the pain, never felt the thrill of the peril, of course this could end, of course there are unforeseen dangers ahead, never heard you whisper: of course I will leave you alone and everyone will see you broken.
SUMMER SONG

The crickets and cicadas hum’, the first strain of your requiem.

I used to love summer. The warm days, the trips to the shore, the long days of books, daydreaming, more books. I read everything in our library’s section of young adult literature. By twelve I had moved on to Nicholas and Alexandria, to Agatha Christie mysteries.

Just before dark, the lightning bugs blinking their soundless songs. We’d try to catch them, but always release them once they lit up for us. No jars with holes punched through the thin metal of their lids. Once captured, the lightning bugs soon went dark, waiting quietly for freedom. Only then would they blink again: freedom! I escaped! I escaped!

Now, the humid heat that requires air conditioning reminds my body that it’s grief-time. You would have picked Mozart’s requiem, you loved Amadeus with a passion. Is that how you saw yourself, an ill-paid genius, and dead long before your work would be appreciated? One problem: everything you meant to write died with you. There is so little for me to piece together. The only way you will gain immortality is through my writing. My reflections of you: sweet beloved, flawed lover, in sickness and death the anchor that nearly sunk me. The night you died, your mother told me: you will make something beautiful of this. Something beautiful, but also gruesome, truthful, terrible, the other side of the fairytale. Yes, your love was my salvation, but also my undoing. I gave up all my dreams and hopes just to keep you alive. My sweet: is our story a cautionary tale or a tale of endless love? Or both?
I would choose Brahms’ Requiem. Mournful, but comforting. Lullabye and forever goodbye. “You now have sorrow; /but I shall see you again /and your heart shall rejoice/ and your joy no one shall take from you.”
ALTARS TO THE DEAD

In other cultures, particularly Mexican and certain Asian countries, the dead are always with the living. They are revered. Little altars are built for their beloved deceased. Candles flicker, flowers droop and wilt in vases, pictures stare out at the living. Sometimes, food is offered.

We started to observe the day of the dead when our first dog passed. On her birthday, we celebrated with her favorite treat, fried wontons. And Swedish fish: only the red ones. Once, Erin had gotten me a bag of mixed fish. I didn’t like the green or orange ones, the yellow were okay. I tossed Margo several fish, hoping she’d eat them so I wouldn’t have to admit that I only liked a quarter of the sweets Erin had brought home. The fish disappeared, so I kept on rewarding Margo with more fish. We realized about a week later that she had hidden the unwanted fish beneath the area rug, like a kid hiding peas under a napkin at the dinner table. We never did get the melted orange goo out of the original rug.

My dresser is an altar to my beloved dead. Erin’s ashes lie in a green and gold box shaped like a book. For a while, I had her picture atop it, the enlarged portrait from her sister’s wedding that we’d displayed at her funeral. But after a while, her presence loomed over the room, and I replaced it with a smaller snapshot of her with her godson. There were pictures of the two of us together, of course, and also pictures of our deceased dogs: Margo and Daisey laying on the couch together.
There’s also mementos: the single surviving champagne flute of the pair we’d purchased in Killarney. I hadn’t believed in omens, but Erin was superstitious; she was upset and frightened when one of them broke in the months before her death. She thought it meant our relationship, fraying at the edges, would end. It would, but not with a break-up - only death would separate us. Her Irish rosary, with its golden crucifix and emerald-green beads, a gift from her father, had also broken in her last year. An amateur jewelry crafter, I assured her that I could fix it. Another bad omen. I never did fix it.

The last gift I gave her, a Moroccan glass, sits on the altar. I’d brought it back from Disney’s Epcot. It was green – her color, and it was intricately etched with gold designs. She thought it beautiful, but didn’t ohh or ahh overly much. A little token of the first trip I’d taken without her in five years. She was more excited over my return, though my absence had afforded her some time with her mother.

There’s a new St. Brigid statue from Knock. The large one that had sat on our dresser for so long had been given to her mother. Her mother requested the statue and also her father’s rosary beads. I’d given her one of Erin’s favorite Irish sweaters and family pictures that had nothing to do with me. She didn’t want to look through anything else. I was left to sort through everything else myself. She painted her guest room green and called it Erin’s room. I didn’t need to paint the walls. My whole world is an altar to my dead.
Elizabeth (Betty) Hawk wasn’t supposed to accomplish much. She never learned to drive. She never graduated from high school, opting instead to try secretarial school. She never traveled far from her small neighborhood of Fairview in Camden, NJ. Betty was just another PTA mom, who eventually became Zoning Chairman, prompting her to run for School Board. She lost her bid for the first few public offices she ran for. Despite these defeats, she persisted, and at the age of 46 she was elected to Camden’s first City Council in 1960. She was the embodiment of a Kennedy Democrat: ask not what your country (or city) can do for you ... Betty met both Bobby and Ted Kennedy. She was invited to attend Lyndon Johnson’s inauguration in 1964. She and her shipbuilder husband, Robert, drove out to Chicago to attend the infamous 1968 DNC Convention.

Yet Betty never stopped being a mother, a wife, or a grandmother. In 1966 she made history when she became Camden’s first female President of the City Council. She tried throughout her decade and a half of public service to improve her city. After she left elected office, Betty served as aide to the ambitious and unfortunately corrupt Angelo Erichetti. In his zeal to revitalize Camden and Atlantic City, Erichetti became involved in the ABSCAM scandal; the character of Mayor Carmine Polito (played by Jeremy Renner) in American Hustle was based on Erichetti.

When she died in 1981, the Camden Mayor’s office issued a resolution citing her many years of service:
The Honorable Elizabeth B. Hawk was elected as a member of the Camden City Council and was sworn to office on July 1, 1961 and served as Councilperson until July 30, 1974. During that period, she served as President of the City Council from July 1966 to June 1969. After leaving office, Mrs. Hawk served as Administrative Aide to the Mayor from 1975-79. During her entire lifetime, Mrs. Hawk was active in numerous community affairs, especially as a member of the PTA in schools of the Fairview section of the City of Camden. Mrs. Hawk was always sacrificing her time and energy for the betterment of her neighbors and community. Her entire career of community service, both in government and civic affairs extends two decades and during that time she brought optimism and hope to all whom she served; The City of Camden, by its governing body, deems the passing of Elizabeth B. Hawk a loss to the community because one of its dedicated friends and neighbors has departed this life; therefore BE IT RESOLVED that the City Council of the City of Camden, acknowledges and expresses gratitude to the late Honorable Elizabeth B. Hawk, former Councilperson and former President of City Council posthumously for her many years of service to the City. The City Council also expresses its sympathy and regret to the family of the Honorable Elizabeth B. Hawk and sympathizes in their loss.

This resolution was presented to her daughter, Judy, at the bereavement luncheon. It was read by a smooth-faced Council aide who was accompanied by a middle-aged policeman with a thick mustache. I watched as my mother took the resolution in trembling hands and thanked them both.

The Honorable Betty Hawk was my grandmother.

* * * *

As a child, I had no idea who my grandmother was, beyond being my Mommom. I just remember bits and pieces of her little red-brick row house in Fairview. There was the basement with a scary hole in the cement floor that I was sure would swallow me if I got too close. There was the tiny bedroom in the front that had been my mother’s, where I slept on occasional overnights. There was her Cherrywood dining table with the pads turned over to the green velvety side so the adults could play cards. Glass candy dishes
were scattered around, filled with gumdrops, spearmint leaves, and chocolate nonpareils. I sat at Mommom’s vanity and would try a spritz of her favorite perfume, Youth Dew; it was the color of strong tea, in a glass bottle with a tiny gold bow. I would sometimes try a smear of lipstick, or clip a pair of her sparkliest earrings on my little lobes. Her room and the bathroom smelled like Caress soap and perfumed powder. I often had to wash my hands after climbing the little front stoop’s iron rails, which turned my hands and face black. And then there was the smell of cigarette smoke. It clung to the bedspread, the curtains, and the couch cushions, and Mommom herself.

Ill health forced her to curtail and then give up her civic duties. She sold her house and moved into the porch we had enclosed as a room for her. My mother juggled ferrying my grandmother to her bi-weekly dialysis sessions, while also raising me and my toddler-aged sister. Mommom never knew my talent for writing, though she always encouraged my love of reading. She died when I was eight, having endured a hard 67 years.

As artists, we are expected to live hard and die young. To blaze brightly and flame out early. Every facet of our culture is youth-obsessed. 23 writers published by 23. Top writers under 30. I once thought I would be one of them. And then life got in the way. I was no longer in my twenties. Older than Keats when he died, older than Lord Byron, Shelley, Plath. I eventually outlived all of the Bronte sisters, with only one minor publication to my name. I often felt like I had missed my calling. That I had deferred my dream too long while devoting myself to a partner who had needed all my attention, then died and left me. I didn’t know what to do my life. I didn’t know if I could have that elusive second act.
Despite her early failures, Betty Hawk achieved what my counselor called *failing forward*. Instead of seeing those first elections as disappointments, she learned from them, and doggedly continued in her pursuit of public office. If there was any family discussion about running for office it probably sounded like this: Mommom: *I’m going to run for City Council. I believe this platform has a real shot. How does that sound?* Poppop: *Whatever you want to do, Betty.* My grandfather was a rare man who looked at his wife as an equal; he supported his wife, and believed that she could accomplish whatever she set her mind to. She was unstoppable once she had decided on something.

When I fail, when I feel like chances have passed me by, and that I am too old to accomplish anything great, I think of my grandmother. The first female head of Camden’s City Council. A strong woman who never let disappointments stand in her way. Who dared greatly, and had a tremendous second act that put her in a few history books. When my writing lacks eloquence or artistry, I remind myself, *this is not the last thing you will write.* Somewhere deep in my bones, lies the same strong marrow that gave my grandmother her courage.

**FAIRVIEW**

Betty was born Elizabeth B. Brooks to Margaret Nichols and Horace Brooks on July 24, 1920. She was the only child of working-class parents; her father was a lineman for Bell Telephone, and her Irish-American mother was a switchboard operator for the Ritz-Carlton Hotel in Philadelphia. We have some pilfered spoons and knives in the silverware drawer to prove Margaret’s employment. Betty was a strawberry blonde, the
kind of woman you would call striking rather than beautiful, until she smiled. Betty spent
her formative years and adulthood in the Fairview section of Camden. Somewhere
between Fairview and West Collingswood she met my grandfather, Robert Hawk. They
eloped in 1934. They ran a store on Mt. Ephraim Ave called the “Cozy Nook” from
1934-1936. In 1936, my uncle Bob was born, and Betty became a full-time housewife
and mother.

Fairview was originally called Yorkship Village, and the elementary school that
my mother attended still carries its name. The neighborhood was a planned community
meant to house workers of Camden’s New York Shipbuilding company. The company
had tripled in size during World War I, due to its war contracts. Yorkship (Fairview) was
meant to alleviate the housing shortage that might have threatened the business. At that
time, 75% of Camden County residents lived in Camden City.

Betty and Robert Hawk first lived near the square, but by the beginning of the
1950’s they moved to a permanent home, bringing their new daughter Judy and her
brother Bob to live at 1337 Argus Road. The neighborhood was far enough away from
the waterfront that Robert had to take the bus to the shipyard each day. Their neighbors
were other young families with children, many of them first- and second-generation Irish-
American or Polish-American immigrants. My mother and her brother walked to school,
and could safely roam the neighborhood with their friends.

My grandmother settled into life as a typical 1950’s housewife. She cooked
dinner every night, mindful of her husband’s dislike for onions and brussel sprouts (he
called them skunk cabbages). She joined other women in volunteer activities, working for
Toys for Tots, helping out at school, eventually taking a leadership role on several PTA
committees. These would be the testing ground for her political career. Working on school issues, she began to see the larger issues that affected her neighbors and her city. As PTA zoning chair(wo)man she traveled to various neighborhoods, overseeing installations of new members, seeing how things were run in other schools and communities. She occasionally appeared in the paper, addressing the Board of Education about school needs, smiling broadly at the opening of new Junior and Senior high schools, serving lunch to the new school superintendent. She was always identified as Mrs. Robert Hawk, as though she had no identity beyond that of wife. She would soon earn her right to her own first name, and become a fixture in the local papers, especially the Courier-Post.

My grandmother had ambitions beyond just the PTA. In the late 1950’s she ran for open School Board seats, and once for Camden County Freeholder. Though she had many friends and their respect, she couldn’t garner enough votes throughout the city or county to attain office. But her efforts did not go unnoticed. Mrs. Robert Hawk would soon become part of political change in the City of Camden.

In reviewing my grandmother’s career, I can see that sometimes you do everything right, but things still don’t turn out the way you envisioned. Things you go after with your whole heart sometimes still slip from your grasp. It’s not for lack of trying, or lack of talent or experience. Sometimes, it just isn’t your time. Sometimes, greater things are waiting for you. Steeled with patience and perseverance, my grandmother just had to wait for the right opportunity.
From 1936-1959, George Brunner reigned as Camden’s longest tenured mayor. He had overseen the boom times of the burgeoning shipyards and the rise of RCA, Campbell’s and other business that brought jobs and profits to Camden City. But toward the end of his career, the city had also suffered from blight, violence, and the exodus of many citizens to the suburbs of Camden County. Brunner realized that his time was up. Alfred Pierce, a former war hero, became the next mayor, overseeing a mayoral-commissioner team in 1959. Pierce promised revitalization and inclusion for those who felt disenfranchised by the City leadership.

In July 1961, Pierce decided to alter the face of Camden politics by changing to a Mayor-Council form of government. Pierce would serve as Mayor along with seven at-large Council members. His council would be made up of members who represented various communities within Camden. Michael Piarulli represented Italian-Americans, Matthew Casper was a Polish-American labor leader, Elijah Perry, a war veteran and a former member of the Lionel Hampton band, represented the rising African-American population. Mario Rodriguez, a Puerto Rican, represented the increasing population of Spanish-speaking citizens, and Harry Kerr stood for the city’s influential Jewish population. To round out the ticket, Pierce wanted someone to appeal to the Irish-American and female voters. He chose my grandmother.

At that time in American politics, there was a great optimism which had been ignited by John F. Kennedy’s inauguration as President. The Pierce ticket ran on the slogan of Walt Whitman’s “A City Invincible.” The entire council was elected, along with Pierce, and set to work on re-invigorating the city. My grandmother could finally bring forth the concerns of her friends and neighbors, and work on solutions. She told a
reporter that being a woman was “an advantage over my male colleagues. I don’t have to hold down a job to support my family, so I can be a fulltime council member.”

Betty never considered herself a pioneer or a feminist; she was simply a public servant devoted to her constituents. She did advocate for more women in politics, not because of any ideal, but because she believed women “had more guts” and were “content to remain in office until they completed their tasks.” She relished her work on the City Council, arriving at her office at 9AM, working ‘til 5PM, then returning home for dinner with the family. My mother was still in high school, and my uncle lived at home until his marriage in 1967. If there wasn’t time to fix a meal, the family would go out to a local restaurant. The family was growing in status, but not necessarily financially. My mother remembers my grandmother’s salary as $2500 a year. It wasn’t much, but it was more income than the family had previously. One thing was certain. The longer my grandmother worked in politics, the higher and blonder her hair grew.

NATIONAL POLITICS

Betty Hawk was a staunch Democrat, and believed in the inclusive message of the Kennedy administration. She began to take a greater interest in national politics, as national figures, particularly the Kennedy brothers, came to Camden to lend their support to local politicians.

In 1964, the Democratic National Convention took place in Atlantic City. Most of South Jersey’s Democrats found themselves helping out at the Convention, and Betty was
no exception. Because her mother Margaret had moved to Atlantic City, she spent the week there, and my own mother went down to watch RFK eulogize his brother. Betty’s work and enthusiasm did not go unnoticed; she received an invitation to LBJ and Hubert Humphry’s Inauguration. Though she did not attend, she put it proudly away with her other political mementos.

Betty continued rising as a political force. On July 1st, 1966, she was elected unanimously as the first female President of the City Council. Her fellow councilmen called her “the catalyst needed to achieve unity” within the occasionally divided council. She had shown her willingness “to undertake the brunt of the work… (She would) “show the public that her dedication to service will not be surpassed.”

Betty graciously accepted the praise of her colleagues. She acknowledged it was “unusual for a woman to be president” and that she was aware that some people were “skeptical.” But Councilman Rodriguez, who at times had sparred with her over different issues, assured others that “her ability to get along with people and her dedication turned many a skeptic, and I was won over to Betty’s corner.” My grandmother would remain Council President for three years, through contentious times for both Camden and the country.

1968 began as a hopeful year, with Bobby Kennedy intent on claiming the White House and continuing his brother’s campaign to bring social change to the country. “He was to maintain his commitment to racial equality into his own presidential campaign, extending his firm sense of social justice to all areas of national life and into matters of foreign and economic policy.”
Betty hosted RFK at Camden’s Convention Center. Kennedy made urban poverty a chief concern of his campaign, which led to enormous crowds at his events in the cities. But in April, Martin Luther King, Jr. was assassinated in Memphis. Racial tensions boiled over in many cities, and Camden was no exception. After dealing with disgruntled citizens during the day, my grandmother no longer rode the bus home. She was escorted home by an aide. My grandfather worried for his wife, but knew better than to try to stop her from doing her job. Nothing stopped her.

When Bobby Kennedy was assassinated in June, even more of the Kennedy magic went out of the Democratic Party. If social crusading was going to get you killed, maybe it was time to scale back on the dreaming and struggling. Hubert Humphrey became the Party’s nominee for President. Betty liked him as a person, and campaigned for his election, but didn’t expect him to visit or care very much about her city.

My grandmother was a delegate to the 1968 Democratic National Convention; she and my grandfather drove out to Chicago. My grandfather did not fly. Though their days were spent on the Convention floor, it was impossible to ignore the war protesters outside. Reporters Dan Rather and Mike Wallace were roughed up on the convention floor when they tried to conduct interviews. A huge riot took place on August 28th, resulting in thousands of anti-war protesters being beaten and tear-gassed by the police. So much tear gas was used that it spread throughout the city, disturbing Hubert Humphrey at his room in the Hilton. The protesters chanted “the whole world is watching”, and the riot became the iconic picture of the Convention.

My grandparents did not talk much about what had happened, and as a politician, Betty never spoke out publicly against the war. Luckily, my uncle Bob had served his
time in the army prior to the Tet Offensive and could not be drafted again. Perhaps
disgusted or bewildered by the Democratic National Committee’s action, Betty
concentrated her efforts on the problems of Camden.

END OF AN ERA

Betty Hawk’s tenure as City Council President lasted a difficult three years. In an
interview, “she expressed neither regret nor resentment” at not be re-elected to a fourth
term as President. She “displayed the same radiant smile that has become her trademark”
as she spoke of her successor, Councilman Elijah Perry. Just as she had been the first
female Council President, Elijah Perry would be the first African-American to hold the
post. She would stand beside him, though she wasn’t certain “if he’ll be able to keep the
racial strife out of the city.”

Betty’s time as President had included confrontations with “black militants”. “She
never flinched … from a blistering situation. She always remained firm, but fair, when
critics … hurled insults at her and the council. If she was brave during a tempestuous
meeting, she exhibited equal character in measuring up to the many problems she faced
and often resolved.” Her most difficult test was when she had to publicly break away
from former Mayor Alfred Pierce, the man with whom she had worked for many years.
When he began to undermine the Council, Betty had to admit that he “was no shining
knight.”
While Betty hoped that some of the redevelopment dreams that she and Pierce had started would come to fruition: Centerville-Liberty Park, Northgate II, she knew that many businesses were leaving the city. Two of the largest companies, Esterbrook Pen Company, and the New York Shipbuilding Company, had closed. My grandfather had worked at the New York Shipbuilding Company since the 1930s. Once displaced, he had to seek employment elsewhere, and finally found it with the Pennsauken School District. Many others had to leave the city to find jobs.

Betty was also praised for the breadth of her legislative work. Among her accomplishments, the Philadelphia Inquirer listed: a shorter workweek for firemen. Abolishment of a 63-year-old blue law prohibiting Sunday sales and approval for women to sit at bars and limited Sunday liquor sales.

Betty always did enjoy her cocktails. With a cigarette.

Though she would remain on the Council for four more years, her position would be limited to contributing to meetings, not running them. Betty would never stop fighting for her city. She would also face the loss of her mother, Margaret, in 1970, and the diagnosis of lung cancer in her husband, who had also been life-long smoker, in the fall of 1972. He had a lung removed, but before he could begin cancer treatments, he died in the April 1973. Betty worked through her grief by continuing to do the work she knew best.

As I write of my grandmother’s accomplishments, I am filled with both pride and a lingering sadness. I never got to watch my Mommom work, and I never got to ask her
about her years on the Council. I never learned about how she handled herself as a woman in a man’s world of politics, or what Bobby Kennedy said to her. Luckily, she never lived to see Camden sink to its current state, or become the most Dangerous City in the US.

None of the family lives in Fairview anymore. When my mother Judy met my father Shelly, they were married at St. Joan of Arc’s in Fairview and had a large reception at Kenny’s in Camden. Then they moved to Cherry Hill, and my Uncle Bob and his wife Lorraine moved to Somerdale. After the house in Fairview was sold, Mommom spent time at both houses, finally settling at ours.

My grandmother was admirable, but far from infallible. She still smoked when she could, despite open heart surgery and kidney disease. She would bum a cigarette off the neighbor whose backyard met ours. She and my mother didn’t have the closest relationship, despite all that my mother did for her. But she was a good grandmother, and she loved us. Before she died, she lost her mental acuity. She thought my sister was me, and she chided her for climbing on the iron railings outside the Fairview house no longer hers. “Kymmie,” she said. “You’re all dirty.”

When my grandmother died, it was the first death that I had experienced. Suddenly, death was real, time was real, and it could run out. Other people I loved could die. I was petrified of losing my own mother. I didn’t understand the whole funeral home ritual, and I didn’t understand why there was someone from Channel 6 filming us as we climbed into the limo for the freezing ride to the cemetery. I didn’t understand that my Mommom had been important to people who were not just part of our family, but part of her city.
As I grew up, I began to notice more than just the beautiful costume jewelry she’d left us, but I also looked through her scrapbooks. There were albums full of newspaper articles about her, and pictures of her with politicians I recognized. Every election day, I wear her pin of the Democratic donkey with boxing gloves. Both my cousin Colleen and I have the picture of Mommom sitting behind Bobby Kennedy.

The older I become, the more respect I have for Betty Hawk the woman. She succeeded against all odds, despite her humble roots, despite her lack of formal education. And she did so at an age and at a time when not much was expected of a 46 year old housewife, other than to host card parties and volunteer for committees that were more about being social than accomplishing something of real value to the community. To honor her legacy is not just to write her story. To honor her is to continue to try, to never give up. To never accept an expiration date for my ambitions, or my dreams.

It didn’t matter to my grandmother that she become something more. It mattered to my grandmother that she do something more. Maybe in the end it doesn’t matter that I become something more: more successful, more famous, more respected as a writer. Maybe it just matters that I do more: write more, share more, and work more on my craft. I am proud to share the legacy of late bloomer with my grandmother. Second acts are definitely possible.
Sometimes, I wonder what the actual point of “us” was. That we would have a love so intense but so short. Was it to teach either of us a lesson? Was it a reward? Was that my reward, for twenty-five years of solitude? A short interlude of boundless love to last me for the rest of my years and days, however long they be? The beautiful day in which you held my hand as the sun set behind our home, that I failed to preserve in memory perfectly, not knowing that I would watch the sun set on a thousand more days without you. How could I know? Yes, there were hints from the beginning of your impending mortality. And I thought foolishly, romantically, if I have you for just a short time, that love would be enough. I’d keep you in my heart forever. Its glow, its embers would sustain me. Bullshit. I knew nothing. I knew nothing of disaster, or heartbreak. Only what I’d read or seen in movies. Life is not a lovely, heartbreaking novel. It is a mess of pages written by an insane author, who can’t even keep a proper plot going.

So maybe you were sent to break my heart open. To crack and stretch the tiny, cold stone that served me as a heart. You turned it into a living, growing creature, one with a fragile, shiny skin, like a naked bird. And you nourished it with the love you fed me. The love you bathed me in, wrapped me in, and kept me warm through fourteen winters. Even if the love was a little frayed at the ends, those last few years. Even if it was a little threadbare, as we lost more and more: a dog a dad a home. Your career and your salary. My peace of mind. Your car. Still, you said, your heart skipped a beat when you heard my key in the door. I know you loved me until the moment you died, my gloved hand catching your last heartbeat.
You’ve been gone three years now. Three years and one month, once the clock turns 11:40 tonight. Tell me the date and the time and I’ll tell you to the minute how long I’ve been without you. I am a whiz at grief math. My dreams came true when we met, and then my bright new world crumbled the night you died. So, as Ram Das says, was it my destiny just to walk you home? To hold your hand down the long road to that beautiful home that you so longed to see. To make conversation for the walk, to have parties along the way, to share a thousand laughs and secret jokes and shared thoughts that we’d blurt out in unison. But the road ended, sweetie. I had to leave you at Heaven’s gate and continue on. And it’s so hard. Fucking hard. Harder than anything else. And memories can only sustain me so long. Who will walk me home? No one’s here with me. If you got me, who do I get? The ghost of you? The memory of you? Someone else? Or no one at all? Just the lonely road I always imagined?

The lonely road I always feared.

You were just a reprieve.
WISDOM FROM FIVE YEARS IN…

You will survive. Though at times it will feel as though your grief will kill you, it will not. It will wound you in places that will never fully heal. It will paralyze you for a time. You must give grief its due. You may live five days without the darkness, and then grief will take the next three. I had the great and dubious luxury of having my life explode completely a few months after I became a widow, so there was no escaping my grief. We lived in the same small apartment, grief and I, and it stole all the covers at night, or it stole sleep completely.

So I learned to do the work of grieving. Time doesn’t heal things. You must deal with what you have lost, go through the stages, whether you do it alone or with the help of a support group, a grief counselor, or a supportive family. Within one year, I lost my home of 10 years, my wife of 13 years, and my job of 14 years. I was alone except for a sweet dog who demanded very little of me. I didn’t have to keep it together for the kids, or my co-workers, or my family. Everything fell apart and I left the pieces on the ground for several months.

Eventually you will learn to deal with the loss. Not in a few months eventually, but after a few years - eventually you will be a grief survivor. You will never banish it, but you learn to live with it as an unwelcome houseguest who eats all the good food and leaves you the crumbs. One day, the memories will be something you can cherish, not something that makes fall to your knees. There will be reminders of your loved one in the most random of places, at the most arbitrary times. A squished sticky note wishy me a good day, with her trademark winking smiley face staring out from a drawer.

Grief will come each holiday, each anniversary, and each birthday. By that time you will expect grief, you will know how it takes its coffee. Five years later – does the pain go away? No. The pain never goes away. But it becomes a part of you. Somedays, it is a little ache, others days it can still be an avalanche. But you know now that the storm will pass, that you have survived it before, and you can bare it now.
Your will have to re-map or re-imagine your future. Erin was my world, especially because she was chronically ill, and I was her caretaker. For any caretaker, you will not only lose your beloved, you will lose your sense of self for a while. The world that consisted of hospitalizations, medicines, treatments, emotional cheerleading, mental and physical dependence on you, will evaporate. What do you then? You cry, you scream, you curse the thing that took away your love one. And eventually, you start rebuilding your life in a new direction.

My life has changed so much in the past five years. When Erin died, I was chained to a job I both loved and loathed, because healthcare for both of us was of the utmost importance. We were living in a dark little house, because we’d lost our other home, but Erin hadn’t wanted to move into an apartment. I had to do everything, yard work, indoor cleaning, cooking and dishes, all between my variable shifts at a retail management job.

Now, I have a one-bedroom apartment. I am a graduate student in an MFA program for Creative Writing. I have a few part time jobs: I teach, I tutor students, and I do some translation work. I have the time to write without feeling like I am neglecting my wife. I have healthcare, thanks to Obamacare, and the fibromyalgia that pained me so much when I was first diagnosed in 2010, is mostly under control. I lost our little dog, Molly, to cancer. That wounded me deeply – she was the last part of our little family, it was once the two of us and our two dogs. I hold onto their memories, and try to write my way to a brighter future.
LONGEST NIGHT

The first time I attended the Longest Night Service, I’d been a widow for nearly six months. I’d just been let go from my job of 14 years in a management reshuffle at Barnes & Noble, as they turned away from bookselling to E-reader sales. My parents were doing their best to keep me distracted: holiday concerts, cookie baking, and daytrips, anything that might ease the loneliness of that first season alone. It is a cliché to say that my wife loved Christmas; many people do. She was obsessed with Dickens’ *Christmas Carol*. I had even used a line from it for her eulogy: having her in my life had “opened up my shuttered-up heart” in a way that nothing else had.

On December 21st the world suffers through or celebrates the longest night of the year. To some it is Yule, to others it is the first official day of winter. For me, it is the one night I get to grieve publically, in a safe place where people don’t judge. For the past six years, I have been attending the Longest Night service of Remembrance at the Haddonfield United Methodist Church, my father’s place of worship.

I am the product of a mixed marriage: my mother is Catholic, and my father is a Methodist. They have never quarreled over religion as far as I know. My father agreed to be married in the Catholic Church, and as part of the Marriage Mass the couple promises that any children born will be brought up in the Catholic faith. There may have been a few questions and compromises once I and my sister actually came along, but I was oblivious.
As a child, I thought I had the best of two spiritual worlds. I mostly went to church with mom, where there was a “quiet room” in the back, so toddlers wouldn’t disturb the priest or the other parishioners. But on special weeks, I would go to church with my dad. Or rather, I would go to the nursery school while my dad attended services. Dad’s church was a little more fun. I got to do crafts and read stories with others kids, instead of kneeling, standing, and sitting still through an hour of prayers and sermons in an extended exercise of quiet leap-frogging up and down.

I much preferred the look and feel of Dad’s massive church. It was filled with white columns, cherry pews set with red velvet cushions, and high windows that let the light of Grace stream into the sanctuary. The church looked like a New England replica, minus the stringent rules. There was a friendliness and warmth to the congregation. In contrast, Mom’s church was modern, made of beige brick, with abstract stained glass and bare tan pews so we could think about our sins.

* 

At seven, I had to give up the Sundays at Dad’s church for CCD classes on Wednesdays and mass every Sunday. I received my Holy Communion and First Confession that year. Confession terrified me. I admitted to my 7-year old sins: I had lied twice to teachers. I was given 3 Hail Mary’s to say and my guilt was lifted. Communion was more exciting – I got to dress like a little bride in white, with a veil attached to a sparkly crown missing half the rhinestones, a hand-me-down borrowed from my cousin Colleen. From then on, I was a Catholic.

*
When I came out, I was no longer attending either church devoutly; I had become one of those spiritual C(hristmas) &E(aster) Christians. Erin and I sporadically attended service or mass on Sundays other than holidays. My mom and sister remained devoted members of the parish I was raised in. It was their good standing that allowed us to hold Erin’s Funeral Mass in that church. The fact that we were a lesbian couple was never mentioned. My mom and Erin’s family sat with me at the meeting to choose readings and songs. Most of them were a repeat of the readings Erin had chosen for her father’s funeral 15 months before. Erin had been raised Catholic, and her family were casual Catholics, though they went through the usual rituals: baptism, church marriages, and now, funeral masses.

The Catholic Church had re-named some of their sacraments in order to give them a more positive spin: Last Rites (for the deathly ill) were now called Anointing of the Sick. The Funeral Mass was called the Resurrection Mass. We were supposed to rejoice in Erin’s passing on to a new and better world. I created the program for the funeral with a picture of her smiling on the front. For so long the caretaker – she had suffered from lung disease and sarcoidosis, I kept all the pieces moving. I created the program, wrote the eulogy, and had my favorite cousin fly up to sing the music. The post-funeral luncheon was arranged by my parents. Check, sniffle, check.

I gave the eulogy before the mass began. I wrote and re-wrote it, trying to capture the essence of a woman whose greatest talent was loving others. We had spent thirteen years together. My co-workers sobbed in the pews behind my family. Erin’s family sat more toward the middle. The flowers at the altar were a mixture of our favorites: Erin’s white roses and my blue irises. When mass was over, the funeral director gestured for me
to the lead the procession, and I followed Erin’s box of ashes down the same center aisle
I had walked down after my Communion and my Confirmation.

Though someone else might have wanted the last night of their wife’s life to
stretch forever, once I had made the decision to retreat to palliative care – a certain death
sentence – for me the final goodbye couldn’t come quick enough. I had known things
were deteriorating even before the doctor had outlined Erin’s future – if she had one –
hands amputated, respirator forever necessary, bedridden or wheel-chair bound, brain
function questionable. While her family – brother, sister, and mother, left the choice up
to me – and it was legally mine to choose, they reeled in their sorrow. Their once
energetic and effervescent Erin had been ravaged by a rare disease made possible by her
compromised immune system. They had never believed her to be that ill. I took a deep
breath and steadied myself for the last kiss, and to stay strong for her family. I paced the
hall outside her room, peering in, feeling like I had already lost her. The nurse assured me
that as soon as the morphine was ordered up for Erin, he would begin removing the
equipment.

It had been a very long day. I was staying at my mother’s house, 10 minutes
closer to the hospital. My early-rising mother had allowed me to sleep in that day (which
meant past 8 AM). The hospital called for the authorization of Erin’s third surgery in four
days, a complete removal of her colon which meant a colostomy bag and a feeding tube.
Yes, I acquiesced. I’d said yes to every procedure suggested to me in the days since I’d
brought her in. I thought it was just another bout of pancreatitis, but it ended up being the potentially fatal infection *c. diff*. Erin was young – 42 – and the doctors were eager, almost enthusiastic, in their efforts to fix her. Up until late in that last day, there seemed to be a feeling she could pull through. Our life would be altered forever, but I was prepared to take care of her.

Our final precious moments together I begrudgingly shared with her sister, her mother, her aunt, and my sister. I truly wanted it to be just the Erin and I, no family, no nurse, nothing but the two of us until the end, just as we had always pledged. But as always, I was accommodating, realizing that Erin’s family needed closure, just as my sister wanted to be my support. Her family stood on one side of the bed, my sister and I on the heart side. I whispered for her to let go and she let go, the final pulse beating a weak farewell beneath my gloved finger.

I didn’t stay long after she’d gone. I knew she’d joined her beloved father somewhere that I couldn’t follow. We all left the hospital about a half hour later. Her mother encouraged me to return with their family to her sister’s house. But I wanted to be with my family: my parents, my sister, and our little dog.

As we crossed to the parking lot near midnight, Erin’s mother whispered to me an expectation and a curse: *I’m sure you’ll make something beautiful out of this.*

Comfort comes in the most unexpected places. The one person who surprised me by her messages and then her arrival at the funeral was a high school friend I hadn’t seen in person for years. Dani had never met Erin, but she looked a bit like her, the same fine
raven hair, hers in an elfin cut. When she came up to me at the post-funeral luncheon, she came armed with a shot of Jameson. I had been sipping Chardonnay, talking to Erin’s relatives and classmates, and doing my best not to become embarrassingly drunk.

She simply handed me the shot glass, and clinked hers to mine. “She was Irish, wasn’t she?” I nodded. You’re going to need this, she smiled, reaching for my hand. We’d shared the same disparate interests in high school: both music – voice for her, violin for me, and gymnastics. Dani had known my routines and bar settings; she’d prevented me from falling off the uneven bars or beam time after time, both of us laughing and covered with chalk and determination.

“I know what it’s like,” she confided. From what I knew of her life on Facebook, she’d married young and had five kids. She fingered Erin’s wedding band and emerald engagement ring, hanging on a chain around my neck. “Hers?” she asked. I nodded. She held an iron-like ring on a chain around her own neck. “My daughter, Kayla. She was twelve.” Kayla had died suddenly, quickly, of meningitis. I hugged her hard, and received more strength back. That was my induction into the survivor’s club.

Everyone experiences grief: some are small losses, and some change everything about you. Dani gently introduced me into that group as I stood there with her. The funeral luncheon was being held at one of our favorite places, Max’s. We’d had Valentine’s dinners and birthday dinners there, amid gleaming maple wood and red brick. Erin would always order her salads with the homemade blue cheese dressing. We’d dissect and reconfigure them the way couples do: the tomatoes for me, the black olives and onions for her.
“Did you come here?” Dani asked knowingly, taking in the crowded room. Nod. She held my hands, her chocolate brown eyes appraising me. For a while, everything and everyone will remind you of your loss. The places you go. The taste of chunky homemade dressing. The smell of Jameson. The well-meant pity on the faces of your friends, family. The pizza cashier who cries the next time you go in to pick up your pizza, who only met Erin twice but had felt something so special in those conversations.

The longest night service was my first gathering of bereaved. I knew there were groups out there, some for those who’ve lost children, parents, spouses, or more generalized groups. But I was unique: a young (30-something) lesbian. Since many groups were either run by or associated with a church, I might not even be considered a spouse. But Dad has assured me that everyone was welcome; I knew one of his pastors by sight, and the other pastor actually met both Erin and I at a service once. Pastor Jess was our age and perhaps was more liberal in her views.

The service was held in the chapel, which was on the other side of the church from the main sanctuary. There had been new construction, and we passed down black-floored hallways until they began to merge with the old black-and-white checkered halls I remembered from my nursery school days. My dad introduced me again to Pastor George, who shook my hand gently. I was given a program of songs and readings. The chapel was a smaller, simpler version of the sanctuary. The lights were so low that all seemed candle-lit. The windows were high, and the sky beyond was midnight winter black.
We slid into a pew, Mom and Dad flanking me. My dad shook the hands of some
congregants, and waved at others. He whispered the losses of some of them: sons, wives,
sisters, parents, even grandchildren. Some were new losses: last month, last week. And
some, like my dad’s, were years ago but still painful: the father who died of a heart attack
in front of him at seventeen, his mother, already gone twenty-four years.

Pastor Cathy gave the sermon. What I remember from it, beyond the sobs that
rose like hiccups, fast and involuntary, was the fact that she didn’t talk about her own
losses. She’d lost her mother to illness the previous winter, and her brother to suicide
during the summer. She talked about a man whose widow complained about how long it
took her husband to get any errands done. After he died, she found that these errands
were his chance to visit new friends, and touch many people she didn’t know.

“Like Erin” my mom whispered to me. I had already gone through the stash of
tissues I’d shoved in my purse; Mom handed me more. But that was okay. Church is one
of the few places it is safe to cry in sorrow or in joy. My parents, and indeed our
anonymous, take-that-beating-and-keep on-going society, had taught me that tears were
only okay in private. Tears were reserved for darkened bedrooms or toilet stalls. Here,
there was no judgement, and there were certainly no side-glances among the similarly
bereaved sitting around me. We had all brought our sorrow, not expecting to be relieved
of it, but just to express it.

We joined the short procession of mourners going up to the altar, passing a long
lighter to set fire to the collection of white candles that represented each lost – or was it
risen? – soul. Pastor Jess asked me if I wanted her to pray for Erin. I sunk to my knees on
the step, and she whispered prayers over me. I was a leaking mess, but it didn’t matter. In that chapel, we left just a little bit of the pain, reminded that light would come again.

The two of us always wanted to make it back to Ireland. By the time I traveled there with my family, Erin had been gone for three years. I’d been in grief counseling for two years and had just been accepted to graduate school for my MFA. When we’d previously traveled to Ireland in 2000 with her family, we’d stayed in the south. We’d bought our wedding bands, gold with delicate Claddaghs with simulated emeralds, and exchanged them on New Year’s Eve with little ceremony. We had felt married from that first date. We’d discovered the smooth, sweet burn of Jameson which would ruin us for American bourbon forever. Our travels did crisscross some of the places we’d visited together, but instead of dropping her ashes in Galway Bay where she’d once stood for a picture, I held onto them. In Ireland, it was legal to drop cremains into any body of water.

I held onto them until we visited Kylemore Abbey, a manor house where an order of nuns lived. It had everything that Erin loved: nuns, a dog that bounded around the gardens, history, and a lake that mirrored back the beautiful arches of an elegant stone house. There was even a tragic love story: it was built for a beloved wife who died young. The husband brought her remains home and built both a crypt and a miniature Gothic Cathedral. My sister played look-out (I wanted privacy) as I let a bit of Erin’s finely ground and fired essence drop into the lake water. In the shallows, it mingled with the sandy bottom, but glowed with a singular paleness. I felt a bit of her spirit slip through my fingers. This was a wishful part of letting go, just a symbolic gesture as I whispered an I love you to the stream. She would never leave me.
The Cathedral reminded me of both my religious legacies: the pews were a pale birch color, but the scale of the building was like the Methodist chapel, and there were Conomara marble columns that were purely Irish. I placed one of Erin’s Mass cards behind a memorial candle and lit it, whispering her name softly. I had faith that the card would be collected by one of the nuns, and Erin’s name would be entered into the litany of their prayers, just as I was confident that the currents would eventually carry her cremains to the center of the lake, where she could stare up at the Irish sky forever.

For my Scandinavian and Celtic ancestors, December 21st meant Yule, a celebration begun centuries before Christmas. The Pagans also celebrated in December. The early Christians most likely celebrated the birth of Christ as winter came so that no one would suspect them of being a rogue religious sect. Biblical scholars argue about the time of Jesus’s birth, setting it from March to September. My father, who has an entire bookcase full of religious studies that are dog-eared and highlighted, told me early that it was not important when exactly the birth occurred. Just that it did.

Some of my friends are Pagans, though more are atheists. Dani is a Pagan, and I always wish her a happy Yule, though I know she does celebrate Christmas with her surviving children. I know there is a part of her that doesn’t want to fill stockings, and she may have already packed away those special ornaments that were Kayla’s. There is a part of her that wants to stay in bed and just hold onto her memories. A part that knows
on waking every day that her baby is gone, a part of her that finds that the sun shines too brightly, every single day.

Mom had planned for us to make a stop in County Meath, on our circuitous route back to Dublin. Newgrange is one of those Neo-lithic, mysterious phenomenon like Stonehenge. Actually, it is older than both Stonehenge and the Pyramids of Giza. Usually, I’m not interested by an arrangement of ancient rocks, but since I felt so at home in Ireland, the history intrigued me. Just getting to Newgrange was a trek: the site was down a lovely path flanked by emerald and jade grasses, scarlet and lacy white wildflowers. The going was slow – it was drizzly, and everyone was snapping away on their phones.

Finally, we came to a road, and before us lay a huge circular pseudo-building made of bright stone walls, with a grassy rooftop. We were separated into groups and told what little they knew about the erection and history of Newgrange. The specifics were not that important. The important fact was that there was a small entry, with a narrow passage and a “roof-box” opening that worked on a single day each year: December 21st.

They allowed us to sardine into the passage with the vague outline of runes in a dead language no one had translated. The tour guide flipped a switch, and though it was nothing like a real first light we witnessed a simulation of the sun rising brilliantly after the longest night of the year. There was a quiet intensity that hummed through your soles after standing in a place that had existed for so long. People came from all over Ireland, and indeed all over the world, to witness the sunrise. The tourism board had instituted a lottery system, to limit the amount of visitors to 5,000.
I could imagine the two of us there. I could imagine Erin holding my hand, excited by the moment, the hope for light after the longest night. She’d be fully awake, talking excitedly to everyone around us, her American accent bouncing off the rocks,

“Isn’t this amazing? I can’t wait for dawn!”
In *A Christmas Carol*, Scrooge refuses to follow the Ghost of Christmas Past until promises “Reclamation”. Not just a chance to right the wrongs of his past, but to reclaim the person he should be.

When I first fell in love with Erin, I believed I had found my reclamation. I had become the loving, open woman that I was always supposed to be. She carefully pried the shutters away from my heart where I’d nailed them so tightly. I learned that I could be brave, I could be the strong partner when needed, I could endure worry, and pain, and still go on and do what had to be done.

But in loving Erin, I did lose a bit of myself. I deferred my dreams, I put aside my writing. I decided life was more important than empty words. Eventually, I felt creatively stifled. But there was too much to do, too much to take care of.

When I lost Erin, I lost all of my new identity: wife, caretaker, bestfriend. I was alone, and devastated. Everything else slipped through my fingers: our home, my job, my will to go on. I had to eventually pick up the rubble and put myself back together.

In reclaiming my self, I had to assemble all the parts: the lover, the widow, the writer, the mourner, the strong soul, the jubilant heart, the damaged heart, and the voice that needs and wants to be heard.