Perspective

After the Cure

My mother's childhood bout with polio paralyzed more than her body. I've spent much of my life trying to understand that paralysis.



The author's mother, Carole Evitts, circa 1950s.

By Elizabeth Evitts Dickinson

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n an autumn morning in 1949, over a bowl of oatmeal, my mother, Carole, then 7 years old, started feeling ill. She begged my grandmother to let her skip school and return to bed, and in a rare turn my grandmother acquiesced. A firstgeneration German American, my grandmother had survived the Depression. She knew how to pull flavor out of the cheapest cut of meat, she saved pennies for special occasions in envelopes, and she believed only an actively vomiting child should skip the wonder of public education. My aunt, just 3 years old, couldn't believe her sister's luck. She dipped her spoon into my mother's abandoned bowl and finished the extra helping of cereal, and then she scuttled off to the small bedroom that the two girls shared. My mother lay in

fetid darkness, curtains drawn. "Get Mommy," she said meekly. "I'm really sick."

A fever bloomed through my mother's body to fight the invading virus, but the poliomyelitis had already taken hold in her central nervous system. Her limbs ached and then atrophied, and by evening my mother could move only her eyes.

She was ferried by ambulance from her rowhouse in East Baltimore to Kernan Hospital for Crippled Children, where she remained pinned to a bed in a ward with other paralyzed girls, some so ill that an iron lung breathed for them. In 1949, researchers were still confirming how many strains of the poliomyelitis virus even existed. Jonas Salk and Albert Sabin were years from releasing their inoculations. Meanwhile, polio had spread to epidemic levels in American cities, felling mostly children. With no known prevention or cure, national headlines trumpeted the fearful news: "Polio Panic" and "Polio's Deadly Path." My mother had become so terrified of the disease in the months

before she got it, she later told me, that she once leaped behind a bush to hide from the family of a sick child.



Carole with her mother and younger sister. (Photos courtesy of the author)

Parents were allowed to visit the polio ward only on Sundays, a rule that my mother believed was meant to keep the children from getting too homesick, but that was more than likely in place to help contain a highly contagious disease. It was a rule my

grandfather couldn't abide. My grandfather – who worked at the American Can Co. - conceived of a plan. He smudged kohl on his face to approximate a beard and stained his lips cherry red. He donned a patchcovered suit, sewn by my grandmother, and transformed into Mr. Nobody, a hobo clown in the vein of Red Skelton. He was a natural-born entertainer trapped in a factory job. My grandfather drove an hour across town in his late-model Plymouth, a luxury bought in the flurry of postwar optimism and before the polio came, and he sang and entertained the kids at Kernan so that he could sneak extra time with my mother. Every time he left the hospital, he later admitted to my mother, he vowed to God: *If my* daughter walks again, I will dedicate my life to those in need.

After months of staring at the ceiling, my mother had strength enough to sit up. Slowly, she left her bed. One year after she arrived, my mother limped out of Kernan. A few months later her frail legs managed the length of a church aisle at her cousin's wedding, a flurry of rose blossoms in her wake, and the guests shed tears for more than the bride. (My grandfather kept his promise. He volunteered in hospitals and nursing homes until his death at age 85, and those efforts earned him a citation from the governor of Maryland.)

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This is where my mother's version of her story stopped — at the happy ending. Her account, delivered when I was young, had the polish of myth. Neat and contained.

Except that's not where my mother's story ended, not really. Yes, my mother walked again. She even danced ballet to minor acclaim. But my

mother never fully inhabited her body again. She never relaxed back into the animal joys of her fragile human casing, never dived after my brother and me into the salted ocean on summer vacation, or felt the wind in her hair as she coasted next to us on a bike ride down the hill near our house. The world was fraught with calamity, my mother understood, and she refused to be caught unawares. The moral of my mother's story isn't that of miraculous recovery. It's that polio, the thing she feared most in the world, had found her, and it paralyzed more than her body.

I've spent much of my life trying to understand that paralysis. My mother was not an easy person, at times distant and cold, at times nose-close and seething. We understand attachment theory now — the ways in which parental bonds, or the lack of them, inform our adult selves. We become who we are in the sun, or the shadow, of our parents' attention, and we carry the seeds of that early experience in our bodies. A story took root in me at a young age: Something was wrong with my mother, and by extension, with me. We were tangled up in one another, the way so many mothers and daughters are. I wanted nothing more than to fall into the effortless affection of two people who loved one another unguardedly, and I believed that if I could save my unhappy mother, I might save myself, too.



Carole Evitts in the 1970s.

rowing up, I knew something was off with my mom. She didn't behave the way other mothers did. She rarely hugged me or my older brother, Mike, and she never reached for our hand to hold as we walked along together. Hers was not the kind of lap that invited crawling into. My mother must have kissed me in my childhood — surely she must have — but I cannot recall a time. There is no memory of the warmth of her lips on my forehead as she bent over me at bedtime, or kissed away a sadness. My father was the one who read the bedtime stories and tucked me in. He was the one to salve hurt feelings.

We lived in the foothills of Virginia's Blue Ridge Mountains then, near the college where my father taught history. To the outside world, my mother seemed perfect. Coifed and pretty, with a precise swipe of coral on her lips that brought out the gold flecks in her hazel eyes. She volunteered at the college and supported the arts, and she outwardly doted on her children, mostly by bragging about our perceived accomplishments. "Elizabeth is learning French. Isn't that wonderful? Elizabeth, say something in French!" It was the 1970s, the equal rights movement and second-wave feminism were in the air, and my mom struggled to shift perspective. Her vision of marriage and motherhood remained locked in 1950s perfectionism. She was meant to be healthy and pretty, to know how to dress a table with her monogrammed silver set and wedding china. Books about hostessing lined our kitchen shelves, filled with tips for mixing potpourri or offering guests finger bowls of warm lemon water after the appetizer course.

When it was just the four of us, my mother was quite different. She abhorred clutter and frequently raged at the messiness of childhood, the grass-stained knees and the piles of Lego bricks. Weekend mornings were spent polishing the house to a shine, the smell of lemon Pledge in my nose, and a gut-level fear that my mother might turn from Bruce Banner into the Hulk at any moment. My father tried to make light of it, whispering so she couldn't hear: "Kids! It's time to boil the house."

My mother abhorred the mess of feelings, too. Children read their parents like maps, forever turning to them for direction, and I learned that I couldn't get upset. I tamped my reactions as best I could while looking for some kind of a legend to my mother - her body movements, facial tics, tone of voice – that might help me navigate her. My mother raged at the tiniest thing. It was hard to predict what might set her off. She verbally lashed out, never apologized. Much later, as an adult, I could see that a steady pilot flame of anxiety and anger lived inside her. It stoked itself at the slightest provocation. When it did, my mother went blind and could no longer see her children or her husband standing in front of her; she could see only the white-hot flame. It engulfed her. And then it engulfed us.

When my mother got this way, claustrophobia closed in on me. My brother felt this, too. Mike and I would escape as often as possible outside. We'd hike to a nearby creek or crawl through a secret hole in a large boxwood hedge that bordered our yard.

I also took to reading, the way many kids do, looking to escape an uneasy home life. In my books there were two types of mothers: good and bad. Good mothers were nurturing, kind and selfless. They gave over body and soul to their children. They were patient beyond measure, like Marmee in "Little Women." They were industrious and stable like Ma in "Little House on the Prairie." Often, the mothers were simply absent from the narrative. They were missing at the outset, no explanation. Think: Cinderella. Think: Orphan Annie. Nancy Drew was motherless and raised by a doting father. I always assumed that her mother had been good and that she must have died. In children's literature, it's hard to keep a good mother alive and on the page.

The mothers who got the most ink were the bad ones. They locked their daughters in turrets, mad with jealousy over their beauty and youth. These women often took the form of a stepmother so that their evil could be distanced from bloodline. My mother must have been truly troubled, then, for she didn't seem to know how to love her own flesh and blood.



The author and her brother, Mike.

n America in 1946, just as birthrates exploded, so did polio. There were more than 25,000 reported cases that year, and the annual number ticked steadily upward, topping 58,000 in 1952. The disease spread fastest in warm months. Each June beaches and movie theaters, swimming pools and ice cream parlors went eerily quiet. Some cities shut down public parks; some businesses banned anyone under 18. Summer became known as "polio season."

"For children and adolescents, polio now became the fastest growing

infectious disease," historian David Oshinsky wrote in his book "Polio: An American Story," which won the Pulitzer Prize in 2006. Newspapers ran images of children struggling in leg braces or lying prostrate in iron lungs. They kept tallies of victims, including age, sex and level of paralysis, much the way they tracked sports scores, and the psychological impact was significant, according to Oshinsky. "There was no escaping the damage that polio did, the random way in which it struck, or the gruesome truth that everyone was at risk," he wrote. My aunt had finished my mother's breakfast that fateful morning, and the arbitrary nature of the virus bothered them for years, neither understanding why one sister got sick and the other was spared.

Women like my grandmother became the "foot soldiers" of the crusade to cure polio, according to Oshinsky. The March of Dimes had appealed directly to the public for donations for years, but in 1950 when my mother was still in the hospital, a volunteer in Phoenix launched a new campaign. On a January evening, at 7 p.m., an army of women carrying shopping bags took to the streets for one hour. They knocked on every house, apartment and even hotel door in the county. They had widely publicized beforehand with the slogan: "Turn on Your Porch Light! Help Fight Polio Tonight!"

"The portrait of mothers marching against polio became one of the indelible images of postwar America," Oshinsky wrote. My grandmother volunteered for the Mothers March on Polio in Baltimore. Nationally, mothers helped to raise over \$250 million in four years for the March of Dimes.

The March of Dimes also started a wide media campaign of success stories. Those who survived the disease became poster children to encourage the public's continued generosity. In 1959, my 16-year-old mother told a reporter for the Baltimore News American that when she left Kernan, she was determined to live her life so that no one would notice she'd ever been sick. She would "show people she could get back to normal — and better." With her

recovery, my mother was a shining beacon of what was possible. That year she was crowned the queen of a March of Dimes parade that wove through the city. There's a photo of her in the Baltimore Sun. She's perched on the seat of a convertible, a tiara clipped into her silky black curls and a fur cape wrapped around her shoulders. She cradles an armful of roses. The photographer clicked the shutter just as my mother's car had stopped and she leaned in to offer Maryland Gov. Theodore McKeldin a kiss on the cheek. She is radiant, healthy. She looks less like a polio survivor and more like a true beauty queen.

My mother struggled to embody love because she couldn't abide that kind of vulnerability. In high school, I began reading up on polio to try to understand my mother. Researchers had identified three coping styles used by survivors of the polio epidemic, and she fell into the category of those who could "pass." To meet my mother when I was in high school was to never know that she'd had the disease as a child, or that she continued to suffer the physical effects of the virus, what is medically known as post-polio syndrome. Her muscles ached. She had trouble raising one arm over her head. But she vehemently refused to see doctors.

Mental health experts were rarely staffed in polio wards to help children process the natural fear they felt. My mother didn't talk about her time at Kernan in much detail, but what scraps of story she did relay signaled that she had felt confused and abandoned. Whenever I suggested that she might benefit from physical and mental therapy, she turned the argument on me. I was the one who needed help, she said. I was delusional. At the height of my mother's yelling — to end the argument or stun me into silence — she would sometimes say that she should kill herself.

In college, I still believed I could help her. My mother had always struggled to keep close friends. She had alienated family, too. My aunt rarely spoke with her, in an effort to protect herself from my mother's cruel moods. My mother relied solely on my father. She also relied on my brother and me to be there whenever she called and needed something.

I sensed she was lonely, and I worried about my father being similarly isolated because of her choices. I reached out to a local post-polio survivors' group. One night over dinner, I presented my mother with their pamphlet. The rage rose in her so quickly that I almost didn't duck in time. She grabbed a plate off the table and threw it at me with enough force that it shattered against the wall behind my head.

So I left. That summer I graduated college, and I escaped with a backpack and a few hundred dollars I'd saved and went to Europe with a good friend. I put an ocean between my mother and me to see who I might be without the weight and worry of her.

LEFT: Carole as queen of the March of Dimes parade. RIGHT: A clip from Carole's scrapbook from 1959 includes a photo of her as the queen of the March of Dimes parade kissing the governor of Maryland.

was nearing 30 when I finally had a name for what truly ailed my mother. My sister-in-law, Anne, had been a social worker for decades, aiding families struggling with mental illness and addiction. She and my brother had been dating only a few months when Anne mentioned borderline personality disorder over a glass of wine in her kitchen. "Your mother is textbook," she said, "with a healthy dose of narcissism disorder and obsessive-compulsive disorder thrown in." (Years later, a psychiatrist called in during one of my mother's frequent hospitalizations confirmed Anne's assessment.)

I read the American Psychiatric Association's definition of borderline with a shock of recognition. The inability to stabilize mood and emotion, the lack of friendships and family ties, the heightened anxiety and rage that come from distorted beliefs in danger, the frequent suicide threats. Those suffering from borderline feel an acute fear of abandonment, and ironically their behavior is often the very thing that drives people away, proving that fear true. Those who stick it out — like my father, my brother and me – often become enablers incapable of confronting the individual for fear of sparking their dramatic reactions. I always knew my mother was challenged, but now I understood that she wasn't experiencing just the physical and mental aftershocks of polio. She was suffering from a truly debilitating

mental illness, one that she didn't even realize she had.

Borderline isn't fully understood by the professionals. It's not chemical, in the way of bipolar or schizophrenia, so medication isn't as effective. Personality disorders occupy a nebulous space between true psychosis and mood destabilization. It's often believed that a serious trauma can lead to the personality split. The more I learned, the more I came to believe that lying paralyzed in a hospital bed for months on end, feeling abandoned by her parents, had cracked my mother's psyche.

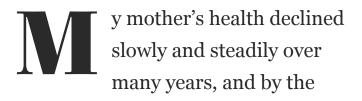
Borderline is also notoriously difficult to treat, in part because the person with the illness refuses to believe there's anything wrong with them. It's everyone else who is to blame. All those years of trying to get my mother into therapy were never going to work.

As Mike and I forged our own families of friends and spouses, my mother remained horribly alone, except for my father as her steadfast, if wary, enabler. When he died of cancer in December 2010, my mother became increasingly unmoored.

Six months later, my daughter was born. I went into labor on a warm June evening, and when I first held my baby girl, the intensity of my love for her overwhelmed me. I understood in a flash the old saw that being a parent is to forever walk around with your heart outside your body. Mother love is pure vulnerability. I saw, too, how love couldn't stay love inside of my mother. It morphed into something else. Fear. Control. Anger. My mother struggled to embody love because she couldn't abide that kind of vulnerability.



The author and her mother in 2003.



spring of 2019 vascular dementia complicated her already fragile mind. Her days slipped away, and time no longer held much meaning. My mom and I were at the emergency room every few days. Not long before Mother's Day, Anne and I found her unusually disoriented in her apartment. This time, the busy ER didn't have a bed for her, so we waited in the crowded lobby. Thin and frail, my mother no longer occupied as much physical space as she once did. The nurses thought her sweet, if confused. My memories of her, though, the person she was, still loomed large.

Her hair was a mess, knotted and sticking out. I found a brush in her purse and went to her. I pulled the matted tangle of hair in my hands. I felt the papery coolness of her skin, the warmth of a pulsing vein in her neck, and the intimacy of it shocked me. We weren't a mother and a daughter who cared for each other this way.

I eased the brush through her coarse hair, and that's when I found the matted blood. She had a goose egg on the back of her head.

"Mom, what happened?"

"I think I fell."

I waited outside the imaging room as a CT scan found a pool of blood on her brain from the head trauma. I have always been seeking out what's wrong with my mother. Palpating what's just beneath the surface, trying to understand the things that haunted and hurt her.

Later, three nurses circled her hospital bed trying to calm her. My mother looked like a cornered animal, fearful and screaming. I attributed her reaction to the dementia, to the head injury, to the mental illness. I felt the familiar constriction in my body, the claustrophobia that closed in when my mother was in the grip of her addled mind.

When I got home, my daughter was already in the bath. At 7, she was the same age my mother had been when she got sick. My daughter had wanted to understand why her grandmother was in the hospital so much, and I had told her weeks earlier about the polio. I found myself hewing to the original parable, the one about the brave young girl and the god-fearing grandfather turned entertainer. I would be more honest with her when she was older and could understand the nuances of mental illness.

I sat on the floor next to the tub and read a Harry Potter book as she played. I paused my reading when the water stopped splashing. My usually active daughter lay stock still, her thin arms and legs floating.

"What are you doing?"

"I'm imagining what it was like to be paralyzed," she said.

My daughter had questions. How did her grandmother go to the bathroom if she couldn't move? How did she eat? How did she read?

I couldn't answer her. I had never braved asking my mom what daily life was like in the hospital. I'd spent my whole life surviving her; I had not been able to empathize with her.

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pictured my mother then. Not as 76, but as 7. Long-limbed and thin, a raven-haired twin to my blond-headed daughter. I saw her amid dozens of girls marooned in the polio ward during an epidemic that overwhelmed the health-care system. In 1949, the year my mother got sick, the United States had more than 42,000 polio cases, then the highest on record, and the season extended into the fall when normally it should have tapered off. By 1950, the influx of polio patients flooded city hospitals, and the Red Cross made an emergency appeal in the Baltimore Sun for more nurses. During her year-long rehabilitation, my mother was a little girl being lifted because she could not lift herself, being moved to change sheets and to

mobilize her limp limbs. Her body physically manhandled.

It hit me then: My mother believed she was back at Kernan.

I kissed my daughter good night, got in my car and drove across town to the hospital. The night nurse nodded me over as I walked down the corridor to her room. "We gave your mom something to help her sleep," she said, "but she's restless."

My mother lay in a tangle of sheets, anxiously muttering. When she saw me her furrowed brow relaxed. "Oh, Mommy," she cried. "You came back! I thought you left me." She believed I was her mother, and I didn't correct her.

"I only stepped out for a minute, but I'm back now."

I smoothed the sheets and told her to rest. I sat next to the bed and watched her fall into an uneasy sleep, her eyes flickering beneath the lids. My mother may have walked out of that hospital 69 years earlier, but she had never really left. Like her, I was also trapped in time. I was still that little girl suffering her mother's mercurial nature, still the child hiding in the boxwood and hoping to stay off the radar.

My mother woke and muttered in soft sobs. "I miss you. Oh, I miss you." I assumed she was still back in time talking to my grandmother. Then: "Elizabeth."

I leaned in. "Yes, Mom."

"Oh, Elizabeth," she trained her medicated, milky eyes on me. "Oh, Elizabeth, I love you."

Love doesn't always come in the form that we hope it will. It doesn't always even look like love. A therapist once explained to me that a person suffering from borderline often worries obsessively about the things that matter most to her. My mother's neurosis focused on my brother and me precisely because she cared about us. We don't have a name for that kind of mother love, the kind that's fractured through mental illness and feral from fear. My mother loved me. I could see that now. She just didn't know how to love me well.



Carole in 1963.

he died on May 20, 2019, one week after Mother's Day. Later, my brother and I sifted through my mother's apartment, packing the ephemera of her life. The silver. The china. In the living room, a large chest of drawers held the trappings of entertaining: blank invitations never sent, colorful napkins for parties never thrown. Drawer after drawer filled with the dream of a happy and social life that never quite materialized. Mixed in with it all, I discovered a small black notebook. Inside was my mother's neat cursive writing. Grocery lists. Notes about bills. And there, amid the mundanity, were quotes from writers and philosophers. Passages my mother had assiduously copied, each related to living a better life. One quote was starred, the page dog-eared. It read: "If you change the way you look at things, you change the way things look."

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had thought my mother atrophied all those years, immobilized by her fear and unwilling to change. I found in those pages her secreted selfreflections. How much was she trying to alter the tape loop in her head? In the storybooks of my youth, the daughters escaped their bad mothers. They galloped off on horseback with the prince, or forged independent lives as motherless adults. They flicked a match and burned the proverbial bridge to their past. But what does it look like to stay? To change how I look at life and rewrite our story? To allow her to have been more than a difficult mother, to allow myself to be more than a long-suffering daughter. To make myself vulnerable enough to try to love my mother for who she truly was.

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