

## **The Story of How I Became a Caregiver**

### **By Kathryn Adams**

I got the call late in the evening—even in California, it was about 10 p.m. My dad in Minnesota said, “Kate, it’s bad.” Turned out, my mother had fallen and broken her hip, on the *damned* (as I would now call it) stoop coming into the house.

My mother was 83, but nearly 20 years with Parkinson’s disease made her increasingly frail. Although she had already fallen a few times, each time she’d been “okay.” Before this night, she still walked and managed independently, but required quite a bit of help with daily tasks from my dad, especially medication management.

Unless you know someone with Parkinson’s, you may not realize what a cruel mistress it can be. Meds are needed multiple times a day at regular intervals to fend off symptoms such as stiffness, tremors, weeping, fatigue, and confusion. Yet when the meds are at their peak effective dose, older people like my mom can experience a different kind of confusion, like mild psychosis, complete with imaginary people, strange delusions, and restless agitation.

As a geriatric social worker, I had known she needed more assistance than she was getting and that she was at risk for a worse fall. In fact, I’d been working for over two years to convince my parents to consider a cross-country move—away from the Minnesota winters. My mom was completely amenable to this plan. But it had been a long, difficult decision for my dad to give up his house and all it represented. He tends toward the dramatic and more than once said, “If I leave that place, I’ll die!” However, facing another winter ahead, he had finally put it on the market.

After he told me the story of the fall, the ambulance, the X-rays, and the plans for surgery in the morning, he mentioned that there was another bit of news: he had gotten the first offer on the house that same day. And I could only think: *I should have gotten her out of that house sooner.*

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The community hospital barely kept her three days. She was discharged on a Saturday around dinnertime, under the influence of strong pain relievers. We found her at the nursing and rehabilitation facility in a large private room with linoleum floor and cinder block walls, empty except for an older metal hospital bed, bedside table, flat screen TV, and large recliner chair.

A kindly RN named Paul greeted my dad and me while he took Mom’s medical history and examined her body for any bruises and scars, noting them on his clipboard. While we talked, one discouraging thing after another came to light. First, there was no walker for Mom available till Monday when the Physical Therapy department could see her and evaluate her for one. She would be transferred by wheelchair to the bathroom.

Second, as we discussed the importance of administering the Parkinson's medication in a timely way with Paul, he pointed to his paperwork and said, "I show here that she gets that once a day." I took a deep breath and said that was not right; it was four times per day—a fact that had to be established via phone with the hospital before the order could be changed.

Third, my dad focused on the bed. Unlike at the hospital, the bed here had no side rails, and the floor beneath was shiny and hard, not carpeted. My mother lay without anything to prevent falling or accidentally climbing out of bed on either side. We learned that bed rails had to be ordered and that maintenance could put them on, once ordered, but no sooner than Monday.

Though in reasonably good health, Dad was very tired on Day 4 of this ordeal, his 86-year-old shrunken frame looking smaller than ever. Our mutual sense of frustration and impotence was palpable. He began to speak very loudly, "She will FALL OUT! This can NOT stay this way!!" As I tried to smooth things over with some suggested alternatives, he became even more angry and loud. "Shut up and STOP interfering!" he yelled.

I'd been in Minnesota less than two days, rushing in with all my good knowledge and intentions, but I was also tired. To my embarrassment, tears began to stream down my face. Even though my geriatric social work background gave me many tools to understand his behavior and know it was not personal, my father made me cry.

Meanwhile, my mom was coming out of her painkiller fog. There she lay, half exposed, in a strange room, hearing voices raised and seeing my tears. At that moment she said to me, her voice pleading, "Can't you try and be someone else right now?"

I took my hurt feelings and my seemingly useless professional expertise out of the room for a bit and let them work something out. In the end, Paul was willing to move the bed up against one wall and to move the bedside table and wheelchair with its brakes up to the non-wall side to provide a makeshift barrier to keep her secure.

Mom had missed dinner, but when I returned, she was eating soup and crackers propped up in her bed. As I stood by, she said to me quietly, "I'm sorry. No one deserves to be talked to like that." I told her it was okay, trying not to cry all over again.

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Three months later, my mother is in a different nursing home. She forgets that she cannot walk, but the floors are carpeted, her bed goes very low to protect her, and she is supervised throughout her day. The aides, nurses, dietary staff, social workers, and therapists are kind to her there. It seems clear that Parkinson's disease is having its way with my mother, but she continues to appreciate small pleasures. She eats with gusto and is usually cheerful, thanks in part to medication adjustments, a regular schedule, and excellent care.

Mom tells me that the nursing home is a school. She knows the aides are helpers but assures me they are also students and she is a professor there. And sometimes, in a whisper, she describes her wild romantic drama with one of the male aides. He wants to marry her, or perhaps “be with” her, but she must choose loyalty to my father.

Luckily, Dad has chosen to be with her, too. After selling the house, he moved into an Assisted Living apartment in the same facility and spends much of each day with her.

In between my frequent trips to see them, every phone call fills me with anxiety. I offer support, manage finances, and make decisions, but I often defer to the good judgment of the nursing home staff. On the other hand, I am not shy about asking for anything I think is a reasonable request. And I try to make sure staff members deal with my father directly about issues concerning him, since their chances of enlisting his cooperation may be better than mine.

I’m learning the elaborate dance for the long-distance caregiver: Advocate ... listen. Keep in touch ... stay detached. Get involved ... hang back. Care for them ... care for yourself. Love them. Do your best.