

Dodging Grief: The Demon of Desolation, The Angel of Surrender

Sometimes the realization of physical loss sends me into Overwhelm. I feel as if the light begins to dim as the path descends. Other times a more subtle disappointment causes me to curl into a protective ball so quickly, I'm not aware that it is happening. I don't even know I've entered the dance.

In early 2003, I realized I had gone months without writing. Then, an impressive woman named Candy Pettiford spoke at my church. Candy is an actress who writes and performs dramatic presentations about the women of the Bible and about African American history. She becomes a dozen characters in the space of an hour. She sings in a voice that caresses you one minute and slaps you the next. She literally changes hats to change characters. As she does, you see her hands, made into claws by the ravages of Rheumatoid arthritis. She has had both knees and hips replaced. She is a powerful woman.

After her performance, I went to the bathroom to pee and discovered that, not for the first time, my hand was too floppy to use the catheter my neurologically-challenged bladder requires to empty. My daughter, Alexis, then five years old, was with me. "Mama needs to take some time to cry," I told her, simultaneously surprising myself and recognizing a truth.

I took December away from my writing project. December stretched to January and then March. "Why aren't I writing?" I asked myself over and over. I made up answers: "I'm too busy. My schedule is out of whack. Winter darkness is affecting me. I have writer's block." As soon as I said them to myself, I knew them to be excuses. I moved quickly to the next task, the next thought, to avoid the facts: It is a new year and I am in mourning.

I was diagnosed with MS on December 12, 1981. I was married on December 27, 1982. I was born on January 12, 1961. These significant dates are clustered around Christmas and New Years—all of them markers. Each date is an opportunity to look at where I am, where I was a year ago and what I've lost. I do not want to have lost. I rage over the losses, when I allow myself to feel them.

"I gave you my legs—don't you dare take my hands," I scream at the disease, as though it was open to negotiation. Believing disease is a demon might be easier. It

would have a personality, a face, a pronounceable name. Instead, I rail against a brew of biological circumstances and their mercilessly impersonal progression.

We went to Hawaii for our Christmas holiday and twentieth wedding anniversary. It was in Hawaii that I first identified the difficulty catheterizing (though I'd been experiencing it for a couple months). Travel is not easy for me. Each time I take an airplane, I vow never to do it again. The airlines have it all figured out, in theory, but the reality is exhausting. For the trip to Hawaii, we "gate checked" my electric scooter so I could take it to the door of the plane. Because my walker would not fit in the airplane aisle, I clung to the seat backs as I walked to my seat. We try to sit near the front of the plane, but they often reassign us. On our return flight, I "gave up" and let the flight attendant help me to the restroom with the airline's "aisle wheelchair". It was so much easier for me that I promised myself I would use it next time—even to get to my seat. As always, I wage internal wars between my own and others' convenience.

Returned from Hawaii, I expected to write about surfers slithering through the curve of the waves, little children squatting next to Koi ponds. I wanted to tell delightful stories of tourists walking down the street with video cameras whirring in front of their eyes, of eating mahi-mahi steaks beside a sunset beach, watching Polynesian dancers swaying in the gentle rain, wandering over Plumeria-carpeted tropical grass next to shining waterfalls. Those pieces of paradise *were* part of my vacation.

I wrote just such a paragraph. And then I stopped writing.

The next paragraph might have been about my struggles dealing with the not-very-accessible bathroom in the hotel where I often had to have help to stand up from the toilet. I might have described the exhausting transfers from scooter to rental car that climaxed with me looking down to see my foot in a pool of blood generated by a scrape my toes were too numb to feel. I might have whined about my exclusion from visiting the rotating restaurant in Waikiki or the historical sites of Hawaii because of stair step entrances. I was lucky enough to go to Hawaii. How can I feel anything but gratitude?

"Everyone loves a cheerful cripple," I wrote in my journal during my second exacerbation. "Well, sorry folks, but those cripples we see on TV are an illusion. The cheeriness is a thin veneer that has to wear off sometimes. There has to be someone to whom you can say, 'I'm terrified. I'm tired and I want to give up.' But there isn't. In the

ten minutes it takes me to stand up in the mornings, I philosophize: ‘One day at a time, one step at a time, somehow I’ll make it through.’ So far I have, but every day the steps seem higher and there are more times I wonder if I’ll topple over.”

The ancient Greeks told a story about Philoctetes. Pricked by a poisoned arrow, he whined continuously about his wound. His brave companions could not abide his complaints and stranded him on an island. That story reflects my fears: if I say too much about my real life, you will abandon me. Practicing to hide my grief from you, I become expert at hiding it from myself. It becomes a heavier and heavier weight until I finally remember to release it.

“About once a month,” I told the members of a support group for people with chronic illness, “I have to fall apart completely. I have to cry and rage and whine.” Looking around the room, I saw gleams in people’s eyes. The idea of letting themselves go, of giving in to the burden of illness, was lustrously attractive. We so seldom give ourselves the permission. For those of us dealing with chronic conditions it is a psychic necessity.

Looking out the window of our twelfth story room in Kauai, my eyes traced paved routes toward the water. All ended in drifts of dry sand. “What good is a vacation by the sea if you can’t reach the sea?” I pondered. Repulsed with the idea of being a spectator to life, I vowed to get to the ocean. I plotted a course with the least dry sand. At the end of the sidewalk, I revved my scooter into the dune. Ralph pushed the scooter from behind. Out onto the packed sand at the edge of the ocean, I could drive the scooter easily. When I stopped the motor, though, I could feel the scooter start to sink a bit. But I still had not touched the water. I bent over to put my fingers in it. My weight pushed one side of the scooter into the wet sand. The scooter tipped over and I with it. A wave came up and washed over both of us. I sat sideways in the sand laughing as saltwater filled my mouth. Tanning tourists ran to help Ralph get us upright and back onto pavement. Like a comic book villain, I was dry and clean on my left side, wet and sand-covered on the right. “Let’s clean the scooter off here,” Ralph suggested, brushing sand off the metal parts. He stripped the scooter carpet free of its Velcro fastenings and handed it to Alexis, then five years old. “Can you wash Mommy’s carpet in the ocean?” he asked. She could. Knowing that the waves come in and out, Alexis threw the carpet

into the ocean. We never saw it again. I picture it sunning itself on a beach in Fiji next to a glass with a paper parasol in it.

That adventure is one of the highlights of my vacation. It teaches me that engagement in life comes with risk. It reminds me that I have choices. Wisdom is found in experiencing sunset-washed beaches and bloody feet. Too often, caught by my ambition to be inspirational, clenched around my determination not to be a burden, I smile and move on. I dodge the grief. Denying myself permission to fully experience the costs of chronic illness, I find instead that I have refused its gifts.