

## **In Stroke's Shadow: My Caregiver Story**

## **CHAPTER 1**

By Kyle Ruffin

On March 5, 2010, five short months after I left corporate life and only two months after the official January 2 launch date of K Ruffin & Associates, LLC, I got a call.

It was a perfectly sunny day. The kind of day that signaled the emergence of my favorite time of year. Spring. The sky was a beautiful pale blue with only the hint of clouds. The air was refreshingly cool, rather than down in the bitter winter temps with wind chill factors that added insult to injury. Those days were giving way to what I knew would be the best summer ever. A wonderfully free summer for the first time in my life. I'd be able to take off whenever I wanted to. Head to the shore on a Tuesday. Drink with friends during the week at outdoor cafes in Philly. Play hooky whenever I felt like it. After all, I could control the flow of my work, and I only had to answer to me.

That morning, I was in the car on my way to a meeting. When my cellphone rang, I hesitated before hitting the answer button. The call was from my cousin Clairees in Maryland. Our conversations tended to be lengthy, and I was already running late. Then it hit me. A weekday call in the middle of the morning from Clair was unusual.

Maybe I should pick up. So, I answered.

"Kyle, I have your mother on my other line. She's not making sense," Clair calmly explained.

"Really?" I answered. "What do you mean she's not making sense?"

"You may want to go check her on her. Something just doesn't seem right."

Even though Mom and I lived twelve minutes apart, we didn't frequently speak to or see each other. She was always on the move, travelling the world or just hanging with her posse. They were the African American equivalent of Ladies Who Lunch. Retired and enjoying the spoils of life's labor.

By some unexplainable twist of fate, the meeting I was on my way to was very close to my mother's house. Within minutes, I pulled into the driveway of my childhood home for the thousandth time. But this time would be different. Like my 2:00 a.m. arrival fourteen years before, after my mother called me to say she couldn't wake my father, this arrival would change my life forever.

I went into the house and headed straight up the steps to Mommy's bedroom. She was sitting at the foot of her king-size bed, smiling and repeatedly saying, "Okay. Okay. Okay." No matter what I asked, she responded "Okay."

Mommy was being unusually agreeable. Yes, at forty-eight years old, I still called her Mommy. No matter how old I got or how successful I was in my career, in our relationship, I would always be the child, the youngest, the baby.

I asked if she wanted to go to the hospital. She cocked her head to the side and liltily replied, "Okay." I had asked her this question a week before when I paid a rare weekday visit and discovered her in bed at one o'clock in the afternoon. That day, she complained of being light-headed and a bit dizzy. She refused any intervention.

"All I need is rest," she said. I didn't push.

On this day, with a strangely euphoric look on her face, Mommy agreed to go to the hospital and immediately began getting dressed. I called 911 and fielded calls from Doreen, Clairees' sister, who had already been alerted to Mommy's strange behavior. Doreen, who works in a hospital in Atlanta, gave me a quick test to help determine what was happening. She told me to ask Mommy to smile. When she did, only one side of her mouth complied. That nearly confirmed our worse fears.

The paramedics and police came quickly, filling a bedroom that at any other time felt large, with all their beeping equipment and physical girth. After conducting their assessment, Mommy finished getting dressed and walked out of the house on her own power to the ambulance waiting at the curb. She had worked her way into a well-fitting pair of brown corduroy pants and a thick olive-green turtleneck. On her way out, she grabbed her short brown shearling jacket, which was proof that her stylish ways were still intact. There was no limp. She wasn't visibly favoring one side over the other. Physically she appeared fine. But that would soon change.

After I snatched up a few hospital essentials—her wallet, her cellphone, my breath—I followed the ambulance to the hospital that served as the local stroke center. The phone tree had already come to life. Within an hour, friends and family began to crowd her curtained-off space in the emergency room. Part reunion, part support group, everyone was there for me and Mommy, the only remaining members of our immediate family.

We each came and went, spilling into the hall or in and out of the nearby door to the outside, making and taking phone calls. For the next several hours, doctors, technicians, and nurses came in and out. They conducted more tests, while Mommy asked over and over “What happened?”

The results of a CAT scan confirmed she’d had a stroke, and that’s what we told her each time she asked. She continued to show very few physical symptoms. She could raise both arms and legs. She could grip the nurse’s hand. She could adjust herself on the bed without help. The asymmetry of her face and her limited vocabulary were the only discernible evidence of stroke.

It was then that I began to realize that I was now entering a world I only knew from a distance through the public service announcements and partnerships I had established at the KYW Newsradio in Philadelphia. I had been the liaison between the station and all those good causes that rise up or reach down to meet people on sad, unexpected journeys like the one I was about to begin. I had worked closely with The Delaware Valley Stroke Association after the station’s young news director suffered a stroke, so I knew a little, but not a lot. I never imagined that this tragedy would touch me.

In October of 2009, I bailed out of corporate chaos. One of worse economic downturns in US history had turned my dream job as the marketing director for KYW Newsradio, one of the top all news stations in the country, into one I was driven to flee. I took a giant leap of faith and started a boutique communications business, where the only overhead required was a computer and a phone. I already had both. The decision may have seemed questionable, given daily reports of layoffs, salary cuts, and businesses disappearing overnight.

But I’m not a risk-taker. I don’t play now and ask questions later. I had a plan. A roadmap for taking control of my destiny. My husband, Fred, and I are DINKS, the sometimes envied, sometime despised double income no kids couple. We had very little debt, not even a car payment. There were no insanely high college tuition bills in our future, and our retirement plans were adequately funded, considering we were still young enough to continue to contribute respectably. I had nothing to lose. I had solid work relationships earned over twenty-five years of delivering in some of the most challenging environments. I had respect that came from working at companies or nonprofit organizations that were household names. Those two things alone would land me a job if chasing my dream didn’t work out.

I traded the dense, hyperactive swirl of working in the city, where I danced around Independence Mall, weaving in between international tourists and school groups to grab lunch or the rare treat of non-newsroom coffee. No more driving to work in the morning, hearing what I wrote yesterday on the air today and knowing that more than a million people were hearing it too. But my new adventure was bittersweet. I was no longer connected to big brands that meant I’d instantly get my calls returned. But also, no more cocked eyebrows from those impressed that I,

a young African American woman, could rise to the heights of marketing director for Philadelphia's iconic all-news station. No more stunned and often apologetic looks from men in dark suits when they realize that with a name like Kyle, I was not white, nor was I a man. No more dancing to someone else's beat. I would set the rhythm of my life. Finally.

Immediately after Fred and I moved into our home in 2002, we turned one of the bedrooms into an office. It made sense with four bedrooms and only two people. The cool sea mist-colored room housed one long desk that we splurged on at IKEA. Each of us occupied our designated half anchored by his and hers personal computers. The burnt orange desktop with its black frame and legs complemented the black IKEA bookcase crowded with professional books, software boxes, and pictures of our godchildren and other family. Our diplomas hung on the wall, his from Penn and mine from the University of Delaware.

Fred's end of the desk was perfectly suited for his type A sensibilities. Clear, organized, and with only a few sentimental trinkets. My end was cluttered with business cards, proposal drafts, design projects in progress, newspapers and clippings, client folders, notebooks, to-do lists, a coffee cup or water bottle, and whatever I picked up at networking events. Everything I was working on scattered around me on the desk and the floor, hoping to catch the bounce of my attention.

My messy work area was no indication of my well-mapped-out strategy. In accordance with my perfect plan, I made sure there were at least five meetings or events on my calendar each week. I started The Multi-Tasker's Marketing Minute, an audio blog that I emailed every other week to a growing list of nonprofit and small business contacts. My logo, my business cards, my website, ambitions, and attitude were all lined up for a bright future.

Within weeks, my effort was attracting business. My phone was ringing. My days were filled with self-promotion, advising clients, making new contacts—all the precursors for launching and maintaining a successful small business. The relationships I'd collected over two and a half decades of paying my dues were working to serve me rather than the objectives of my employer.

The discipline I had learned working for others was now yielding personal rewards, and the world was behaving just the way I wanted it to. The business buzzwords of the day were my real-life experience. I was molding my personal brand, leveraging relationships, learning new technologies, achieving work-life balance, being my authentic self. I was a real-life law of attraction petri dish and on the kind of high that came from believing I was in total control of everything around me. For the first time in over a decade, I was home when Fred came in from work. And I was soaking up the love of my two associates, our new kittens, one of which spent most afternoons nestled in my lap while I pounded away at my computer keyboard. Life wasn't good. It was great!

During my career, I had learned to muster up the courage to ask questions when I didn't understand. If I only pretended to understand, my work and my reputation would suffer. If the white men in suits could amiably answer my questions, so could the white and brown men and women in white coats and scrubs. I owed it to Mommy to use the lessons I had learned in business survival training to advocate for her.

My past work with so many nonprofits prepared me to ask questions like, "What type of stroke was it?" "How long had this episode been underway?" I was searching for answers from the medical team that would assure me that this was a temporary situation that would quickly right itself. I'd heard about people who, after having a stroke, left the hospital completely normal. I was told that hers was an ischemic stroke, which is caused by blood clots blocking arteries leading to the brain. If I had discovered her and gotten her to the hospital in less than three hours of the stroke's onset, they could have administered the drug Tissue Plasminogen Activator or tPA, which would break up the clot and render the stroke harmless.

Mommy's cell phone log was the only way I could tell if anyone had spoken with her within that window. I scrolled through the call log, searching for evidence that someone had talked to her before Clairees called her. Someone to confirm that she sounded normal. Sadly, the log revealed just the opposite. She had not talked to anyone since the evening before. This was surprising since the phone was her lifeline, her constant connection to everyone she valued in her life.

The CAT scan showed that the area affected was large. Still, my hopes remained high since she was speaking and moving both arms and legs on command.

"Maybe the long-term effects will be minimal," I wishfully shared with Fred, who had joined our group of friends and family. Then one of the doctors warned me that it could take up to seventy-two hours for the full extent of the damage to show.

Stroke terminology began to edge out the business and media buzzwords that shaped my thinking and my language for decades. I was determined not to fall behind. I bit down and did my very best to understand what was happening to Mommy. I struggled to process the monsoon of medical jargon, asking questions of every nurse, doctor, or therapist when they nonchalantly tossed around acronyms, words, and phrases that were part of their everyday life but not part of mine. And thanks to surprisingly reliable Wi-Fi in the hospital, I started my education right there in the ER on my phone.

I learned the difference between the two types of stroke. According to the American Stroke Association (ASA), ischemic strokes account for eighty-seven percent of all strokes. Hemorrhagic strokes are another kind of stroke that occurs when weakened blood

vessels rupture. The ASA pins most of the blame for those on uncontrolled high blood pressure.

TIAs or Transient Ischemic Attacks are often referred to as mini strokes. They're the results of temporary clots and are a clear warning sign that bigger trouble is likely brewing. Mommy was probably having a TIA the day I found her napping in the middle of the day. Sadly, it was a warning we both ignored.

As far as the doctors could tell, atrial fibrillation or A-fib (an irregular heartbeat) was behind Mommy's ischemic stroke. The American Heart Association attributes fifteen to twenty percent of strokes to A-fib. As countless doctors explained, a valve in her heart was not closing entirely during the pumping process, so blood pooled in front of the valve. That's where clots formed. When this particular clot broke off, it snaked through her system and turned a preventable condition into a massive life changer. For some, this is instantly fatal.

Women suffer strokes more than men, a fact I found startling. This interesting bit of info came from AHA's Go Red for Women. Due to a family history or other risk factors, even a woman who has always thought of self as perfectly healthy can find herself suddenly experiencing the symptoms of stroke.

Take a look at the statistics:\*

- About 795,000 Americans each year suffer a new or recurrent stroke. That means, on average, a stroke occurs every 40 seconds.
- Stroke kills more than 137,000 people a year. That's about 1 of every 18 deaths.
- On average, someone dies of stroke every four minutes.
- About 40 percent of stroke deaths occur in males, and 60 percent in females.

\* ([http://www.goredforwomen.org/about-heart-disease/facts\\_about\\_heart\\_disease\\_in\\_women-sub-category/facts-causes-risks-prevention-stroke/](http://www.goredforwomen.org/about-heart-disease/facts_about_heart_disease_in_women-sub-category/facts-causes-risks-prevention-stroke/))

I was asked over and over for Mommy's medical history. Every doctor or specialist from the ER to the ICU to which she was admitted that evening started with the same questions. Did she have a history of this or that? High blood pressure? Diabetes? Heart disease? Did she smoke or drink? I knew nothing of her current medical condition. I knew she tried smoking when I was in high school.

Like the ladies in the Virginia Slims commercials, she wanted to be cool and elegant, experimenting with the vice that consumed my father and many of her friends. I'd sneak into her bathroom when she wasn't home and secretly smoke the majority of her pack of MORE Menthols, blowing the smoke out of the narrow window. I don't think she ever noticed the missing slender brown sticks. If she did, she kept it to herself. Even after she had to talk my high

school principal out of suspending me for smoking in the bathroom, she still didn't seem to make the connection.

I had no one to ask when the last time was that she'd been to a doctor. I certainly couldn't recall. We didn't talk about these kinds of things. I recall a conversation back in the seventies or eighties between my parents that took place behind closed doors. It had something to do with a health issue, but it was one of those things parents don't share with their young children.

Over the years, if I tried to talk to her about her health, she'd find a way to shut the conversation down. My best guess was that it had been no less than twenty years since she saw a doctor of any kind. As far as I knew, she had not gone to an eye doctor, dentist, or gynecologist or gotten any kind of checkup. At sixty-eight, she hadn't even had a mammogram. Now we were starting from scratch, assessing and understanding what was percolating beneath the surface of her perfect brown skin.

Even though she didn't do medical things herself, she spent a great deal of time visiting hospitals. Her mother, who we called Joanna (pronounced like the guy inside the whale), began regular hospital stays when at eighty-four she was diagnosed with a perforated ulcer. Joanna believed that doctors caused more illnesses than they cured, so up until then, she refused to see one. But she was strong. Even after major stomach surgery, she lived to ninety.

My father developed serious health problems after a virus attacked his heart. His diabetes slowed and possibly even stopped the healing process. He was hospitalized often before his sudden death from congestive heart failure in 1995 at the very young age of fifty-eight.

My sister, Lynnette, spent much of the eight months between her lung cancer diagnosis and death in the hospital. Mommy and I spent days at her bedside. Yet this familiarity didn't stay off Mommy's white coat syndrome. Perhaps it was because the most memorable hospital experiences didn't end well. Or maybe the roots of it went much deeper.

She knew about so many atrocities perpetrated against African Americans by the medical establishment in her lifetime that it was hard to imagine that they didn't affect her decisions not to seek care. The irony of her medic-free life escaped no one who knew Mommy. She famously harassed, berated, harangued, and nagged everyone else about taking care of themselves. From a girlfriend's runny nose to her next-door neighbor's colon cancer, she was expert at schooling other people on diagnosis and treatment. She appeared to know what was best. Up until this fateful day, that seemed to be true. Her friends raved about how healthy she was. She was the only one among them who wasn't taking a daily regimen of prescription pills and visiting teams of specialists.

I teased her often about how much faith she put in natural remedies, most of which she saw on afternoon TV. She ate raw garlic or took garlic pills, which made her breath unbearable. She drank hibiscus tea or anything with the word “acai” on the label. She walked for exercise off and on and traded wives’ tale remedies with her posse.

A tiny bit overweight, her five-foot eight-inch frame carried about 170 pounds. She was statuesque and graceful. She walked with the slow elegance of a giraffe, never exerting any more energy than necessary. We thought she was the picture of good health. Mommy never got sick enough for me to worry about her. Yes, there was the occasional cold, and her stomach rejected green lipped mussels every time she ate them, but knowing that, she just avoided them. Nothing ever rose to the level of doctor or hospital visit, so I chose to believe that she was as healthy as she looked.

Why worry about someone who traveled to yet another exotic place every year, stepping foot on six of the world’s seven continents, some more than once. She’d been to Africa several times, Egypt, South America, Italy, Greece, Turkey, Australia, New Zealand, China, and more. During the previous fall, just months before the stroke, she and her travel mates ventured off to Chile and South America, going as far south as Patagonia. She was living the enviable life of a young retiree who still was able to appreciate her resources and would for some time to come.

Mommy appeared to have a charmed life in spite of suddenly losing her husband of thirty-seven years and then losing her daughter in 2002 when Lynnette was just forty-two. She was an inspiration and a source of comfort to many in the way she suffered great tragedies, yet she lived well. Some may have seen the choices she made as a lack of regard for all she had lost, but she chose her path, and all that mattered was what suited her. And it suited me to believe that she’d always be healthy, with little need of my assistance.

But suddenly and without notice, my priorities had changed. In the blink of an eye, my focus unexpectedly shifted in a way I never saw coming. The freedom of having an independent, active, and healthy mother ended like a splat on a wall. The assumptions that ruled our lives were now like a marbled liquid mass, sailing gracefully through the air, only to suddenly encounter the equal and opposite force that would render us shapeless and unrecognizable.

There was no way to know where we were headed or how this would play out. There was no way to prepare, because this was barren land for Mommy and me. Land we would now colonize. In the space of twenty-four hours, I went from looking out primarily for myself to having to consider everything through the filter of Mommy’s care. I had no children, so the role of caregiver was completely foreign to me. Like a new parent, I had to learn on the job. Only I didn’t have nine months to prepare.