

Caring for Mother
A Daughter's Long Goodbye

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An Opening Note to the Reader

I had never seen the logic in asking “Why me?” when some calamity befell me. Couldn’t one just as reasonably ask “Why not me?” But when my mother developed Parkinson’s disease and began to show signs of dementia, I found myself asking on her behalf, “Why her?” If ever a person did not deserve such a fate, it was my mother. She was a good, generous, funny, loving person who had already suffered a number of tribulations in her life. But deserving has little to do with disease. Like the rain, it falls on the just and the unjust. And, as suddenly as a summer thunderstorm, my mother’s care fell to me.

In this country, millions of people, most of them women, are living through similar experiences right now. And, except for the occasional PBS special on aging or Alzheimer’s, little notice is taken of such a pervasive and well-nigh inevitable human experience. Paul Hogue, director of Harvard’s Generations Policy Program, at the 2005 White House Conference on Aging and Policy Committee, provided Congress with the following statistics:

The first of the baby boomers are celebrating their sixtieth birthdays this year (2006).

By 2030, the number of elderly people in this country will double.

At present, the eighty-five and older population is the fastest-growing segment of the older population.

In 2000 there was twenty-six times the number of people eight-five and older than there was in 1900.

Women will predominate among the elderly, especially among the oldest old. Most of these women will be widows.

These numbers remain abstractions, however, until, usually quite suddenly and with little time to reflect, one becomes the caregiver for an ill and aging parent. My own decision to return to my family home to help my eighty-year-old father care for my mother was more of a reflex than a decision. This is the way most adult children, no longer young themselves, fall into the role of caregiver. Yet no other alteration in life circumstances, with the possible exceptions of marriage or incarceration, changes one's life so drastically.

For me, the move meant geographic dislocation and career disruption. Worse, I had to witness the slow and painful disintegration of the woman who had been, all my life, my model and mentor. No other event during my sixty years shook my faith so deeply.

This book covers the year and a half my father and I cared for my mother at home until her dementia became so severe that keeping her at home was no longer safe for either of my parents. This section includes the difficulty of dealing with a dozen different doctors and the narrowing search for any remedy that might lessen my mother's suffering.

The following five years she spent in that place children and spouses often swear they will never resort to—a nursing home. Since I spent several hours almost every day there, I had ample opportunity to observe and record the special conditions that create the “nursing home culture.”

During those years I kept a rough journal, mostly to track doctors' appointments and medications for both my parents. I noted responses to drugs, behavior patterns, and, gradually, I began putting down my own reactions in order to keep from going crazy myself. Eventually I began to structure those notes into a narrative, hoping to find some sense that could be made from what often seemed a chaotic welter.

This is not a self-help book for caregivers. What I hope this book provides is a clear and realistic account of caring for an elderly loved one when the caregiver is nearing the elderly category herself. Also, in consequence, it raises awareness of the spiritual challenges encountered on this path, not least of which

are the fears about one's own future disintegration. I consider my experience to be fairly typical, neither the worst-case scenario nor the sunniest outcome. I make a few practical suggestions, but my main intention is to throw light on a rather dark and unexamined corner of our society.

People who are just starting down this path of caregiving might be overwhelmed by reading the book. Others who have put in a few months or years, however, may find comfort in seeing their own experience reflected here. They may also find the questions they have feared to ask or acknowledge formulated for them. C. S. Lewis is reported to have said that we read in order to know we're not alone. In addition, the book may help those foreseeing their own stint at caregiving loom-ing ahead. If this book helps them to anticipate and thus fore-stall a few of the emotional ambushes along the way, so much the better.

I give as clear an account as I can muster of what dementia looks like and how it affects those who live alongside it. This is not a cheerful book, but it is truthful. It brings to the surface of our busy, active lives a question we usually keep submerged—until some circumstance drags it up and into the light. The question scares us, but dementia forces us to ponder the matter: what makes a being human?

Is it memory, the capacity to reason, volition? When all these are taken away, what are you left with?

Of course, the more immediate and pressing question for a dementia-companion is, How can I live with this person? How can I survive the madness?

During the almost seven years I spent with my mother's dementia, it often seemed as if she were trapped under the rubble of an earthquake, her rationality, curiosity, humor, and generous spirit slowly suffocating under the wreckage of her ruined brain.

All I could do was squat beside the avalanche, listening for any sign of life; sometimes I could hear a faint but familiar echo of her voice or gesture from under the heap. I would grow frantic trying to reach her; how could I let her know she was still

loved, still valued? Most of all, I was desperate to reassure her that she was not abandoned there under the rubble.

My mother's dementia was, in the beginning, stroke-related. Later, Alzheimer's was added to her diagnosis, though after a while finding the precise category to put her in had ceased to matter. After a certain point, all dementia begins to look alike.

Nothing had ever confronted so forcefully my faith that an ultimate graciousness dwelt at the heart of the world and cared for us. Watching my mother's mind erode bit by bit challenged my notion of what a human being is.

I have not solved that problem or answered the questions in this book. No mere words can do that. Some questions are so big they can only be lived with, lived in, lived through. What I offer here is a sense of how those questions come and, I hope, a means of clarifying them, a way of putting them into words. Though the words are inevitably inadequate, they are at least markers on the path through this barren landscape. You will know someone has been here before you.

My highest hope, however, is that, while these words will not lessen the anxiety or alleviate the anguish, they will brace you for your own hard vigil. Do what you can to comfort with your presence when there is nothing else to be done. Like earthquake survivors waiting near those trapped in the debris, simply stay.

At the Back of the Book

It all started with a phone call.

I usually phoned my mother in Texas a couple of times a week. She was nearing eighty and had been diagnosed with Parkinson's disease the previous year.

"How are you doing?" I would always begin.

"Fine," was her equally routine response. She had always been in good health, always taken care to eat well, exercised regularly, stayed active and engaged. My mother had never been one to complain. She bears up. She manages. She rarely took sick leave during her long working career.

But today she says, "Not so good," in answer to my standard opener.

My grip on the phone instantly tightens. "Oh? What's wrong?"

"I fell."

"Fell?" I repeat. Six months earlier, she had tumbled onto the carpet while bending to make her bed. When her right shoulder hit the carpet, her clavicle snapped in two. The bone had taken all summer to heal and caused her a good bit of pain. For Parkinson's patients, falls are a constant threat, and my mother's osteoporosis compounded the danger.

My own voice is edgy as my questions tumble over one another. "Did you hurt yourself? What happened? Did you go to the doctor?"

"Yes, I went to the doctor," she says testily, as if I hadn't credited her with good sense. "I didn't break anything. They took those—what do you call them? Pictures . . . x-rays. But it's very painful. He said I had bad bruises inside."

I stop myself from pointing out that you can't see bruises on an x-ray. "When was this?"

"Oh, I don't know." Impatient now. "Wednesday maybe. I didn't go for a couple of days. I can still hardly breathe." She sounds suddenly on the brink of tears.

"Why didn't you let me know?"

"Well, there wasn't anything you could do about it, was there? And they didn't keep me in the hospital."

My mind is racing, recording and assessing every nuance, every modulation of tone. Wednesday? Today's only Thursday. "When did you say you went to the doctor?"

"It was after that . . . sometime . . . not right away. I thought I'd be all right at first."

She sounds uncertain about the time, and I consider asking to speak to my father. But he is so drastically deaf he couldn't hear me. I take a deep breath. "Well, I think I probably need to come home, Mother."

"No, no. You don't need to do that. I'm okay now." Still, I can hear uncertainty seeping into her protest.

"I just want to see for myself. Check up on you." I say this lightly, trying to sound as if I'm joking with her. We often play this game—me acting the officious schoolmarm.

But her voice remains stiff, refusing to play her part, as she says, "That'll be fine." Letting me know this is no laughing matter, that when you're seventy-eight with bones that snap like dry twigs, falls are no joke.

The year my mother turned seventy, I took her on a long-promised trip to Europe. She wandered through the British Museum, climbed the stairs in the Anne Frank house in

Amsterdam, scanned the slopes above Salzburg for the dancing figure of Julie Andrews. Through it all, the hunger for such marvels sat naked on her face. I wanted to give this woman the world to which she had first awakened me, the world of art and learning, the one circumstances had denied her.

It was on this trip that the first signs of what turned out to be Parkinson's disease began to manifest themselves, though I failed to recognize them as such. She would hesitate as the subway doors slid open. "Come on, jump!" I'd urge, taking her elbow. I called her slowpoke. Years later, after we discovered how the disease had stifled her muscles' response, I felt rotten about this. But at the time, I was only frustrated that her movements, always swift and sure before, whether at the typewriter or cutting board, were growing awkward and hesitant.

We put it down to age at first. Then last year my husband, whose stepmother had died with Parkinson's, pointed out the way my mother turned.

"Did you notice?" he asked after my parents had come to dinner at our house. "When she turns, she moves her feet in these tiny, jerking steps like the second hand on a clock."

He stood up to demonstrate. "That's just how Ruth moved."

I saw it at once. The Parkinsonian gait is distinctive from a normal elderly shuffle. The previous summer I had taken her for a series of tests at a medical center in Houston to have her growing difficulties diagnosed. All the doctors had studied the computer printouts and declared nothing was wrong, except maybe a touch of arthritis.

Yet even after David's observation, I was reluctant to name my mother's affliction for her. She had a brother-in-law with the disease; already he was bedfast, incontinent, and his speech incomprehensible.

Instead, I scouted out a neurologist who held a weekly clinic in my parents' hometown and encouraged her to consult him, even threatened to make the appointment myself if she didn't. All through the fall and winter she dallied. Then, a few weeks before she knew I'd be coming home for spring break, she called me one morning.

"I've been to that doctor you wanted me to see," she said.

"And?"

"I've got Parkinson's." She paused, and, when she spoke again, I could hear her voice lift with determination. "I'm all right though. I'm doing fine. The Lord is going to see me through this."

I told her how sorry I was to hear the diagnosis and assured her I would be home again soon. Still, I expected nothing less than the courage she had always shown.

David and I had already begun discussing in a haphazard way what the future might hold. I was vexed with myself for not having already pushed my parents to make alterations to their home—wheelchair-wide doors, a handicapped bathroom. But to make those suggestions might sound defeatist now, I worried, as if we were rushing her into invalidism.

These discussions with my husband thus produced little more than speculation and fretting. The situation seemed too open-ended for strategizing. My mother's condition could hold steady for years yet. My father could have a heart attack tomorrow. Each scenario called for a different solution. How, after all, was it possible to plan?

I had satisfied myself, instead, by accumulating information about Parkinson's. Fact-finding is my customary mode of coping, the way I convince myself that control, if not easy, is nevertheless possible. I reread *The Man Who Mistook His Wife for a Hat* by my favorite literary neurologist, Oliver Sacks. I ordered *The Parkinson's Handbook* from the National Parkinson Foundation. But as the editors themselves admitted on the last of its twenty-four pages, the booklet was merely an attempt to summarize. "Not all the facts about the disease are presented, nor are the problems discussed fully." Something, I was to discover, of an understatement.

My younger daughter hunted down several back issues of a Parkinson newsletter published by a group in Kansas City. It was heavy with articles like "Exercise, Go for It!" and "The Caregiver's Bill of Rights." Ordinarily, I spurn the self-help genre, but now I scavenged for facts from articles like "Top Ten

Ways to Live with Parkinson's," which admonished patients to "eat well," "get some sleep," and "stay informed."

Immediately after her diagnosis, my mother had also begun collecting books with Parkinson's in the titles. These usually contained chapters on the disease's symptoms, most notably tremor, and line drawings illustrating helpful exercises. The last time I had visited, however, I had noticed that these books had disappeared from my mother's coffee table.

"Weren't they helpful?" I asked her.

"Oh," she waved away the question, "they all start off upbeat, you know. How you should just keep going, lead a normal life. But when you get to those chapters in the back of the book," she gave a little shudder, "it's not such a pretty picture."

"Well," I had said then, "we won't worry about that now. We'll cross that bridge when we come to it."

But on this October day as I listened to my mother's jumbled description of her fall that morning, I was recalling that over half of the elderly women who fracture their hips become permanently disabled. Twenty percent die within a year.

But I don't tell her this. Instead, I tell her I love her and that I'll be home that weekend. I put the phone down and pick up my briefcase. At the office I clear my calendar for the following week and glance ahead nervously to the remaining months.

I was afraid that bridge we were going to have to cross was already looming up ahead.

2

Crossing the Bridge

That phone call echoed ominously in my mind during the rest of the day, like the first dislodged pebble that clatters downhill and starts an avalanche.

As I cooked dinner that evening, I called my mother's cousin back in Texas. Margaret and my mother are the same age and grew up together, as close as sisters. They call one another every day. Tucking the phone between my shoulder and ear, I move about the kitchen.

"How's Mother?" I ask as soon as Margaret picks up.

"Oh, dear. You've heard?" Her voice, always pitched high, ascends another notch. "She's not doing too well, honey."

My mother, Margaret says, fell on Monday. She was in one of the extra bedrooms where she keeps her old painting gear and squirrels away gifts for upcoming birthdays and Christmas. She told Margaret she had stumbled over a box, then grabbed for a floor lamp, pulling it over as she fell against the corner of a cedar chest. My father, watching television in the living room, did not hear her fall or her calling to him afterward.

"She says she lay there for fifteen or twenty minutes before he found her," Margaret continues. "She couldn't get up by herself."

Two days later, early Wednesday morning, Margaret came to check on them. She found my mother in bed, obviously in a good deal of pain. She finally talked my mother into going to the doctor. The x-rays showed no broken bones.

"But she's got great big old bruises," Margaret confirms, "all purple and green. The doctor gave her some kind of pills. For pain, I guess."

This worries me. People with Parkinson's have to be wary of mixing medications.

It troubles Margaret too. "She acted a little strange. Said there was someone hiding in the back bedroom and wanted me to go look for them. I asked her who would be hiding there and she said 'the people across the road.' She says she sees them outside at night, packing stuff in boxes. She thinks they're doing something illegal. Drugs or something. And now she thinks they're inside the house."

I slump against the kitchen counter, a knife still in my hand.

"She was whispering all this to me while your dad was out of the room," Margaret continues, "like she didn't want him to know. She said she'd told him about it, but he didn't believe her. I asked her what she thought these people wanted, and she said 'to take away our house.' So I asked her what they would do with her and Lamar. 'They'll just put us out in the woods, I guess,' she said. She wanted me to go back in that far bedroom and look for them."

I find myself fighting a sudden urge to snicker. "So what did you do?"

"I told her I'd go look, but I didn't think there was anyone there. I went back to the bedroom and even got down on my hands and knees to check under the bed—though even a three-year-old couldn't wiggle underneath it, there's so many boxes stuck under there."

I picture Margaret, down on her elbows and knees, poking under the bed for intruders and want to laugh again. "Why, for heaven's sake?"

"I knew she'd ask me if I'd looked under the bed, and I didn't want to lie."

"That's crazy," I protest. "The whole thing was crazy."

"Yes, I guess so. It didn't do any good anyway. When I told her no one was there, she just looked at me like she didn't believe me."

I take a long breath, trying to think. "You say the doctor gave her pain pills?"

"I guess that's what they are. I don't know how many she's taken, or if she's taken any at all. You know how careful she is about mixing her medications."

"Still, that must be it. Maybe there was some kind of interaction with her L-dopa."

Margaret agrees, meaning to be reassuring.

"But wait," I say, suddenly aware of a discrepancy. "When did you say this happened—the people in the back bedroom?"

"Wednesday morning."

"Before she went to the doctor? Then it couldn't have been the pain pills, could it?"

"No, I guess not." She sounds relieved that I've figured this out for myself.

"I'm coming home," I say. "Daddy can't handle this kind of thing."

"I believe you're right, honey," Margaret says, her voice stronger now. "I definitely think you need to come home."

Home was 554 miles away and up a red clay road to the house at the top of the hill, a house built by my grandfather and deeded to me by my parents two decades ago. Now it's the place our children mean when they say they're coming home—for Thanksgiving, Christmas, funerals. My parents' house is nearby.

My dog Tilly leaps out as soon as I reach my house and open the car door. She wades belly-deep through drifted leaves. Inside my house, the air trembles ever so slightly, like water brimming to the lip of a glass. The windows, all facing south on the ground floor, are light-filled eyes looking back at me, watching to see what I will do. Then, because I know they are expecting me before dark, I get back in the car and drive down the road to my folks' house.

Always, when I come home, my mother's face lights up when she first sees me, as though I were a herald of the Second Coming. Always. There would be food on the table, waiting for my arrival, no matter how late. She would have cooked and cleaned all day in preparation, and by now she would be looking out the window every few minutes to see our headlights coming up the lane.

But tonight when I come through the door, for the first time she looks up expressionless from her rocker, then reaches to shift a book slightly on the lamp table beside her, not saying a word. My father rises from his chair, making his customary welcoming noises, but standing back, as usual, for me to greet my mother first.

"Hello, you," I say, and bend down to kiss her. Tilly dashes about the room, then tries to jump in her lap.

"Oh!" My mother cries out.

I speak sharply to the dog, tell her to get down, get away, go lie down.

"Look. Look what she did," my mother says, pointing to an old bruise between the metacarpals, ridged like fan ribs on the back of her hand.

"That spot looks like it's probably been there a while, Mother," I say, making light of it.

"Well, it hurts," she protests in a voice I have seldom heard from her. Then, as if realizing her welcome has not been warm, she adds, "Did you have a good trip?"

I am just beginning to answer when she tells my father she needs to lie down. Avoiding my eyes, he helps her out of her chair and down the hall to their bedroom. I trail behind. She sits on the side of the bed and, as he lifts her feet onto the bed for her, she cries out, "You're hurting me." He still does not look at me.

When he leaves to find her hot water bottle, she pulls up her shirt to show me the bruise on her left side from the fall. Again she tries to describe how the accident happened, her visit to the doctor, the x-rays at the hospital. But the time sequence grows confused and she breaks off.

My father returns and snuggles the hot water bottle against her ribs. Then we leave her to sleep.

In the kitchen, my father, his eyes bent on the dishwater now, tells me in the loud whisper of the hard of hearing, how she sent him up to the attic the previous night, looking for an intruder.

"I explained to her that the doors were all locked," he says. "'How could anyone get in the attic without our knowing about it, honey?' I asked her." He shakes his head. "She said the man came in through the vents in the roof."

I stare at his lips. They are trembling in jerky little twitches.

He sets the plate he has been washing in the drainer. "I don't know how to handle this kind of thing," he says, bracing his arms against the counter. "I probably shouldn't be telling you all this. I feel like I'm ratting on her."

"No, Daddy," I say, putting my hand on his arm. "I need to know."

"It's not *fair*," he cries out, his voice thick with tears, "it's just not fair for her to get like this."

Fair? I don't know what to say. What does he think this is—a bad call from the Cosmic Referee? Nevertheless, I put my arms around him, oddly gratified by his anger on her behalf.

Back at my house I open a can of soup for me and dog food for Tilly. Then I go upstairs and crawl under the electric blanket, turning the control up as high as it will go. I'm shivering.

"I didn't know it was this bad," I say aloud, startling myself with the sound of my own voice in the darkness.

But it would get worse. It was a good thing I didn't know then just how much worse.