Introduction

Are not two sparrows sold for a penny? Yet not one of them will fall to the ground apart from your Father.

MATTHEW 10:29

In the suffocating midnight blackness, I hear heavy breathing somewhere in the humid night closing in on my daughter and me. Certain it is a monster, a terrifying, dangerous man, I grab Kate's hand, and we dash down dark alleyways, darting left and then right, hopelessly lost. Now the breathing I hear is our own. Kate's hand trembles in mine, like the beating wings of a rescued bird.

My heart pounds like a drumbeat, pulsing in my own ears. In my peripheral vision, I see shadows gaining on us. My lungs are on fire. My legs ache and feel leaden and useless. As fast as we run, the monster's footfalls are faster. The beast grows closer. All I want is to protect my child. My baby. I gave her life, and it is my duty—the very purpose of my existence—to protect her.

We race down another littered alleyway in this unfamiliar city. And it brings us to a chain-link fence. A dead end. My daughter screams. I push her behind me and whirl around. Never underestimate a Mama Bear. I scream, "Leave us alone!" in an ear-shattering primal roar. It is my voice. *My voice.*

And then I wake up.

Tears roll down my face. And in the darkness I wait.

Voiceless.

Screamless.

The monster, the real terror, scarier than any nightmare fantasy, is ALS.

Hearing muffled moans on the monitor, my caregiver comes into my bedroom. She has been with me and my family for a long time now. She knows my looks. My "move that hair off of my face" look. My scared looks. My joyful ones. She begins the preparations to get me ready for my day as an Episcopal priest.

I have to be hoisted into my chair. I need help with toileting. I can't brush my own teeth. Despite this—or maybe even because of this—I insist on some lipstick. (My husband, Matt, has gotten pretty good at putting it on, but he draws the line at painting my nails.) I still want to look like . . . *me.* Me. So much of me has been taken by this monster, this danger threatening me, ALS. It wants *everything* from me. It wants it all, including my life. And earlier this year, in the springtime, usually the season of renewal and hope, the holy Easter season, my voice was silenced. Instead, a machine—I call her "Joy"—speaks for me now. She reminds me of the ubiquitous Siri. Those television commercials depicting this smart phone or that one, those mechanized voices are *my* voice now. But in my dreams? My dreams and nightmares are of me, able-bodied. Speaking. It is when I awaken that the reality of my body's betrayal hurtles me back. In my dreams, sometimes I fly. But when I wake up, I land with a thud back in my own body. A body that refuses to obey me, damn it. A body that the monster wants to possess.

The medical name for the disease that has stolen so much from me is amyotrophic lateral sclerosis. Some people refer to it as Lou Gehrig's disease after the Yankees hero who contracted it. Professor Stephen Hawking has a form of it and is perhaps the most famous person living with it today. Jim "Catfish" Hunter had it. So did jazzman Charles Mingus and actor David Niven. And Mao Zedong. And me. Maybe this book will make me famous too. Though I can assure you I would prefer that my fame not be for having a progressive neurodegenerative disease that affects nerve cells in my brain.

From one of my hands growing weaker at the end of my time in seminary through the onslaught of this disease taking away my freedom and dignities day by day, sometimes hour by hour, to today, my life has been utterly changed. I write this manuscript, a tiny silver dot on my forehead leaping and dancing from letter to letter on a tablet, painstakingly. Once my hands flew over the keys, a typical Type A woman living life so fully, gulping at it.

Before that, before my life as a wife, mother, and career woman—and then a seminary student and priest—I was a young ballerina. I can picture myself leaping across the wooden floors of a stage, dancing *en pointe*, perching on my toes, gliding gracefully. Effortlessly. My muscles obeyed me, and I thought nothing of it. There I was, light and floating like a butterfly, flitting in my chiffon skirt, its layers fluttering in the movements of my own legs.

Now nothing moves below my shoulders. My muscles defy my brain.

I am a prisoner in this body. I sit heavily in a chair, posed just so by someone else, like a life-sized doll. If a stray hair irritates me, if I sneeze and need a tissue, if I simply want to hold my husband's hand, someone else must move the hair, wipe my nose, take my hand.

But the monster, the monster doesn't realize what it's up against. My spirit remains *en pointe*, soaring and gliding. In my world, I am dependent on others physically, but God is my partner in the *pas de deux* of life. She lifts me high when I need to leap; he shelters me and then holds me effortlessly as I arch backward. Faith doesn't make you afraid to leap dangerously from across the stage into the waiting arms of your partner. *Faith is feeling the terror—and leaping anyway.*

So, monster, I am not done here. You will not defeat me. I am still dancing my life dance. I work at least fifty hours a week in my role as an associate priest. I bring communion to nursing homes. I counsel the faithful—and those wrestling with their faith. I teach the little ones, their faces upturned and eager, drinking in God's Word during the children's sermon. I prepare sermons and lessons—parts of which are incorporated into this book. *I am a priest.*

Those words still fill me with awe. There are many inspiring jobs out there, and many people working very hard to put a roof over the heads of their family and to put food on the table. While I receive a salary for my work, the word "job" doesn't convey the way being God's priest makes me whole. Ministry, with its three syllables, seems better suited, even weightier somehow. But my job means saving souls. When I assist someone from darkness into the light of faith, the light of us all is *that much brighter.*

I feel I have the best job in the world. I counsel those seeking a closer relationship with God—or maybe even seeking God for the first time in their lives. So, monster, my mind remains as vibrant and strong as it ever was. My work—my avocation and vocation—that part of me that cannot be suppressed, goes on. I have so much still left to do here.

When I started writing my memoir, I saw so many miracles strung together. Most of all, I saw that God knocked. I answered. When I took the "call," a term that has come to be associated with answering God's calling for a person to take up a vocation in religious work ("call" comes from the Latin for "vocation"), I was filled with such a sense of grace and peace. It was as if I was breathing God's air. I answered the call wanting God to use me as an instrument of her peace, to extend the peace, love, faith, and grace that I felt from her, out from me into the intricate web I wove. Every human weaves his or her own fabric of life. We each create the patterns and threads of our world. I could not have known that God and the sacred threads she was weaving with me would sustain me throughout this new time, the time of the monster. More than that, even, God is still using me. Every day. Maybe this is a version of spiritual symbiosis.

When I watched the Ice Bucket Challenge go viral in the summer of 2014, I was grateful to see that the warriors fighting ALS were getting attention. (I prefer to think of it that way instead of giving the monster itself attention.) I felt that the time was right to now share my memoir to bring further attention to ALS and other "orphan" diseases, those diseases that are not adequately funded in terms of research dollars. I wanted to share the utter devastation that can happen to a *family* when someone they love must fight a battle like mine. To be clear, ALS is not *my* disease—though of course there are agonies only I alone will understand—it is *our* disease. My husband's battle, my son's war, my daughter's suffering, my mother's burden, my friends' pain, my church's cause. This vile disease impacts my thread and all the pieces of fabric through which I am woven.

My church is a piece of fabric through which I am stitched, and which is stitched on my own heart. I was brought to this amazing community on my journey—a place I had no idea, when I first arrived, that I needed in quite the way that I was going to find out I did. Every day I marvel. If ever there was a community to lift up someone with ALS, it would be this one—a true glimpse of what a church family can be. A piece of heaven on this earth.

More than anything, more than this disease, more than all of the pieces of my life that comprise this memoir, my story is about faith. Everyone has a faith walk, and I am no different. I didn't suddenly earn a halo and wings by having the disease of ALS. However, my faith walk deepened in profound ways. My message to my readers is simple: God loves you. I pray you never have to walk a path like mine, but should you face dark, dark trials, God is with you. He'll meet you on the road, like the Good Samaritan, and without a word, will dress your wounds, carry you on her back, and find a place for you to rest.

My story is a story of hope and of the ways miracles and grace are hidden along the way of life. No matter our burdens, when we need a reminder of God's love, the miracle will appear if we are patient and still enough to accept it.

I named my story *Sparrow* because I am certain that like the little sparrows who fall, God knows me and knows my own very real struggle, my own free fall. Yet throughout my story of my life both before and with ALS, time and time again God has sent me signs to remind me she is with me.

I do not fall alone.

I am a sparrow. And I still soar in the clouds of God's grace.