

WHAT PRICE LONGEVITY? A Care Giver's Journal

Mom never drove a car. By 1994, about the time she turned 86, her incredible natural strengths began to diminish. She no longer could make the bus shopping trips that she previously enjoyed; nor could she maintain the small garden of her mobile home as she had loved doing.

Medical appointments began to multiply; housekeeping became difficult. Besides transportation needs, my sisters and I increasingly shared property maintenance and repair, business matters, and household safety. We took turns supplying all that was needed, to allow Mother to stay in her home as naturally she so very much wanted to do.

Mother also was growing forgetful--such as when one day I left her determined to roast a chicken. I called later, to ask whether she had turned off the oven. She assured me she had; but when I returned anyway in late evening I found the oven still on, at 450 degrees.

Then she had her first fall...

2004

In late summer, on a visit to a farm, Mother, now 96, sat on a stack of folded carton boxes and slid down to the ground. By September the full effect on her already painful, severely arthritic spine was evident; simply standing up was excruciating. On the 23rd we insisted on hospitalization, where she was transported on a stretcher. X-rays revealed that the vertebrae of Mother's lower spine were cascaded into an indistinguishable pyramid.

We took shifts at the hospital; and, by the time of discharge on October 8, we had her home equipped for recuperative living, had arranged therapy visits, established a Lifeline telephone monitor, and drew a schedule for daily periods of attendance by us for meal preparations, prescription monitoring, and all other necessary chores.

Medical appointments were numerous and medications complicated with frequent changes. Besides outpatient therapy for the spinal damage, there were skin sores, visits by home nurses, a bleeding bladder episode (involving a “urodynamics test,”), surgery deliberations, a ‘pessary’ appliance that required regular review by the gynecologist, an emergency room visit for a questionable leg bruise, glaucoma exams and regular eye drops; foot and shoe problems; pressure stockings to reduce leg edema; sessions with a pain management doctor, and meetings with social workers.

My life and my sisters’ lives now were fully involved with maintaining Mother’s life. Like parents, worry was constant even when not with her (meanwhile, of course, sustaining our families and coping with our own aging demands and those of our spouses). Now, Mother had *four* advocates. What in the world did an aged person who had *none* do, we wondered. How impossible it must be, for an only child!

As time moved on we accepted that *we* needed help. How much worse it may have been, to meet worsening circumstances, had Mother not qualified for and received some financial aid from our county In-Home Support Services division—a service which, deplorably, now is facing extinction in the State’s current fiscal dilemma. We were able to hire a part-time care giver with whom we alternated a few shift hours, and who helped with showering and light housekeeping. Added accounting and payroll tasks were well worth it.

We kept a daily calendar, for there was much to remember. Eventually two large binders were filled with doctor, Medicare, Social Security and “advanced directives” paperwork, equipment and medication data, and resource information, together with detailed logs which, before leaving a ‘shift,’ each of us left for the next person. Pages and pages read like medical records in themselves.

Mother displayed more and more forgetfulness; the number of hours needing someone with her crept up with each passing day. Come the following March it was time for 24/7 care.

Supplementing In-Home aid with personal dollars, we then employed two care givers, various of the six of us taking daytime and overnight shifts. Our personal time fully was dictated by Mother's needs; between April 9 and May 1, for example, there were 12 medical appointments.

So it went, through summer and into autumn, as yet another binder filled with medical and business records, coordinating calendars, and care giver communications. Then, on October 4, Mother spontaneously left her recliner without her cane, walked a matter of 10 steps to the front door, opened it to check the mailbox there, and in turning had her second fall. Her right femur bone broke in three places.

The next day she was taken to the operating room at 12:30 p.m. A large loss of blood at the time of the incision put her in cardiac arrest. The incision temporarily was reclosed and Mother was resuscitated, after which implantation was completed of a 12-inch plate to the femur. In ICU the full following week, Mother was unconscious the first three days. As she regained consciousness she suffered several hallucinatory episodes, perhaps due to the strong narcotic drugs for pain. Her mind, however, never returned to its prior state. Before, although suffering short-term forgetfulness, she could recall memories of her own and her family's life events. Following the surgery, she could not summon memory even our father's death, and wondered why he was not in attendance.

After another week in the main hospital (one or more of us in attendance daily, helping with feedings and vigilantly monitoring), Mother was transferred to the Skilled Nursing Facility for recuperation, therapy and evaluation. The initial goal was to bring her back to 75 percent of her former disabled functioning. At a November 21 family meeting with staff, however, we learned that *perhaps* only 50 percent was achievable, that she would be discharged on November 28, and that she would need full-time nursing care. Mother now was 97 years old and unable to move her

body between bed, chair and toilet. (Two of us sisters already had age-handicapped husbands for whom we were caring, one concomitantly having undergone a quadruple heart bypass.)

Mother's monthly income (Federal social security and a State supplement) was \$833--far beneath the \$4-5,000 cost for private assisted living for an incontinent, wheelchair-bound person. Nonetheless we hopefully visited some in our area, before accepting placing her in a Social Security funded bed in a local home. Mother was transferred directly to the living facility from the hospital.

So fortunate again were we! The home was (still is) probably the best of its kind available anywhere—airy, clean, and with a staff deserving of medals; and we were only a few minutes away. Mother's Social Security stipend went directly to the home, excepting \$30 allowed to be kept for incidentals. That \$30 did not cover incontinence underwear, telephone, clothing or other personal incidentals; but we were far from complaining about *that*.

We eased Mother into her new residence, letting her believe at first (in her cogent moments) that it would be only until she was 'fully recovered.' In a three-person room, Mother was given the space near the slider door, which looked out on a lovely back garden. We brought in her familiar night table, bureau, casual chair, and television, and placed favored items and photos on the wall. And another two full binders and assorted folders of records were closed.

December 2006 through March 2008

One of us was at the facility daily, either at mealtimes or for one of its 'recreational' events. We treated Mother as if she was 'at home,' she often speaking as if she were: "I could fix you a cup of coffee," she would say, moving as if she could arise from her wheelchair. Her hallway was her 'block;' the dining room was a 'restaurant.' It was fascinating to witness how our fundamental nature is the last vestige to leave us; for, despite Mother's condition, hers automatically responded with clarity in times of another's need. When one of her roommates was in trouble, Mother would wheel herself to the door and call out, "We need help here!" Otherwise, Mother lived in the very

moment; the hours of the day seemed to pass unregistered, so that even the morning meal was not recallable at noon.

Yet, absent remembrances about us, our families or her own past, she well remembered how to play Bingo, regularly attending the three-times-a-week games. She didn't remember what her last real home looked like, or where it was. However, not missing it *per se*, there lasted in her that nebulous memory which longs for what is embraced by the meaning of 'home'--a sense of independent being to which the spirit ever wishes to return. If Time is measured by painful thoughts, it was inevitable that ours were the greater in doubled emotions--identifying our own futures with, while deeply suffering sympathy for our beloved Mother's present one.

April 11, 2008: Although Mother had been confined totally to bed now for some days, she had been endowed with formidably strong heart and lungs. We expected that she well would live to her next, her 100th birthday the coming month. We all had visited her this evening and joined afterward for supper at my home. Later we would marvel at how unusually 'free' and joyful we had felt, recounting stories of our childhoods and our youthful lives in our humble but so loving family home. For such a long period up to this night, our hearts had jumped with each ring of the telephone--mind thinking, *oh god, must this be it?* Yet so strangely during this time, worry about Mother seemed lodged in the cosmos.

One sister had left for home about 11:30 p.m. When the telephone did ring at quarter of midnight, I had no thought of Mother. *Sister must have forgotten something*, I thought. But, *no...* Mother had breathed her last. It seemed as if she was able to, then, assured that she who had no benefit of siblings was leaving us as she so much strove to make us: sisters, loving sisters....

How strange is it?—that our modern quest for longevity failed to anticipate its ultimate meanings? But enough already has been written; no more really is needed here, about the aging

industry and its costs, the burden on families, and the dilemmas faced by persons of meager means.

What remains is, how shall society meet it all?

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[This journal is a separate appendix to *Journey With JC*, an as-yet-unpublished autobiography.]