

Monsters and Angels

The lights dimmed. People attending the art and spirituality conference stood in a circle at the edges of the university ballroom, facing the hundred feet of open space. One of the conference leaders, a dancer dressed in loose white pants and a white T-shirt, walked gracefully into the middle of the room. He was pushing a manual wheelchair in which sat Mark, a conference participant. I had eaten lunch with Mark the day before. He had told us of the diving accident that left him quadriplegic. As his assistant forked food to his mouth and raised his glass so he could reach the straw, he had spoken with animation about his job teaching college English. The leader and Mark began to dance. I don't remember music, though there may have been some. The able-bodied dancer pushed the wheelchair and let go of it, so Mark went gliding forward, fast, free, grinning. By the time he'd reached the other side of the space, the dancer was there to catch the chair. They moved apart and together. It was beautiful. It was graceful. It was holy. I left the room, sat out in the dark soft grass of the Carolina summer and wept. One of the conference staff followed me, checking to see if I was OK. "I have Multiple Sclerosis and there's a seventy-five percent chance I'll end up in a wheelchair," I sobbed. "They just taught me that I can be an artist no matter what."

This is a book about monsters. Not the cute, laughably incompetent ones you see in animated movies, but the ones you meet in your own life—ugly thoughts, unexpected losses, inexcusable evils. When I was a kid I thought that I was the only one with monsters. I never heard anyone else talking about them, so I thought I was alone. I disguised my monsters in piles of accomplishment and humor. I wrapped them in pretty words and colors. If I kept the monsters hidden, I thought I could fulfill my destiny as a young, Christian American. I planned to grow up and save the world...and get rich and famous and look good doing it!

The first monster I knew about was my monster-mind. I am not one of nature's optimists. I am, instead, an expert at negative thinking, catastrophizing, expecting disaster. I regularly descend into maudlin depths of self-pity. I wallow in muddy puddles of despair. I burst into floods of angry tears. As far as I know, I have had this moody

disposition since before my parents rolled their eyes and pleaded with me to “stop being so dramatic.” I thought that I would grow out of it. I didn’t.

When I was twenty, I was diagnosed with Multiple Sclerosis, (a degenerative neurological disease known as MS). By then, I had a shelf of self-improvement books with titles like “Learned Optimism.” I tried to be a hero, tried to look on the bright side. Within a month of the diagnosis, I vowed to fight the disease with everything I had. I took up jogging, a strict diet and meditation. I believed that with the right actions and attitude, I would beat the bad guy. I continued to fight for another ten years as my physical health and abilities slid slowly away.

My monster-mind couldn’t have a better partner than the MS-monster. Together, they whipped me into a wild dance, MS tapping out fear, frustration and sadness and my monster-mind twirling it into depression, rage and grief. It seemed like the monsters were in control. The monsters would win.

This is a book about angels. Better than that: It’s really a book about God. Despite my feeling that I was alone, God was with me and had, all along, been sending angels to minister to me. I didn’t recognize them as angels when they arrived in my life, but I know them now. They are creativity, faith and compassion. They come with flocks of lesser angels riding their slipstreams.

It was my exasperated, don’t-be-so-dramatic, parents who pointed the way to two of my angels. At the age of eight, I became a performing actress (a subtle rebellion), began the first of what became volumes of journals and began “making stuff”. My monster-mind was an ally in the creative process...its Big Emotions and churning energy providing the engine for expression.

A decade after being diagnosed, I discovered that what I knew about the creative process could help me deal with the frustrations of living with chronic illness (and life in general). It was easy for me to grasp that drama and writing and painting are creative. It was a stretch for me to find creativity in the wider rhythms of disability, dependence, accommodation and resolve that have been my experience of chronic illness. Yet, the parallel was there. Using it, I entered into a dance with illness and healing, rather than running from them.

The angel of compassion has come to me in the form of support group members. By “support group,” I mean a small group of people who gather and tell each other the truth about their lives in an atmosphere that discourages judgment and advice and encourages forgiveness and growth. The topic that brings people together doesn’t much matter. The gift of the angel is that I understand that I am not alone. Others have felt the way I feel. Others have done what I have done, thought what I have thought and have found ways to live as if they are forgiven. There is nothing more freeing than confessing the worst and having another human keep looking into your eyes and holding your hand. Nothing can break down self-recrimination faster than the words, “Me, too.” In our determination to show each other our best, we deny each other those gifts. I have been blessed to be around honest, generous, unflinching companions who have helped guide me through the real world.

We humans (especially we Americans) love progress. We like to see things getting better: stronger, faster, easier. We expect the same when it comes to our bodies. We also love to solve problems. Tell me what doesn’t work and I’ll try to fix it. Into such a mindset, a chronic illness—or even natural aging—lands with a thud. We’ve forgotten from whence we’ve come.

Not so long ago, we human beings were at the mercy of our environment. We were born, became injured and sick and aged and lived and died without understanding why. But curious, intelligent animals that we are, we started building and testing models with which to understand the world. We expanded our physical abilities by inventing machines to help us do our work. Thinking of our bodies as machines and using the new tool of scientific method, we started to discover cures for diseases and procedures to mend injuries. We began to dream of a world where every illness had a cure, where pain and infirmity were eliminated. But now, in the twenty-first century, new diseases and new variations on diseases are casting shadows over our dreams. Our old enemies are evolving as fast as we are and we find ourselves, still, at their mercy.

The trouble with our attachment to progress and problem solving, our romance with the story of triumph over adversity, is that it robs us of this moment of our lives. In this moment, I am strong and weak, fast and slow, ill and healthy, smooth and wrinkled. You are, too. Our heroes are always moving. They’re riding into town, learning of an

injustice, fighting the bad guys and winning, kissing the girl and riding off into the sunset. A hero without a quest makes a story without a dramatic arc. We love our heroes, our stories and our drama. But in real life, unlike heroic life, there is more being than doing. There is more slogging than riding. There is more diligence than drama. There is more playing than winning. We haven't given ourselves many models for our real lives.

I find myself wanting to play the hero. I want to tell you how to dodge the monsters, how to avoid them altogether. I want to inspire you in ways that will allow you to skip despair. I want the very act of writing to let me stand up and walk out the door without my wheelchair. But that's the dream world. What I have, right here and now, is my seated self, telling you about the ways I've found to be in this body in this world.

When I pretend I have no monsters, when I hide from them, or when I refuse to interact with them, I get stuck. My abilities to love and laugh and be a part of the world are impaired. Sometimes they shut down all together. My heart is closed. To get unstuck, I need to make what I stumbingly call an "internal gesture" and open my heart. By that phrase, I'm trying to explain some combination of deep breaths, mental emptiness and emotional tenderness that turns me toward life. When I choose life, I am released.

If I learn about my monsters...if I understand how they move...if I discover how to move with them...then we (monsters and angels and I) can turn this galumphing into a dance. It may not be graceful or polished, but, with it, I move toward God instead of running away.

In the essays that follow, I explore the landscape of chronic illness and describe its contours. I wish that my journey had been more organized so that I could show you my beginning and end points and draw you a map noting scenic overlooks and washed-out roads. But that only works to chronicle heroic journeys and I am here dancing in hazardous terrain. I have noticed a pattern. I can lay the steps out in paper silhouettes on the floor. I can try to show you how it looks on different days, but when the music starts and the monsters and angels grab you by the hands, your dance may look nothing like mine.

Still, I invite you onto the dance floor.