

FICTION | SPRING 2014

## Caretaking

By Emily Lackey

"Marie," my supervisor had told me a few nights before, "is fifty-seven years old and dying." I was seventeen and a Hospice volunteer for the Visiting Nurses Association and Hospice of Northern Berkshire. Every one of my patients was dying, and Marie was no different. She was fifty-seven with multiple sclerosis, a disease I knew very little about, but it wasn't my job to understand her illness. My job was to relieve the caretakers, to sit with my patients while their loved ones ran errands or went for a run or found reprieve at the corner of a bar, drinking long-necked bottles of beer and contemplating the love they were losing, the grief they were enduring, and the guilt they were feeling when they found themselves looking forward to the time when it would all be over.

I found Marie's house sitting on the side of the mountain like a shelf. It was small, a single-story ranch with no other houses around it. I couldn't see what was around the house, but I imagined there were woods: tall spruces, bare maples, and heavy-limbed firs bearing the small house between their roots.

Marie was my third Hospice patient in as many weeks. I had visited a woman with Alzheimer's at the nursing home next to my high school, and a woman with cancer in her house across the street from the grocery store my mother shopped at every Sunday. Marie, however, lived in the middle of nowhere I had ever been, and I thought for a moment, as I knocked on the door and waited for it to open, how far I would have travel to find a neighbor, how long it would take for help to arrive.

"Hello," I said brightly when Marie's husband answered the door. "I'm your Hospice volunteer." He seemed confused by the smile on my pink-cheeked face, startled by how much I lived and breathed.

"I'm only going to be a few hours," he said, stepping aside and ushering me in. He was short and wizened, his hair graying. He wore a flannel shirt, a Cabela's cap, and a pair of well-worn work boots. Inside the house was little light: a yellow bulb over the stove, a tube of fluorescent white over the sink, and in the dark living room where Marie sat, a glow from the changing scenes on the small television set. "I gave her all the meds she needs for the night, so she should be fine. She might even sleep until I get home." He picked up his keys from the kitchen counter. He seemed slightly skeptical that I was up to the job and simultaneously anxious to get out. "A friend of mine is in a band," he said, as if making an excuse. He slid his hands into his tight jean pockets. "You can reach me on the bar phone if you need to, but she should be fine. She just watches TV." I looked toward the living room where Marie sat in her electric wheelchair, silent, her back to us, her seat tilted to relieve the pressure on her hips. If you looked quickly, it looked like she was in a recliner, kicked back and enjoying her evening shows.

"I'm going to go now, Marie," he called to her. He looked at me and smiled flatly, then slid out the door. I set my things on the counter and looked around the kitchen. It looked like

something from the 70's: brown floral wallpaper, an orange stove, a matching refrigerator covered in appointment cards, linoleum countertops, and fake tile flooring that was peeling in the corners. Some squares were missing entirely, and the plywood floor showed through, black from dirt and wear. There was a tray of plastic pill bottles on top of the microwave and a sink full of dirty dishes. The stove was splattered with orange sauce and circles of grease. The house smelled stale, like a mixture of all the meals Marie's husband had prepared for himself over the last few months—microwave dinners, spaghetti lunches, baked beans for breakfast—and something else, something old and untouched in the corners, hiding behind the curio cabinet and the stand that held the television. It smelled like something that had soured some time ago, something aged and organic like a rotting shoreline.

"Marie?" I called quietly. There was a daybed against one wall, a television set in the corner, and Marie in the middle. There was a curtained window high on the wall, but otherwise the wood-paneled room was empty.

"Marie?" I called again. I came around Marie's chair to face her. She was sleeping. Her head fell to one side, her arms slack. Her legs, all skin and bone and no muscle, were covered with a pink afghan. I looked around the room for a lamp or overhead light to turn on, but there were none that I could find. Every source of light that was available was on: the light above the stove, the light above the sink, and, now that I was in the living room and could see it, a small oil lamp in the back corner of the room that burned a dim circle of light around its base. I considered all the rooms in Marie's house that I hadn't seen, all the dark corners that I hadn't checked to make sure were clear. I sat next to Marie while she slept and tried to distract myself with the old black and white movie playing on the television set.

A few months before I had begun training with Hospice, I had sat up in the middle of the night, legs crossed, arms folded around me like a coat, and had thought, *My god. I am going to die.* I had been watching a movie when it struck me, my room dark except for the glow from the television. I felt the realization flood through my spine: I—my brain, my body, my consciousness—would one day be nothing. It felt standing on the edge of a cliff, knowing one day you would eventually have to jump.

Gradually I learned that the best solution to my anxiety was the presence of someone else. The only nights I was spared were the nights I slept over at a friend's house or the nights I left my bedroom door open so I could watch my mother moving around our quiet house late into the night, paying bills, straightening the couch cushions, wiping down the kitchen counters.

It was after this that my friend asked me if I wanted to volunteer for Hospice, and I saw it as an opportunity to face my fears. I imagined that if I saw what I was so afraid of, if I sat beside it and held its hand, I would gain some insight that would relieve my fears. If I could help people through what I was most terrified of, I rationalized, maybe I wouldn't be so terrified.

Marie moved beside me. She turned her head away from me and moaned quietly. She stayed still for a moment, and I hoped that she wouldn't wake up, that she would sleep through my entire visit. It was like watching an infant sleep, wishing for more respite before they stir, rub their eyes awake, and start crying for food.

Marie moved in her chair again, turning her face back to me. Her eyes fluttered open and her brow furrowed. She looked at me.

"Hi Marie," I said. "My name is Emily. I'm your Hospice volunteer." She moaned.

"I'll be sitting with you tonight while your husband is out. Is there anything I can get for you?"

She moaned again, this time trying to raise her arm and point, but her finger moved wearily between the television and her knee.

"Do you want me to change the channel?" I asked. She moaned in response. I stood up from my chair and went to the television. Two antennae stuck out of the back, searching for a signal, and the picture wobbled when I came near it. I flipped through the channels until I found the news.

"Is this what you want to watch, Marie?" She turned her head away and moaned. I turned the channel again and stopped on a late night crime drama.

"Better?" I asked. She moaned louder, her chest and stomach pushing out from the effort. I flipped through the channels again and found an episode of *The Three Stooges*.

"This might be our best bet." I sat back down in the chair beside Marie, and she turned her head, moaning louder and longer this time. It seemed desperate, like an expression of something deep and restless inside her.

"Marie," I tried. "Can you tell me what you need?"

I had learned in training that we revert to infancy in death, that we become helpless and demanding like babies, needing to be fed, needing to be wiped, needing to be shushed to sleep. I thought of this as I watched Marie. I did what little I could to comfort her.

"Marie, I'm going to lift your head a little bit," I said. I knelt down beside her and squinted in the dim light to see the buttons on her armrest. I tried one and it lowered her body until she was almost flat. Marie moaned even louder.

"Oh god, I'm sorry," I said. I tried the button next to it. It raised Marie's body into a seated position, but as she approached upright, her moaning became panicked, her head close to falling forward.

"I'm sorry," I said. "Shit, I'm so sorry." I pressed the first button until she was in the position she had been in when I arrived.

Marie kept moaning.

I took a pillow from the daybed and moved it to her legs, lifting her bony knees to slide the pillow underneath her. Marie turned her head away from me and moaned even louder. Her moans were louder than the television, louder than the *yoink*, *bop*, *zing* of the stooges. They were louder than the kitchen clock, tick tocking like a reckoning. She curled her hands into weak fists and banged them on the armrests.

I left Marie in the living room and walked through the darkly lit kitchen toward the hallway, feeling along the wall for a light. When I couldn't find one, I moved toward the bathroom blindly, my hands outstretched, my eyes open wide, waiting for my eyes to adjust to the limited light. When I felt the floor change, the plush carpet turn to tile, I made out the dark silhouette of a sink and the rounded promise of light bulbs. I felt underneath them for a switch, and the room erupted in white light, the mirror lit on either side like a vanity. I blinked quickly, my pupils contracting in the sudden light. I could hear Marie moaning in the living room.

The bathroom was gutted. The drywall and insulation had been ripped out so that the only thing holding the room together was the original frame—a renovation project that must have been interrupted indefinitely when Marie got sick. Copper pipes and colorful electric wires lined the walls like a maze. A woman's shower cap, soap stained and dry, hung from a shutoff valve above the toilet.

"Don't cry," I told myself. "Don't be such a baby."

But that only made it worse. I started to cry. I stood in that empty bathroom and cried for Marie and for myself, for how utterly helpless we both were against her pain, against death.

I had imagined that volunteering for Hospice would give me an insight into death that would be comforting, like a river I could wade across and poke around on the other shore. If I got close enough to it, I thought, if I stood among its reeds, its murky water, I might be able to understand what I was so afraid of, or at least be able to steel myself against it. But what I didn't understand was that the distance between Marie and me was as wide and unfathomable as an ocean. We were as far apart as continents, and the shoreline she was standing on was nothing like the soft-sanded beach I had imagined: it was brutal, rough, unrelenting, and cruel.

I went back to the living room and sat next to Marie. I watched her twist her head from side to side and listened to her moans, deep and incessant. She looked as if she were fighting something within her, fighting her failing body, fighting the high water mark of her disease inching its way up her body. Eventually it would take all of her. Eventually—in a few days or a few weeks, when she no longer had a way of expressing how awful this was, how terrible and terrifying—she would be still.

When I was young—maybe four or five—and had a nightmare, I would go to my mother's room and wake her.

"I had a bad dream," I would say, standing beside her bed, shivering in my nightshirt. "Oh, sweetie. It's okay," she would say, half asleep. "Just think of something nice."

In my room, I'd get back into bed, close my eyes, and picture something nice: bunnies hopping through a field in the middle of a forest. But the distraction never lasted. Eventually the bunnies would disappear into the trees, and the characters from my nightmare would creep into the field, men with guns crouching menacingly in the tall grass. I'd return to my mother's room.

"It's not working," I'd tell her. "I'm still scared." She'd follow me into my room then, ducking under the eaves to sit beside me on my bed. I don't remember her saying anything—maybe she shushed me like she did when I was a baby, mimicking the soft sounds of her womb until I was calm—but what I do remember is how she would rub my back: the weight and warmth of her hand tracing slow circles on my body until my skin was buzzing and I was fast asleep. Knowing that she was beside me, feeling her there, was all I needed to feel safe, to be still.

Marie turned toward me and moaned. I moved my chair closer to hers. I took her hand and held it on the armrest of her wheelchair. In the flashing light of the television, I held her hand in mine and traced small circles on her skin, moving my thumb softly over the sensitive spot between her thumb and forefinger so she could feel me there, so she would know I was beside her.

I don't remember anything after that—not Marie's husband coming home, not what I said when I left, not finding my way off that mountain and home—but what I do remember is how Marie stilled when I touched her, turning away from me and burying her face in her headrest. We sat for the rest of the night like that, a woman and a young girl from opposite shores, reaching toward each other, neither of us knowing how to stop any of this.

Emily Lackey is an MFA student at the University of New Hampshire. She is currently working on a collection of short stories set in Okinawa, Japan.

© 2015 Intima: A Journal of Narrative Medicine