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MOURNING SONG FOR MY MOTHER:
A MEMOIR

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ABSTRACT

“Mourning Song for My Mother: A Memoir” is an original creative nonfiction piece about my mother’s diagnosis with stage IIIIC ovarian cancer. Based on my personal experiences with my mother’s illness and decline, this memoir highlights the challenges faced by loved ones in caring for the terminally ill as well as the bewilderment which ensues in the loss of a parent. The piece follows our mother-daughter relationship through treatment, death, and grief, exploring the ways in which the bonds of motherhood stretch beyond life.

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“You will lose someone you can’t live without, and your heart will be badly broken, and the bad news is that you never completely get over the loss... But this is also the good news. They live forever in your broken heart that doesn’t seal back up. And you come through. It’s like having a broken leg that never heals perfectly—that still hurts when the weather gets cold, but you learn to dance with the limp.” – Anne Lamott

Exactly one week before my twentieth birthday, a doctor sat across a table in a haphazardly decorated “family counseling” room and told me my mother was going to die. I was floored. We thought she had a cyst, not a fatal disease. The doctor painted a very bleak picture.

“*IF* your mother responds to chemo, she has a 25% chance of *ever* seeing a remission. Ovarian cancer is going to kill her. It is our job to slow down that process. There is no cure.”

I sat frozen in my cushioned armchair that had suddenly become very uncomfortable. I felt numb.

My mother was my best friend. I don’t say this in a “oh yeah, my mom and I usually managed to get along” kind of way. I say this in a “we talked on the phone four times a day and still had sleepovers in my bed” kind of way. I was her only baby, and trust me, she gave me a nice life. We shopped, we cooked, we got pedicures, we cleaned the bathroom, we painted, we sang songs, we laughed, we cried, we watched movies, we went on bike rides... together, always. I was thirteen when my parents divorced. It’s a story I’d rather not dwell upon. But my mom and I stuck through it together. She was my rock; basically my whole family, as far as I was concerned, inhabiting one body. She remarried when I was fifteen, and I was her maid of honor. My stepdad, Tim, travelled often throughout my last few years of high school, so our life in the girl-clubhouse continued. When I left for college, we began racking up the cell phone bills and planning a few relaxing weekends at home each semester.

So when I say that my world was absolutely and horrifically crumbling around me as the doctor spoke those words, I hope you can begin to realize where I'm coming from. So much of me was wrapped up in this one person, and I couldn't bear to think of how I'd cope without her.

Later that night I tearfully repeated the prognosis to my mother, who had been in another room getting an exam while I'd had the lovely chat with her doctor.

"What? Oh please. He doesn't know me," she said, with a flick of her wrist.

"Mom..." I started.

"Nikki, look. That doctor doesn't know us. He never should've said something like that to you. He has no idea what he's getting into with me. I'm a fighter. And I'm not going anywhere."

That was that.

From that night forward my mother and I had an agreement. We were not going to entertain the idea of her dying. We couldn't plan for a death every day. It was too depressing and didn't serve a valid purpose from where we were standing. She was alive. We had to live.

One week later we celebrated my birthday with a bunch of my extended family members. My mom made sure we had ice cream cake: her and my favorite. There was no trace of finality, no suggestion that maybe this would be our last time celebrating it together. We laughed on the porch in the early summer until it was too dark to see.

My parents took me to Ocean City, New Jersey, just about every summer since I was a baby. When they divorced, my mother and I made it into a special mother-daughter trip. We swore it would go on like that, she and I going to the beach every summer together, for the rest

of our lives. Husbands and future kids would have to stay behind; those five summer days would always be ours.

Granted, New Jersey isn't the most fabulous beach getaway I can think of. The water is freezing, you have to pay just to go on the beach, and the traffic over the bay bridge is horrendous. And how could I forget all the Jersey Shore stereotypes of fist-pumping, vodka-chugging guidos? But there is honestly no place in the world I'd rather be when I'm in a tough spot. Ever since I was a little girl, my mom had a little trick to get me to calm down whenever necessary. If I was worried and scared sitting in a dentist chair, it was "Go to the beach." If I was freaking out because I had a paper due in three hours that I completely forgot about, it was "Go to the beach." If I was sobbing about having to go to the hospital at 4 AM because I didn't realize I had acute tonsillitis but instead wholeheartedly believed my throat was swelling shut, it was "Go to the beach."

When the going gets tough, the tough go to the beach.

When my mom got her diagnosis, we were scheduled to leave in two weeks, just a few days after my birthday. I asked the doctor if we could still go considering how quickly he wanted to start my mother on chemo. He said we should. We threw caution to the wind – we were going to the beach and no terminal cancer diagnosis was going to stop us.

Until it almost did.

My mom called me the morning we were supposed to leave. I was at a friend's house, planning on meeting her and then driving halfway to the beach, as to prevent my mom from overdoing it all in one day.

"Nikki, now don't freak out, but my leg is swollen. Like pretty badly. Like elephantitis."

"What? Mom you do not have elephantitis. That's in Africa."

“Well, I don’t know, but it’s blown up to twice its normal size. I have no ankle.”

I’m no nurse, but I knew that this wasn’t good. It seems like a minor symptom at first, but what is the actual problem? A blood clot? I’d always heard of people getting blood clots in their legs. If blood clots travel to your heart, you can die. But I didn’t think she’d have any reason to get a clot. Was it instead something weird to do with the cancer? Maybe, but how the hell would I know?

“Well, what should we do about it?” I asked, bracing myself for the impending cancellation of our much-anticipated trip.

“We should definitely go to the beach,” she answered matter-of-factly.

“Are you sure, Mom? I’d understand if you want to wait and go to a doctor.”

“No. I have cancer. I don’t want to wait around. Let’s go. The beach has hospitals just like anywhere else. If we have a problem, we’ll go to one.”

So we were off. When I met up with my mom, I was surprised. She wasn’t kidding. Her right typically-chicken-leg looked like someone had inflated it with helium. Her skin was stretched so tightly across the spot where her ankle used to be, it looked painful. It was. But she never complained, never even let me drive.

When we got to her friends’ house in our old hometown of Stroudsburg, her leg was severely swollen. Seeing it in their living room looking like, well, Elephantitis, I almost wanted to rush her to the hospital right then. But she wasn’t having it. She was talking to her friend Caris, a riot of a woman with red hair and the most comical mix of genuine-caring and high-maintenance I’ve ever seen, and she wasn’t going to be interrupted by a giant leg propped up in the emergency room for four hours. We compromised and she let me prop her leg up as high as Caris’s throw pillows would pile. I’d heard that elevation reduces swelling.

By the time we went to bed, her leg looked pretty much the same. I didn't tell her, but I resolved to myself that Karen Marie Robbins was going to be admitted to Pocono Medical Center's Emergency Room if it didn't look normal in the morning. This was my mom for pete's sake; the beach would be there for years to come. That night I prayed for God to please just let her be okay; we had such a long road ahead of us, both to the beach and with chemotherapy scheduled all summer long, and I just wasn't ready to face the hard stuff yet.

The next morning, my mom's leg was as chicken-skinny as ever. Her ankle was looking like the most beautiful ankle I'd ever seen, and the side of her ankle-bone was sticking out like a proud prince. We kissed Caris goodbye and set off toward the ocean and the five hottest days that summer had seen so far.

I wish that I had twenty-five more summers to go to the shore with my mom, kick her butt at Goofy golf, ride bikes up and down the boardwalk in the early morning wind, and enjoy the best ice cream on the East Coast, vanilla and orange sorbet twist from Kohr Brothers. But even though those trips are over, my mother's advice lives on. In times of distress, I go to the beach in my mind. I focus on the images of her and me – with salt-coated and wind-mussed hair, walking along the wooden boardwalk – until I believe we're really there.

“The curse and charisma of cancer: the knowledge that from this point forward, all you have is the day at hand” – Terry Tempest Williams, *Refuge*

When we returned home after our beach trip, my mom went to her oncologist at the Warren Cancer Center to find out why her leg had swollen. We found out that her tumor had grown unchecked for so long that it was partially obstructing the flow to and from her kidneys. We drove to Pittsburgh and her surgeon inserted kidney stents to ensure that her kidneys would remain functional despite the mass.

This was the first of several surgeries. Next, my mother had a port installed on her chest, which allowed the nurses at the cancer center to access her veins without having to prick her arm multiple times. Chemotherapy began and lasted all summer. The carbo-taxel reduced her tumor count considerably. Her hair and her weight were also subject to this reduction. She let her hair fall out naturally; even when we bought her wig she continued to maintain her precious “sprigs,” as she lovingly referred to them. By August, her hair was completely gone. The wig became sweaty and itchy during long summer days. She loved to take it off – “Too hot!” she’d say – and wear multi-colored turbans around the house. “My head gets so cold,” she’d then tell us, laughing.

By September, after six rounds of chemo, her oncologist deemed her ready for her major surgery, which they referred to as “de-bulking.” My mom would constantly ask, “When can I get this *thing* out of here?” referring to her tumor. I notified my professors and took a week off from school. We all headed to UPMC Mercy Hospital in Pittsburgh for the big day, September 9, 2010.

Despite a challenging week spent in recovery and my mom’s insistence that she never wanted to have nerve-blockers for pain management *ever* again, the major surgery was a great success. I could’ve high-fived Tim when we were back in the “family counseling” room, this time listening to the surgeon say, “It couldn’t have gone better,” and that we had “every reason to hope for a long remission.” We drove my mother home and I returned to Penn State, relieved and ready to move forward.

We lived for three months in bliss as my mother continued chemotherapy, I continued balancing schoolwork with coming home, and everyone cheered us on the road to recovery.

But then my mother was admitted to UPMC Mercy Hospital in Pittsburgh just a week after Thanksgiving for an emergency surgery on blocked intestines. The doctor opened her up and found “cancer everywhere,” delivering the prognosis of six to eight weeks to Tim and me. We went to the hospital chapel, still waiting for my mother to leave the recovery room, and sobbed.

Tim was insistent that we couldn’t tell her the six-to-eight-weeks part. I said that was ridiculous, that she was the patient, that she had the right to know. He said that it would destroy her spirit. I asked if he even knew her, knew what she was made of. I thought he was in denial. He thought I was negative. He made me promise him I wouldn’t tell her.

Later that night, I left our hotel room across the street and went up to the 8th floor to see my mother. She was asleep. I quietly wept next to her. After a few minutes, she woke. “What’s wrong?” she asked, concerned.

I wiped my eyes. “Nothing,” I said.

She didn’t believe me. “Nik, what’s wrong? You can tell me. Please.”

After a pause, I let it out. “Tim didn’t want me to tell you, he made me promise not to. But I can’t do that to you. You always tell me the truth. The doctor gave us a prognosis while you were in recovery.”

She remained calm, steady. “What was it?” she asked, searching my eyes, “Not good?”

I bit my lip, hot salt dripping down my face, “No.”

“What is it? A few months? A few weeks?”

“Six to eight weeks,” I answered quietly.

She was silent for a moment, nodding. Finally she said, “Okay. Well we just go from here, right? Thank you so much for telling me the truth. Tim didn’t understand. I am not going to give up just because they gave us some timeline. I am fighting this. I am fighting for you, for my family. I will not just accept six to eight weeks. You know that, baby.” She hugged me tightly to her chest. I buried my face in her machine-warmed blanket, dampening it with tears.

I did know it, which is why I felt so compelled to tell her. It seemed so wrong to not let a patient know that a prognosis was given. The doctors never gave my mother much information, instead deferring to Tim and me. This felt wrong, but my mother never pushed the doctors. There is a delicate patient-doctor dance that takes place, and my mother was treading softly, trying to go with the steps.

But maybe, too, my telling her was selfish. Because I wanted to tell her so she could comfort me. I wanted to tell her so she could tell me it wasn’t true.

I still don’t understand why the doctors told us more than they told my mother. Was it easier to make us the bearers of bad news? How was telling her or not telling about her own condition her our call? What happened to a patient’s right to information? It seemed as though a patient’s rights can be determined by their loved ones. When my mom’s surgeon would stop by her room with his gaggle of med students surrounding him, my mother would attempt to ask

questions about her status. “What can I eat?” was one such question, which she asked after her ileostomy.

“Anything and everything,” her surgeon laughed, “You need some meat on your bones.”

He often evaded questions about her exact condition, avoided reporting the gravity of her health situation to her face. He laughed her off. He rarely spent more than two minutes in her room.

Within hours of this conversation, my mother got extremely ill after eating grapes; her intestines had been badly beat up and food with skin was incredibly difficult on them, which we found out later from nurses. At this point, there was a major sense of “Us against Him” – my mom, Tim, and me against the surgeon. To be clear, other oncologists and nurses were incredibly supportive, constantly helping us to navigate my mother’s ever-changing care. But the surgeon is the man who sees inside. He sees the cancer firsthand, and he therefore is the most informed about the current conditions.

I strongly feel that my mother should have never been in the dark about her cancer. She was of completely sound mind even if not of sound body.

Days later as she recovered, I fed my mother lemon water-ice with the tiny wooden spoon. The spoon looked like a shovel burrowing for gold. She ate four bites. “You have the rest,” she said.

“You need to eat,” I said, “You’ve lost so much weight. They won’t let you leave until you can eat comfortably.”

My mother had always been thin, but once she had surgery, removal of the original tumor had taken away fifteen pounds. Now she was hovering just above one hundred. An ileostomy threatened her weight even more. Removing the obstruction from her intestines required the full removal of her colon. Her large intestine now exited her body through a small hole on the side of her abdomen. The procedure was irreversible, meaning that for the rest of her life all waste would exit her body into a small bag.

She was mortified by this new foreigner attached to her side like a limp balloon, though she accepted it as she had accepted her terminal diagnosis: it is what it is, so where do we go from here? The question of where to go next always helps assuage the sentiment behind “it is what it is,” which, my cousin Laurie says, “never describes anything good.” In spite of this new challenge, she focused on where she was going next, which was, fortunately, home. I had the vision of cozy family time, just in time for the holidays.

Leave it to my mother to invite someone new into our home for her last Christmas. We returned home just a week before the holiday, after she recovered from her ileostomy and received her reduced prognosis. She and Tim decided to extend an invitation to our home to a kind, bashful woman named Wendy. Wendy had lost her husband the previous year to cancer. Her husband was employed at the nursing home in which, several years earlier, my mother was the Director of Social Work and Activities and my stepfather was the Administrator. I cannot lie; I was not thrilled to have a guest for our family holiday. I wanted this time, especially now that every minute felt more and more fleeting, increasingly precious. I was hoarding the seconds.

But as I tried my hardest to batten down the hatches, to hide my precious family away in a bunker of our own, my mother blossomed, opening outward, inviting others in. It didn't matter if it was Wendy, or the hospice nurses, or acquaintances she'd just met in Wal-Mart. She continued to give of herself, continued to spread out.

Wendy came to Christmas. She wore her hair in a long braid down her back and wore skirts that concealed her down to the ankles. She was quiet but always smiling. I bought her, my mom, and me elf hats to wear on Christmas morning. I bought Tim a Santa hat. I didn't expect to feel comfortable, performing our holiday traditions with someone new. But we baked cookies, decorated the tree, and played Scrabble with Wendy, and I heard her say, many times, that she was so glad not to be stuck alone at home. Wendy has no living family. As she cooked and talked and laughed with us, my mother was glowing. She took pride in straightening the house just so, in dishing out food and drink, in distributing the gifts to all of us. My mother needed to be a hostess one last time. Despite my initial grumblings, she was still teaching me things. This time, the lesson was the spirit of Christmas: the ability to give as much as truly possible. She showed me the importance of staying open instead of closing myself off from the world.

My mom and I were always big fans of sleepovers. Ever since I can remember, my mom would set aside a night or two per month to sleep in my bed. We would watch *Candid Camera* and *Kids Say the Darndest Things* and we'd eat popcorn and Twizzlers and admire the beauty of Suzanne Summers and the timelessness of Bill Cosby.

When I was in junior high and my parents divorced, my mom often slept over in my room in our new house. She'd talk to me about my melodramatic middle school problems and

tell me stories about herself growing up. We'd laugh as she reminisced about spinning my Aunt Trish around in the dryer, or the time her brother Doug made her take everything out of the kitchen cupboards when their mom was away, throw it in the middle of the floor "to pay taxes to the king," then put it all back so he wouldn't get in trouble. Those nights made me feel less alone, almost as if I had a sister – as if my family, even if it was mom in a new house, was still a family.

When I was in high school and my stepdad was away all week for work, my mom would sleep in my bed. My bed was the softest haven a girl could ask for. She'd say, "I think I'll sleep on the cloud bed tonight, Nik." Neither of us thought this was strange or that I had grown out of it. She'd come down in her starry pajamas with a magazine and we'd shut off the lights and "go to bed" but really end up talking for another hour before finally drifting off.

The tradition of sleepovers never lost its charm for my mother, or for me. When she got sick and had to stay overnight at the hospital in Pittsburgh, later at the one in Warren, and even later in hospice, she always requested that I spend the night with her. That's how I wound up in a cramped hospital bed, woken up constantly for medicine rounds and by beeping machines, lying next to my mother for so many nights. In those moments, despite the lack of space and the definite discrepancy between a hospital bed and my "cloud" bed, my mother and I were as we always had been. It was only during those nights that I allowed myself to break down, admitting my fears to her, letting her comfort me about her own suffering. As my mother combed her fingers through my hair, I was nine again. I was thirteen. I was seventeen. I was not the caretaker, the bearer of emotional weight. I was her daughter, the one to be taken care of.

In January, I was faced with the question of where to go. I had already postponed my plans to study in London that spring. Many of my friends encouraged me to take the semester off, to stay home with my mom. I considered this option, but not for long. My mom insisted that she wanted me to return to school, to keep pursuing my own goals. As much as I wanted to be with her all of the time, I think we both knew that staying busy was good for me. Throwing myself into school gave me a distraction for part of each week. I still carved out at least three days per week to come home to see her, and I called constantly.

For the first few weeks back at school, I was an anxious wreck. I came home at a moment's notice if her stomach hurt or she was a bit dehydrated. I worried about her ileostomy and how it further compromised her body systems. I wasn't sleeping. With time, I adapted, realizing that it was unrealistic to stay enrolled in school and drive home every other day. I cut back to the plan, three days a week, and we found a new schedule. "Normal" was always being revised.

In late February, my mother began to see the squirrels. It didn't end at squirrels, either; she asked me if I saw that little elderly woman curled up in her armchair, or the man outside the window holding a gun by the pine tree. At first, I was convinced the cancer had gone to her brain. She had recently been transferred to hospice, and I had just arrived that morning after three hours of driving and no sleep whatsoever. I was so tired that I was practically seeing things as well.

I climbed into the hospice bed with my mother, tucking in the satin blue blanket she had bought me for Christmas. She was whispering vehemently, half-awake. She cried out, "AWESOME!" and slapped her hand to the bed.

“What’s awesome?” I asked, as Tim and I tried not to laugh.

“Eisenhower won the game!” she reported happily about her former high school.

“That’s wonderful,” Tim replied.

Finally we both drifted into sleep. When we woke, at least I was thinking clearly. Liquid morphine was the cause of her hallucinations, not cancer. The nurses lowered her dose and assured me the effects would wear off by morning.

That night my mom sat next to me on my cot, talking about boys. We never stopped living our normal lives, and that meant that I still went to my mom about relationship issues. She and I had a wonderful conversation, during which she told me how much I deserved and urged me not to settle. It was solid advice, as it always had been, and I appreciated it. Just as I was thanking her and saying goodnight, she said, “Nik, I know you think I’m crazy, but can you lift your head from that pillow? There’s information for the taxes on the pillowcase and I need to finish reading it.”

In March 2011, my mother had been living at the Warren County Hospice House for several weeks. The Hospice House felt more like a mansion than a home. The house provided areas for three live-in patients, which included spacious bedrooms and bathrooms, as well as two comfortable bedrooms and a bathroom upstairs for family members who wished to stay. A large, yellow kitchen was located at the back of the house, connected to a family room area with beautiful views of the nearby creek and wandering deer. A formal dining room led into a formal living room, both featuring tasteful 1970s decor in pristine condition. Every room was open and airy, and many floor-length windows provided gorgeous views of the surrounding woods. It was peaceful.

The pine trees were covered and drooping under piles of white from a recent snow. The day began like the others before it. I sat with my mom on her bed. The cot I slept on next to her had been folded up and rolled into the corner, where it spent the day. We were talking about something I can't even remember. Then Jodi, the nurse for that day, came in.

I had noticed that my mom's skin looked very dry and worried about her becoming dehydrated. I turned to Jodi and expressed my concern. She sort of waved it off, but I persisted.

"But the doctor said she absolutely cannot get dehydrated. It's dangerous for her kidneys because of the ileostomy. Couldn't you give her IV fluids?" I asked

"No, not now, because at this point the fluid could go into her lungs," Jodi explained.

"I don't understand. She's dehydrated. She needs an IV."

There was a pause. I think that even the nurse was trying not to cry as she said it. Anyone who spent five minutes with my mother couldn't help it; they became attached. She was like one of those spectacular white fireworks that shoots way up into the sky, explodes in a beautiful burst, and then showers down like a stunning willow tree of fire that you just hope and wish and *pray* could go on forever.

Jodi began slowly, "Nikki, her body is exhibiting signs... she should not get an IV because... well, it will just prolong what's going on for a few more gruesome days."

"What does that *mean*?"

"Her body is... shutting down."

My brain refused to register what I had just heard. My mind skipped around aimlessly, shuffling through thoughts as though they were flashcards I was trying to remember. My mom was sitting beside me, talking away. How could her body be shutting down?

A few days before we got the heartbreaking news in hospice, my aunt, my cousin, and I had created a “beach” in the hospice living room. We brought beach towels, chairs, tropical decorations, seashells, and even a sand-filled baby pool. For one hour we took my mom to the beach. She got to take off her shoes and we buried her toes in the sand.

Reality was unshakeable now. The nurse had told us her body was shutting down and even going to the beach couldn’t make it go away. We called Tim and my Aunt Trish, and we all spent several hours with my mom, taking turns talking and crying and discussing what to do.

The disease had been so unpredictable, managed at first by chemotherapy and surgery, then surging back and draining my mother’s health. Suddenly, it was all ending.

“When confronted with approaching death, many of us wonder when exactly death will occur. Many of us ask the question, ‘How much time is left?’ This can often be a difficult question to answer. The dying do not always cooperate with the predictions of the doctors, nurses or others who tell family members or patients how much time is left”

– Hospice Patients Alliance, “Signs and Symptoms of Approaching Death”

Time during illness is strange. Time flew by and I felt robbed of more. My mom and I had an appointment to look at wedding dresses – not because I needed one, of course, but because we didn’t want to miss that special mother-daughter moment. The weekend of the appointment she had gone to the hospital, was then transferred to hospice, and never came home again. I was upset she wouldn’t be at my twenty-first birthday, wouldn’t be able to have a drink with me at a restaurant. I thought about my future children, knowing she would have made an incredible grandmother. I worried about not knowing how to raise my children at all, and not having her endlessly helpful advice at the other end of a phone. She never got to see the gorgeous mural she had requested to be painted on our living room ceiling. It looks like heaven, with swirling clouds, sunlight shining through the center, and angels flying and dancing throughout. One of the angels holds a banner that says “Karen.”

When my mom's nurse told us her body was shutting down, my mind began racing with all of these things that I still wanted to do. I needed more. I wanted to add days to the calendar, to stretch the minutes.

But then time stopped. My mother's body kept struggling on. Ice chips somehow sustained her, though her movements became more and more strained. She vomited dark bile throughout the day and night. Her skin became dry, stretching tight across her face. Her cheeks hollowed. But each new physical sign developed slowly, gradually.

I rubbed lotion on her hands. I continued to sleep in a cot at her bedside. I woke up every time she cried out in pain. I woke up every time she vomited. I woke up for no reason at all, to check if she was still breathing. She was. Her breath was shallow and slow, but still going.

You'd expect that when someone told you your loved one's body was shutting down, that life was over and they would pass on. But it doesn't work like that. You struggle to accept it, you try to convince yourself of its truth, you have the conversations you need to have. You say whatever you can say. You hold hands. You pray. You watch. And then all you can do is wait.

The waiting is like torture. The anticipation becomes all-consuming. It could happen any minute. There were many "false alarms" in which my family gathered at my mom's side, holding her hands and feet, and praying for her to let go. After three such incidences, I thought I would go crazy. They had told us her body was shutting down on Friday. It was the following Thursday. I could no longer make sense of the "Signs of Approaching Death" paperwork they had given us. Each symptom listed would happen very shortly before death; at that time, my mother was exhibiting half-signs of the "pre-active" phases.

I called my dad. My sadness during the week had given way to rage. “Why is this happening?” I shouted into the phone, “Why would it drag out for so long? Why is God doing this to us?” It was one of the only times during my mom’s illness in which I can remember truly being angry at God. I wasn’t angry because I felt He “gave” my mom cancer, I was angry that He would take her in this horrible, drawn-out manner. I was angry that He would deal this hand, then make me wait.

My dad tried to comfort me. He told me about his own mother’s death for the first time. She had passed away, also from cancer, just weeks before I was born. He told me it had taken a long time for her body to give up. He assured me that it would happen, that God couldn’t drag it out forever, as I feared.

“We usually recognize a beginning. Endings are more difficult to detect. Most often, they are realized only after reflection. Silence. We are seldom conscious when silence begins – it is only afterward that we realize what we have been a part of” – Terry Tempest Williams, *Refuge*

My dad was right. Friday morning, the nurses warned us that it “wouldn’t be much longer.” I wasn’t sure what to think, as we had been told this before. My stepdad and my aunt and I stood around my mom’s bed, holding her hands, waiting. She was unconscious. Trish made a comment about how peaceful it would all be. I felt sickened. This wasn’t for me. My mom and I had our conversations, and when she had become too weak to talk, she had squeezed my hand. One night she wouldn’t let me leave her side; she just kept squeezing my hand. Watching her die wouldn’t make me feel better or at peace, I decided. Watching her made me feel defeated, like we had lost the fight that I had strongly believed, in spite of every statistic and every warning, we would win. We had deserved to win, I thought, if anyone did. I grabbed my keys.

As I was leaving, my aunt and Tim said, “You don’t need to watch this.” As if this was a notion of protecting myself. This was not protection. This was denial. This was refusing to anticipate any longer.

Twenty minutes later, my cell phone rang. It was Tim. “She’s gone,” he said.

Despite expecting this phone call, it astonished me.

“There is no experience quite as stunning as when there is nothing where something has always been. To try and imagine the absence of something is to imagine the thing itself, not the hole left behind. Especially when that thing has the first face you probably ever saw, spoke the first words you ever heard, and whose touch has comforted and guided and corrected and made you safe since the beginning of time.” – Alexander Levy, *The Orphaned Adult*

Ovarian cancer took my mother’s life over the course of nine months. During those months, she and I endured pain like never before, but we were together, leaning heavily on each other. She leaned on me physically and I leaned on her emotionally. I learned how to care for someone else, someone as defenseless, at times, as a child. It’s strange to think that my mother was taken away in nine months – it had taken only nine months for her to become a mother in the first place.

Hospice literature suggests that often, the dying cannot let go until they feel ready, until everything is in place. Sometimes that means being able to say good-bye to each loved one. Everything with mom and I was as “in place” as it could have been. My mother and I had been practicing our good-byes for a long time, but we’d never really had to go through with them. I don’t regret leaving that morning. I think that maybe she was waiting for me to go, for me to show her I was able to.

“But the feeling I could not purge from my soul was that without a mother, one no longer has the luxury of being a child. I have never felt so alone” – Terry Tempest Williams, *Refuge*

I spoke at the funeral. Many of my friends were shocked at my willingness, the ability to “keep it together.” I didn’t see other options available. How does one “fall apart”? What is the process involved? Is “falling apart” crying into your pillow after seeing your mother writhing in pain as they shoot stinging potassium into her arm? Is “falling apart” escaping onto back roads in the dead of night, driving in circles until you cannot find your own neighborhood? Does “falling apart” entail an obsession with time, a fixation on the future, or fleeing a classroom when you get a phone call? Death after a long illness differs from sudden accidents. The grief comes early, the death still shocks, then the grief resumes. After much practice, falling apart takes on the guise of keeping it together.

The viewing and the funeral felt surreal. I rehearsed for them as if acting in a play. What are my lines? I acted in fifteen plays and musicals while growing up. My mom brought flowers to every one. Now people brought flowers to her. Purple and yellow-faced pansies, her favorite. Blue and pink hydrangeas, what my grandfather used to grow for her in his garden. White roses, red roses, pink roses. The funeral home was filled to the brim with color.

After speaking at the altar, I returned to the wooden pew, seated next to Tim, my grandmother, and my best friend, Anna. While my mom was sick, Anna became the sister I never had. Anna had seen the underside of illness with me. She made the three-hour drive to the Pittsburgh hospital to visit us three times during December when my mom had emergency surgery. She had made countless care packages, filled our house with bouquets, and always brought cards for my mom. She had distracted me with constant joy at school, had helped me to keep living. She came to the hospice home every day as my mom went through her final days. She promised my mom she’d take care of me.

Tim, my stepfather, had been a bachelor his entire life until he met my mother. He married her in 2006, and lost her in 2011. I worried for Tim, wondering how he'd get by. How would he run the antiques shop and the bed & breakfast that my mother and he had worked tirelessly to open? My mom was a rocket-fueled multi-tasker, able to accomplish a week's to-do list in a day. Tim's personality is far more laid back. Losing my mother was like losing an army. Losing my mother was losing his best friend, the love of his life.

My grandmother sat in her wheelchair alongside the pew, holding tightly to one of my hands. I could feel her veins, her cool, soft skin. She sat looking ahead, though I know she could not see the casket in front of her. Her eyes have gone bad. This marked the third child she has lost out of four, as well as her husband. My uncle Alan lost his life to bone cancer eight years ago, my grandfather died in his sleep the following year, and my uncle Doug passed away from a heart attack only three months before my mom. I realized, sitting next to her, *I do not yet know what resilience is.*

While the pastor finished his sermon, all I could think about was Emily Dickinson. "This is the Hour of Lead/ Remembered, if outlived..."

One thing my mother used to always say to me on the phone when I was stressed or worried or lonely, or for no reason at all, was: "My arms are around you." It always gave me such comfort when she couldn't be there in person.

Some mornings, I'm half asleep in the shower. As hot water pours over my body, I'll suddenly realize I've been repeating this phrase in my head, over and over, like a refrain, my very own daybreak Gregorian chant, or a mourning song.

My arms are around you.

“I promised myself that I would maintain momentum. ‘Maintain momentum’ was the imperative that echoed all the way downtown. In fact I had no idea what would happen if I lost it. In fact I had no idea what it was” – Joan Didion, *Blue Nights*

My friends have told me that the spring of 2011 was one of the worst Pennsylvania springs we’ve seen in years. The winter dragged on and on, it rained for weeks at a time, and it took forever for the earth to thaw and the sun to return. I don’t remember any of this. The weeks and months after my mother’s death blend and melt into a strange fog. My life was on autopilot. I was getting out of bed in the morning and going through the required motions. I got straight A’s. I don’t remember a single thing that I wrote.

I pushed people away just so that I could maintain forward motion. Some people, I couldn’t bear to see. I was terrified of how alone I suddenly was. Even surrounded by friends, by Anna, by my mother’s friends who’d constantly check on me – I felt like a small child weaving between tall legs in a crowd. I couldn’t recognize the ones I’d always known, because the *one* I’d always known was gone.

And then, there was Ben.

To this day, I am convinced that my mother sent me an angel. Just as my world was crumbling into grief and confusion, there was this person I wanted, needed, to be around. I had met him a little over a month before my mother passed away. In fact, I had called her on the phone and told her about him. He and I had gone to the local high school to assist its literary magazine staff, and had laughed afterwards about how unimpressed the high school students had been by our lesson. But we had had a wonderful afternoon; what was supposed to be an hour-long after school class led to six hours of coffee and conversation. I gushed to my mother about this smart, witty boy with brown eyes over the phone. She, of course, had excitedly urged me to keep her posted.

But then she had gotten much sicker, and Ben had fallen to the wayside of my thoughts. Once I returned to college after the funeral, a literary magazine event led me to get in touch with him. I cannot tell you how I managed to date in the midst of the chaos around me, but somehow doing this one “normal” social thing kept me sane. My mother had taught me to stay open, even when I wanted to close up and pull down all of the blinds. Ben tells me now that the night I suggested a pajama party and showed up at his apartment wearing my mother’s moose-printed pajamas was the night he fell in love with me.

In the weeks following my mother’s death, and the months of starting my relationship with Ben, I vehemently told everyone, especially Ben, that I was strong. It was as if showing others my toughness would make it real and natural. I remember insisting to Ben one night, “I don’t want you to save me. I don’t need anyone to save me.”

But he did. And I think that my mother had everything in the world to do with it.

There is a voicemail saved on my phone from February 2011 when my mom and Tim took one last trip to Vermont. They were on their way home and I would be coming home as well that weekend. I always reminded her not to leave me voicemails: “I’ll only delete it,” I’d insist, “If I see I have a missed call, I’ll call you back!” It was no use. She constantly left voicemails, and I constantly had to delete them. For some reason, I refrained from deleting that February voicemail. Days after her funeral while checking my messages, I was prompted to delete old items. The first and only old message that played was this:

“Hi Nikki! We just got our coffee and passed the Bentley Hopperton House and we are heading *home*. I can’t wait to see you! I’ve missed you. I’m sure you miss talking to me, I’m

sure you miss my voice, so when you get the chance, give your mother a call! I think you know the number so I won't give it to you. *I love you...* Goodbye!"

Every month since, I've saved this message. Her voice repeats. Her voice on demand.

I'm sure you miss talking to me.

I'm sure of it, too.

"Those who are dead are not dead, they're just living in my head..."

- Coldplay, "42"

I refused to go through my mother's things. Refused to donate her clothing, one of the first things others insist that the bereft must do. I don't understand why this is a common ritual, but maybe we see it as a small step, a way of curtailing the denial involved with leaving the clothes in the closet. But I couldn't. Nor could I move her make-up, her perfume, her brush or comb.

Tim still pays for my mother's cell phone. He answers both his and hers. The voicemail on hers has not been changed: "Hello, you have reached Karen Robbins..." Sometimes I call when I know he's busy just to hear her.

I wake up from dreams in which my mother is alive. I go about my morning pretending it's true, stopping just short of calling her on the phone to tell her about what I'm up to.

When I studied in London during the fall, I finally felt disconnected from support and familiarity enough to believe that maybe, just maybe, she wasn't coming back. A young man on my program passed away suddenly, overnight, from meningitis. I sobbed for three days, finally realizing I needed therapy.

One of the weekends I went home to visit Tim, I couldn't even stay the night. My house is not the same without being able to sit with my mother on the couch, our dog Ollie curled at her

feet. Being amongst her meticulously-kept décor – the wallpaper she hung in every room, the matching towels and curtains, her seat at the kitchen table – filled me with a strange dread. I apologized to Tim and drove back to my apartment.

The measures I take to avoid reality sometimes surprise me.

Some days feel so crushingly dark. One thing that I inherited from my mother, besides the tendency for my hair to obtain a reddish glint in the sun and besides the freckles and besides the willingness to be unapologetically weird at times, is panic. When I was very young, my mother was gripped by something called panic disorder. According to the Mayo Clinic, panic disorder is characterized by repeated panic attacks, or episodes of intense fear that develop for no apparent reason and that trigger severe physical reactions. People with panic disorder have regular panic attacks and live in fear of the next attack. During attacks, sufferers can feel as though they are losing control, having a heart attack, or dying.

During my early childhood, my mom was terrified to watch me on her own, terrified I might get hurt. She was afraid to leave the house with me or to drive me places. She told me that one time she had to go to the post office, a mile from our house, to get important mail out of our post box. She put me in the car and drove down Main Street. As she climbed the small hill to the post office, panic took hold. She had to turn the car around and go home.

For the most part unbeknownst to such a young me, my mom sought treatment for her disorder. She got medication, which helped her greatly but which she hated taking, so she eventually weaned herself off of it. By the time I was in elementary school, my mom had no problem watching me on her own. However, challenging her panic disorder was a lifelong process. As I grew older, I couldn't understand why my mom refused to drive my friends in the

car with us. When she finally was able to do that around the time I was fourteen, I didn't understand why she had to know the location of all the bathrooms anywhere we were. I didn't understand why she bought a conversion van with a bathroom in it. The van was enormous. I was embarrassed.

My mother found other ways to cope with panic. When it was at its peak in my early childhood, my father took her to friends' houses during the day. We would spend the day with Jayne and her daughter Alex, or Eileen and her daughter Erin, or Ginger and her daughter Jami. The "bathroom van" was another way to cope with panic. One of my mom's residual "triggers" was the fear that she wouldn't be able to get to a bathroom if she needed one. Eventually, I warmed up to the big, black van. I gave tours of it to my friends. I learned to drive in it. As I grew older and got to know my mother as a person, I learned to forgive her for the "embarrassment." I learned that we need to allow those we love to just *be* – to do whatever it is that they need to do.

My own panic disorder has recently developed. It terrifies me. When I first began having the attacks while studying in London, I didn't know what they were. I felt as though my heart would explode. I was terrified – suddenly frozen. I felt certain that I would die. When I returned to the United States, the attacks intensified. On my plane ride home, I spent the first hour with my head between my knees, breathing into a paper bag. For the rest of the eight-hour flight, I watched movies I had already seen; I took comfort in knowing what would happen next.

Maybe the fear of losing her built up in me for so long that when I finally did, in fact, lose her, the fear needed to leave my body. So now it does. It fills me up for an hour at a time, takes hold of my mind and steals every notion of control, drags me through hell, and then lets me go. I usually sleep like a rock afterwards.

My triggers are very different from my mother's. I won't psychoanalyze them here, because they are quite straightforward. I fear not being able to contact someone if I "need" them, but more than that, I fear being alone at all. I fear losing others, and panic can grip me when I get a phone call during class because I assume the voicemail will contain terrible news. I fear my body, fear it isn't working properly, imagine symptoms that will lead to my inevitable death.

I wish so badly I could call my mother and ask her what to do, how to make it stop.

Wake up. Shower. Do homework. Don't dial the phone. Go to class. Don't dial the phone. *I'm sure you miss talking to me.* Eat something. Go to the library. Walk home. Don't dial the phone. Hang out with friends. Eat something. Don't dial the phone. Watch TV. Go to bed. Lie still. *I'm sure you miss my voice.* Sleep. *My arms are around you.*

"You will never be too old to hear my advice and you will seek it forever, as I have looked to my own mother for her advice and a shoulder to lean on" – Karen Robbins, journal

My mom wrote a journal for me in her last two months of life. I had asked her to record advice for my future when we were told in December that her prognosis had been reduced. I made a list of topics, and she created a journal to include advice on all of them: reaching my dreams, meeting the right partner, planning a wedding, having my own children, how to keep good friendships, how to plan my finances, how to stay close to God. My stepdad, Tim, tells me she used to sit on the couch alone and write in the journal at night. He said she would be sobbing, and he would always ask if she was okay.

"Yes," she'd answer through her tears, "Even though this is for Nikki, it is so, so *good* for me to write it."

That small, embossed journal is my most cherished possession. I have already memorized some of its advice. When I read it, I can hear my mother's voice speaking the words to me as we drive in her black van somewhere, anywhere:

“Look around – the beauty of the earth is astounding. As I mowed the lawn last summer, I looked up at the vast blue sky, watched the birds soar, looked at the green grass and flowers and fruit trees, and I wanted to have it last forever. I know that I might have a more limited time to see this beauty that God created and yet, I cherished it... Never feel alone; God is at your side every step of the way. I am at your side every step of the way. You may not see me but you will feel my presence, you will know that I am always protecting you, my arms are around you.”

My psychologist gave me some good advice for dealing with panic. She told me that one of my fears revolved around my mother's absence, or feeling like I couldn't get in touch with her if I needed her. She suggested that I meditate on what my mother would say if she were sitting next to me during an attack.

My arms are around you.

I tried this method when panic crept up on me one night while walking home down a dark, quiet street. I felt the fear building in my chest, I noticed I was holding my breath, I felt my thoughts start to gather and billow outward – *My arms are around you* – and all was quiet.

Thank you, I whispered, over and over, thank you.

Eckhart Tolle, a contemporary philosopher and the author of *The Power of Now*, was hugely motivational for me during my mother's illness. His teachings led me to deeply appreciate and experience the present moment. Every second spent with my mother, I concentrated on being present, on living not for the past or worrying about the future, but focusing on what I had right now.

In his most recent book, *A New Earth*, Tolle explains that our attachment to forms, to our bodies, falls away as we die. Our inner being shines through more radiantly. I found this especially true of my mother. In the months leading to her death, she became increasingly beautiful. It truly was as if a light glowed from within her – her smile was wide, her hair grew back in beautiful, swirling patterns of gray and white, and her eyes sparkled with grace. She was charming, offering helpful and positive advice to anyone near her. She was open, drawing others in. During this time, she was also slowly starving, enduring intense physical suffering. But each and every visitor commented on how beautiful she looked, how peaceful.

Despite our best efforts to live in the moment, we fervently resisted death's arrival. We had avoided it in conversation. We had taken every precaution, refusing to accept it as a potential reality. Cancer was something to battle. Not fighting was never a viable option for us. We somehow believed that if we loved her enough, and if she tried to fight back enough, we could stop it. Looking back on our mindset, "enough" could be the death of anyone.

My mother did not stop fighting until the nurse announced that her body was shutting down. She had battled with every ounce of strength she had. She had sucked ice chips and vomited endlessly and taken the medicine she loathed and had refused to live in self-pity. Never once had she said anything but "I *will* prove them wrong." When the nurses gave us the news, my mother and I took some time alone. I sat on the edge of her bed and she squeezed my hand.

"Nik, are you going to be okay?" she asked.

There was a pause. "Not at all," I finally said.

In the end, strength isn't security. Even the strongest of us will die.

One of the only times my mother cried to me during her illness was when we talked about my future. She spoke with passion, though tears muddled her voice: “I’ve been here for you every second from the day you were born. I made raising you my life’s purpose and I followed through. I deserve to see you... to see what happens to you, to see your life unfolding.” Somehow, I know she will.

One year has passed. The Earth has fully circled the Sun, and my mom still isn’t back. Sometimes that fact surprises me.

My mother’s wig hangs from the post of an antique washstand in Tim’s study. It is tangled and slightly disheveled, as it has been for a year now. Today I gently ran a comb through the chestnut-brown strands, smoothing the ends back into a chic bob. It felt important, but I can’t say how. Something about letting go, or not letting go.

I’m sure you miss talking to me, I’m sure you miss my voice.

My arms are around you.

Thank you, I whisper, over and over, thank you.

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- Received and reviewed manuscript submissions for senior editors

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