

## **The Right Room**

**By Amber Herrick**

Every time my Mother has a stroke, she wakes up a completely different person. This is okay because, as my Dad once observed, we've liked every person she's been. Our health care journey started four years ago when, at five in the morning, Mom began violently tossing and turning in her bed and my panicked father called 911. By the dawn, we'd been informed she'd suffered a severe ischemic stroke. The coming months and years would bring smaller but still devastating strokes, like the aftershocks of a cataclysm.

My mother, orphaned survivor of unimaginable escapades, possessor of a childhood only Charles Dickens could have dreamed up, had met a monster she couldn't defeat. Her body is paralyzed on her left side, her left arm curled and almost useless. Her mind is a wonder; damaged only in places, she can remember the names of people she hasn't seen in twenty years but usually doesn't know what month it is. It's as if a bolt of lightning scorched across a grassy meadow, carving a singed trail in its path but leaving the rest of the greenery untouched. She searches for words that are no longer there, pausing in her slow speech and looking around as if the words might have been seen laying on floor nearby.

When I was a kid, she used to ask, beg really, about something. "Whatever you do," she would say, "please don't leave me alone in a nursing home." It is one thing to make someone a promise when they're well, another to follow through on that promise when they can't move half their body. My Dad, my sister and I put ourselves through caregiver training at a rehabilitation center, trying to make sure our care would be safe and beneficial to Mom. We asked advice from everybody; nurses, dieticians, facility directors, doctors, relatives, other caregivers, everybody. The best advice came from a cousin whose own ninety-year old mother is constantly in the hospital. "Check *everything*," he told me. "If something doesn't seem right, insist on getting answers. Don't just trust that because you're in a top hospital, mistakes won't happen. They will happen." He was right. Each time Mom was transferred to a different wing or facility (a total of five times), I checked medication charts to make sure her information was correct. A potentially catastrophic omission was caught during one of her transfers (crucial instructions about treatment

length), and we had to politely but firmly ensure Mom stayed hydrated and properly fed (she's a diabetic). We had fabulous nurses and some truly kind doctors (one resident even bought me lunch), and the hospital itself was expertly run. But the volume of people coming in and out, the chaos of the situation, the precariousness of Mom's health, all of that left large room for error.

Not all error is preventable or foreseeable. My Dad and I made a pact: No matter what happened, we would not blame each other. We all had Mom's best interests at heart, and we were flying blind. If we made a bad choice, if we forgot to do something or didn't know to do it in the first place, we would not blame each other. When I told a co-worker about the pact, her eyes filled with tears. "If my husband and I had done that when our daughter was sick," she said, "we'd still be married." Fights over medical decisions had derailed their lives.

In the three months Mother was in the hospital and then in rehab, she did not stay alone in her room for a single night. A family member was with her every evening, but this meant that we were in a constant state of exhaustion. It's hard to understand details of services, policies and programs when you can barely keep your eyes open. After three years we applied for and were able to get Mom into Oregon's Independent Choices Program (ICP). To call it invaluable would be a gross understatement. The criteria to qualify is narrow, but it allows the extremely disabled to hire their own caregivers on their own terms. My Dad is able to care for her day and night without worrying about money, and the state is saved the much higher price of a nursing home. Not everyone has family able and willing to give them sophisticated care, but the ICP allows our elders to choose who will assist them and allows it to be family members or spouses if the screening standards are met.

Even the best-designed program cannot fill every need. So much depends on the caregiver. The trouble with many a person's approach to caregiving is that they try to fold in the care with their current life. That won't work. You may be able to force the two existences to mesh, but you will pay a terrible price in stress. I've seen women trying to go about their normal lives with Mom in tow, and I've seen the stress lines etched deep into their faces as they snap at Mom. When you commit to full-time caregiving for a relative with a large need, you have to let things go; hobbies, pastimes, interests, passions. Streamlining your life will lighten the stress load tremendously. My Mom, who never missed a chance to make me chicken soup when I was sick, who stood up to every bully, who tried to give me any advantage or happiness it was hers to

give, who fought every battle that was hers to fight and even some that weren't, deserves to have the best care we can give her. It takes all three of us to make her safe, clean and comfortable but we are more than willing to do it.

As mentioned at the outset, after each stroke her personality changes. Two strokes ago she suddenly developed an absolute passion for westerns. She will beg with piteous, trembling entreaty to be allowed to watch just one more episode of *Gunsmoke*. This from a woman who hated all television when I was a kid and westerns in particular. She is sassier, feistier, and much more fond of coffee. And that is okay.

Shortly after the major stroke, a neurologist came to examine her. "When I saw your Mom's brain scans, I expected someone in a vegetative state," he told me. "She has so much damage. When I came in and saw her talking and laughing, I thought 'I have the wrong room'." He had the right room. We saw people far younger (and fitter) than Mother, people with less injury, make less recovery. Medical care is crucial, of course, but the attention and love of friends and family no less so.

It's been four years since that massive stroke, and every day could be her last one. Her faith and her family has helped her progress, but it has also given her peace about the fragility of her situation. "If I'm going out the door," she told me one day while holding my hand, "just let the door close." I can only hope to face my last years with as much courage, and surrounded by as much love.