
Long-Term Care — Institution, Residence, Hospital, or Home?

by Rachel Reeder

Finding quality long-term nursing care is a growing concern for millions of Americans and their families, especially as the baby-boom generation reaches retirement age. The issue is not money, but the way long-term care is delivered to those who need it. The following story depicts one family's education in the field of long-term care; and is a call to action for everybody facing these tough decisions.

Daddy always looked so young and handsome, but the end for him came quickly.

After he broke his hip, he never really recovered; still he shuffled out to the kitchen every morning and fixed Mama's breakfast — "Carnation Instant Breakfast, it has to be," he said, "and she only likes chocolate." We weren't really concerned about Daddy in those days. It was Mama who worried us — she was constantly falling. Parkinson's Disease had made her balance precarious, her hands tremble, and her speech falter — eventually she didn't talk at all although she knew us and responded to our tears, our songs, and our laughter, as she always had.

When the doctors told Daddy that he had cancer, I thought of quitting my job so that we could keep both him and Mama at home, but that was not an option. The house would not easily accommodate their disabilities; their social security was not sufficient to meet their medical needs, and my working, free lance or outside the home, would have left them without care for long stretches of time. Reluctantly but wisely, we thought, it was time to move them into long-term care, and they agreed — each for the other's sake. We moved them to the nursing home right after Christmas, and on the twelfth day of Christmas, Daddy died.

That was six years ago. My brother, sisters, and I — raucous and rowdy as always — outspoken,

you might say kindly, or opinionated, depending on your encounter with us — took Daddy's place and began to educate the nursing home about Mama's needs. The education that we in turn received about long-term care was as valuable and as painful as any learning experience we have ever had.

As Good as It Gets

The day after Daddy's funeral, we went out to the nursing home to set up Mama's new room. She needed her recliner, a television set, a small refrigerator, and some comfort foods (Little Debbie bars and chocolate pudding). We had to get the telephone installed and the newspaper ordered. A half-size dresser and an even smaller closet were supposed to hold all her clothes. "This place is never going to work; she'll never be happy here," we fumed. We began to fuss among ourselves.

First of all, Mama's powerful reclining chair, her pride and joy and last year's birthday present, was clearly too large. It wouldn't recline in the space she had for it. Second, the room was too dark — Mama was a voracious reader, but her roommate had the window side of the room and insisted on keeping the curtains closed. Two of the seven of us — and especially our social worker sister — had researched the area facilities and assured us that this room was as good as it got. We found that hard to believe.

The next few months were a nightmare. Mama had yet to "qualify" for Medicaid. Daddy's last medical and funeral expenses had to be paid, and the house (already in decline) had to be made livable so that we could keep it insured. We sold the Chrysler Daddy had brought only a few months earlier (against Mother's better judgment), spent down Mama's meager holdings, and bought her a prepaid burial plan. I don't remember how soon we got her a lamp and a new, smaller recliner, nor do I remember how much money we contributed to close out all the unsettled accounts.

I do know one thing, however. Individualizing care is nearly impossible. Even the local newspaper is unable to bend its routine. No amount of pleading could convince its circulation department to mail this one customer, once a week, her choice of metro sections. Sorry, they told me, we make one delivery to this facility, and everyone gets the same metro section, no matter which quadrant of the city he or she comes from.

My memory of this first nursing home was of wide spacious halls leading off from a central nursing command center. The place looked great and sounded wonderful in descriptions given to us by the social worker, administrator, nursing staff, and others. Residents told a different story: from their point of view, call bells went unanswered for long periods (visitors could hear them, too, of course); housekeeping was minimal (e.g., dining tables were often not wiped clean between meals); the food was terrible, and there was little or no nursing assistant staff, especially on the weekends.

We complained to everyone in authority, but we also temporized: Mama simply was not adjusting as she should, her sense of taste was changing as happens when one ages, and she was being unreasonable to expect her daughters to bring her home cooked meals every day. We pleaded, scolded, and complained at length, but the situation did not improve. Finally, one day at lunch time, Kathy grabbed Mama's plate and marched over to the administrator's office. "Just tell me," she asked him, "Would you eat this food?" "No," he said. "I don't think I could." He intervened, but the resulting improvement was negligible.

Mama complained about other things besides food. Suddenly, all our conversations with her were about how upset we were that she was not cooperating with the staff or with us; or how mad she was that we didn't understand what was happening to her. But always, when we talked with staff, we took her view as the right one. We knew that she had suffered losses: her husband, her home, her independence, her ties with the neighborhood. She was especially mad at my sister, who, when we were packing up the house, decided to sell Mama's bed. That, more than anything, told her that this move was irrevocable. (Later, we could tease her: "Don't be mad at me, Mama. P. J.'s the one who sold your bed.")

She could no longer manage simple things like buttering her own bread and cutting her own food. Further, she had "never in [her] life eaten fish, and didn't intend to now." Why couldn't she keep as much of her routine or lifelong habits as possible (e.g., in terms of diet, and schedules for meals and baths)? Staff, she complained, insisted on wheeling

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her into the dining room before she had finished watching "The Young and the Restless." Then, after dinner they left her there, with no way to relax and no one to talk to. Why couldn't she be helped to get the meal "fixed" (i.e., seasoned and buttered) at the table? And staff told us: well, she could, but only if we move her to the "other" dining room, or if you allow us to puree her food. That won't work, we countered. No one in the other dining room was mentally competent or physically able to converse with her; and it would be two or three years at least before the Parkinson's progressed to the extent that she had to eat pureed food. Granted she was a little stubborn, but she also knew that she was being treated as though her physical disabilities had made her incompetent.

Our problem, we realized belatedly was twofold: clearly a “family thing,” and a problem with the facility. Grief and guilt were too evident in our relationship to Mama. Why couldn’t she see that we were, after all, acting for her benefit? Meanwhile the facility administrators insisted on thinking of us not as partners but as an obstacle to their smooth functioning. Our least questions were taken as accusations. Why couldn’t we see that everything they did was for her benefit—and in full compliance with all regulations?

The answer to these questions—and what finally put some ethics into the situation—came by way of Mama’s participation in a “discussion” group led by a trained facilitator. She was invited to join other residents in reflecting on and talking about things that really mattered. They traded stories about who they were and where they had been, and what they needed to find meaning in their new situation. They celebrated birthdays, checked on each other’s health, made holiday table directions, and assisted each other at meals.

Even more, they made friendships that went beyond their assigned roommates, learned to sympathize with one another, and began to take pride in their ability to help newer residents become comfortable in the residence. When we bought Mama a motorized wheelchair so that she could get to and from the dining room on her own (thank God for those wide hallways!), this group (and the physical therapy department) helped her get a “driver’s license,” which she displayed as proudly as she did the pictures of her grandkids.

We were thrilled. Mama stopped telling us only complaints and began talking about her interests. Indeed, she began attending the resident’s council when it met, advocating for herself, and making her own suggestions for improvement (some of which were taken). She and the other residents found out where they could go to make their own case to the administrators—not the staff’s happiest day, perhaps, but a good one for us. She still wanted my sisters to cook and carry her favorite foods (but now they had to make enough to share with Dottie, Nell, and Mr. Y., and as many others as we could accommodate). We began to see the funny side of

life again and to create new family stories to share with Mother’s sisters and each other. The selling of her bed was one such story.

Then, as inexplicably as it had begun, the group ended. No funds were available from any source to continue it or anything like it. And, for reasons unrelated to the canceling of the group, the facility itself began to decline. We noted a new slovenliness in the operation accompanied by belated and haphazard attempts to address some problems. Nevertheless, few residents and their families were prepared for what actually happened: the facility was summarily closed one summer day following a surveyor’s finding of a wrongful death. We were back where we had started.

Not all that we had gained was lost when this facility closed, but each new day brought its share of challenges. Mama’s new “home”—again carefully researched and reputedly the best in our city—was a three-story building with extremely small rooms and narrow hallways. The clinical nursing staff did not know Mama or appreciate her needs. They found it impossible to remember to recharge her wheelchair, and anyway, she was terrified of hitting someone in the narrow halls.

One of her friends from the old place (a younger man who had been disabled following an infection caused by an acupuncture misadventure) followed

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her to this new home, and together they tried to make the best of a bad situation. The administrative staff was not pleased when Mr. Y requested to eat in the same dining room as Mama.

The first facility had been plagued by a shortage of nurse assistants, but the aides who worked there

seemed to really care about the residents. They brought in and introduced their children to the residents, and were not scolded if they stayed to visit someone after working a shift in another hallway. At Christmas, a facilitywide party was celebrated. The residents were adopted by the staff—I don't remember whether they drew names or what—but no one was left out, and the gifts, though inexpensive, were thoughtful, personal gifts that reflected caring.

In the second facility, staff turnover was higher, and the shortfall more severe. But the greatest disappointment was the change in attitude. Here, the aides were treated with suspicion and discouraged from visiting with the residents. They were not allowed to bring their children to the facility, and were often reprimanded for talking too much with a resident's family.

Mama and some of the staff eventually got around this problem; Mama, after all, had grandchildren, who were not all that different, she said, from the "girls" and young men who were now helping her. Mama, you may have guessed, was a natural-born matriarch and self-taught social worker. She had, practically speaking, been the activities director in her mother's nursing home. One day, as the shift was changing, one of the aides ran into Mama's room and hugged her. "I can't stop now, Mrs. S.," she said, "but I'll be back. I can hardly wait to tell you what happened to me last night." Such intimacies were, however, extremely rare in this facility. And the missed call lights, the lack of toileting help, the rudeness in the dining room, the impatience in helping someone dress were all the harder to take because of that.

We Need Help

Mama left messages on our answering machines: "Get over here quick," she hollered, "they're trying to kill me." The problems ranged in seriousness from not getting ice in her water, to bedclothes that were "too heavy," to not putting the call light within reach. On occasion her glasses were lost (and never found), or her dentures were broken or missing. One afternoon we discovered that a faulty electrical outlet had burned large holes in her blanket.

Often the problems Mama and other residents complained about were not serious, but they symbolized a kind of systemic neglect. On countless occasions, for example, we watched staff carefully put fresh pitchers of water on each resident's dresser or table. The water was cold; the pitchers full, but most of the residents we visited were unable to lift a cup, let alone pour water from a pitcher. Years later, I can still count on one hand the number of times I saw residents actually being given a drink (other than when they were receiving medications). And even residents who can feed themselves sometimes need help washing their faces and hands. You can always tell "new families" from those whose resident has been in the facility a long time: the new ones don't know where to find clean towels and wash cloths. Even more revealing: they actually believe that the first time they find their loved ones with food or worse on their faces or under their fingernails, will be the last.

My sister started a family council. Only seven to ten families attended the monthly meetings, but those who did appreciated the chance to share their concerns and get as much knowledge as possible to help their resident adjust to changing situations. The council explored such things as doctor-patient relationships, long-term care insurance, hospice care, caregiver burnout, and other long-term care policies, legislation, and regulation. They discussed activities, personal care, transportation to and from the facility, and how certain medicines are regulated—and sponsored a ladies' tea and an aides' appreciation day.

Some members of the council were caring for more than one elderly or disabled person, and many of them were nearly as old as the person they were caring for. The council asked one of the social workers to represent the facility, and she was very helpful. A major problem in many nursing homes is that social workers, like nurse aids, are in short supply; and those who are there are far too busy with paper work to help residents cope with the psychological and social demands of living in long-term care.

Occasionally a family's frustrations would boil over, but council meetings were not gripe sessions. They were solution oriented.

A Turn for the Worse

One Friday morning at breakfast, Mama told Mr. Y.: "My daughter's coming next week. She'll take us out for pancakes." But I never did. About noon that day, an aide stood Mama up against the railing in the bathroom, then left the room. Mama's legs got tired, and buckled under her. By the time my sisters were notified (about 4:30 that afternoon), Mother was still at the facility, being x-rayed. Both her legs were broken, one in three places. The injuries were so severe that pins could not be used to set the bones; some kind of special rods had to be flown in for the surgery. My sisters were advised to call the family together for last good-byes. Mama survived, but she needed immense doses of pain medicine; and it was nearly a year before we got her back to "normal."

We wanted an investigation. We wanted to sue. We didn't want this to happen to anyone else. Most of all, we wanted our Mother back. In the end, the surveyors found "no fault" with anyone, and the investigator interviewing the aide reputedly told her not to feel bad, "these old people have brittle bones; they're all going to fall sooner or later." The aide was fired (for lying about having left Mama alone). Other than that, no accountability for the accident was ever assigned. We couldn't, however, bring ourselves to sue either the state or the facility, no matter how just our cause; and it did happen again.

A year or so later, a male patient was dropped — whether from a Hoyer lift or from someone attempting to move him without the lift, I don't know. (Hoyer lifts are swings used to move patients in and out of beds. They are difficult to maneuver in small spaces and useless if their batteries have not been charged.) Mr. F's "accident" was not discovered immediately, though "everyone" knew that he was in intolerable pain. His hip was broken on Tuesday; on Thursday he died; and the last I heard, his relatives were suing the facility.

The Daily Grind

In all the years that Mama lived in the nursing home, of course, we had care planning conferences and written care plans. And yes, we talked occasionally to the surveyors and tried unsuccessfully to interest the ombudsman in spending time in this facility. However, few of our suggestions purchased more than a few hours' improvement. Of all the programs intended to help older Americans, the ombudsman program strikes me as the least effective: in my state, it is understaffed and seriously uninformed. I'm sure our demanding attitude didn't win us any points, either, but we worried, when we were alone: what if we couldn't be there to guarantee that Mama

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received at least minimal care? What about the people we saw everyday who didn't have family to advocate on their behalf?

Twice Mama insisted that she was ill — twice she had to "fight" to have her complaints heard — and both times she was hospitalized for serious illness. "Doesn't it bother you," my sisters asked the staff, "that every time there's a change in Mama's condition, we have to tell you — don't you think you should be telling us, or at least noticing these changes before she ends up in the hospital?"

A friend urged me to think about moving my mother to her mother's facility because it was surely much better. Yet she also described going to visit her mother at mealtimes, and coming back depressed. "Staff seems to resent the families' help," she sighed, "and so many residents are fed haphazardly — large spoonfuls of food are thrust at them, or none at all. Or else they are loudly scolded or ridiculed or talked about as though they were mute and stupid as well as old and frail."

World without End

Mama died in January, but that is another story, and one I'm not quite ready to share. The story I have told seems also to be missing the best parts: how much the aides loved Mama, for example, and how many times she surprised us. She never minded our singing no matter how off-key it was (in fact, she liked it); and almost to the day she died, she could correct the details when we lost the thread of old family stories.

Mama's room became the world for her, and those who were there, by choice or not, were our newest best friends. We needed one another. We needed each other's pain to remind us we were not alone; and each other's laughter to bring sunshine into the room. Mama and her family talked about everything, intimate details and all; and her roommate's families, who didn't always know what to say to each other anymore, learned from overhearing, and they too began to tell their stories. Hearing each other's stories helped us hang on to our own, and kept us vigilant. And we needed constant vigilance to protect the quality of care our mothers, sisters, and fathers were receiving in long-term care.

Last night, when P. J. and I dropped in to visit Clara (one of Mama's table companions), she asked us if we had seen her aide, because she couldn't find her call light (shades of yesterday's complaints). When none of us could find the light, I walked back down the hall to the nurse's station, only to be told that Clara's aide was on her break. I stood there some minutes before it dawned on those gathered at the station that possibly someone else might be dispatched to Clara's room.

Throughout this paper, I have tried to show the contradictions between the rights that long-term care residents are supposed to have, according to the Nursing Home Reform Act of 1987, and their actual experience. One right, however, that I never saw denied to anyone is this: every resident's care shall be equal in quality without regard to payment sources. Many people in my generation and younger are working overtime to secure sufficient funds to care for themselves in their old age. But unless we also support initiatives that will improve how that care is delivered, we won't do any better than Mama did, and that's not good enough.