

The Long Goodbye

Augustus Monroe figured he'd drop dead long before he'd need a nursing home. A decade later, his son considers the weighty financial and emotional costs that come with a parent's immortality.

By **Doug Monroe** - January 1, 2012

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We thought Daddy was going to die in 2001. He was staggering around the house in his underwear, gasping in pain, his eyes hollow, his face slashed from shaving with an old-fashioned safety razor. He was eighty-two years old. We took him to a doctor, who said his spine was deteriorating, gave him pills, and suggested he pray. A few days later, Daddy fell at the mailbox, bounced his head on the pavement, and crawled up the driveway, scraping the skin off his knees before collapsing on the front steps. Mama sat in her recliner in front of the TV, worried and clueless, until a neighbor called an ambulance. The EMTs got Daddy propped up in his recliner. He refused to go with them. When I arrived, Daddy was gulping down whiskey. I called the ambulance back, and they took him to DeKalb Medical. Doctors found prostate cancer and operated. My sister and I cried, sure Daddy was in his last days.

That was eleven years ago. Since then, Daddy's long goodbye has drained his retirement income and life savings of more than \$300,000. Where's that money gone? Assisted living, mostly. Of course, that amount doesn't account for his medical bills, most of which have been paid by Medicare and insurance policies that were part of his retirement. Daddy's income—Social Security, plus monthly checks from two pensions—pays for the facility where he lives, his taxes, his life insurance policy premiums, and such incidentals as a visiting podiatrist to clip his nails.

And he has been kicked out of two hospices for not dying.

Daddy is ninety-three now and wears a diaper, is spoon-fed, and urinates through a catheter, drifting in and out of deep sleep in which he gasps for air and appears to be dead. Trisha, my sister, texted a picture of him in October to one of her daughters, who texted back: "Happy Halloween!" When he wakes up, his caregivers dress him and plop him in a wheelchair. He rolls around like a child until it's time to eat again.

I cannot imagine that this once-dignified Southern gentleman, who clawed his way out of the grit of a Depression-era tobacco farm in North Carolina and bought a snazzy double-breasted suit with one of his first paychecks, would be anything but humiliated by what is happening to him now—if he had all his faculties. Yet as one of his nurses told me, "Your father has no interest in dying." It is not heroic measures keeping him alive; he just keeps ticking. He takes only two medicines: an antibiotic for a urinary tract infection and OxyContin for the pain in his spine.

At sixty-four, I am at the leading edge of baby boomers who have ringside seats to the slow-motion demise of the Greatest Generation, watching our parents pass away slowly and stubbornly, dying piece by piece over a decade or more, often unwilling or unable to share their feelings. Most of us, such as my sister and I, head into the turmoil of caring for an aging Immortal utterly unprepared.

Daddy used to laugh at Trisha and me whenever we suggested discussing assisted living and long-term care insurance with him. He insisted—with the unshakable confidence of a career civil engineer—that he didn't need to make such plans, that he would simply drop dead one day and that would be the end of it. He refused to discuss it further.

It didn't work out according to that plan, and there was no other plan.

>> EXTRA

**ESSAY: Read
Monroe's 2002
piece on putting
his parents in
assisted living**

Augustus Currie Monroe was the hardest-working person I've ever seen. When he graduated from the University of Florida in 1942, he got a job at the U.S. Army Corps of Engineers. A big reason? The guaranteed pension. He never trusted the stock market, with the crash from what he called the "Hoover days" always fresh in his mind. He ended up earning two pensions—one for his career as a civilian engineer and one from a second career as deputy director of DeKalb County's water and sewer department.

For twenty-five years, he and a partner operated a private land-surveying business. With me as their rod man, we surveyed many of the subdivisions that went up in DeKalb and north Atlanta during the city's boom years. For twelve hours every Saturday, Daddy stomped through the woods, chopping down bushes, dripping sweat, and stepping over snakes. He never complained or seemed to get tired. At the end of the day, we always got a milkshake at the old Dairy Queen on North Decatur Road. About once a year, he would take me to an Atlanta Crackers game at Ponce de Leon Ballpark, and we always went to the Georgia-Georgia Tech freshman football game every Thanksgiving.

He was tall, strong, quiet, and had a wicked sense of humor. We used to watch Ernie Kovacs on TV and laugh until we were in tears. He was also pathologically stubborn. As an old man, he refused Trisha's efforts to move him and Mama into her home or even her neighborhood. When he retired, he just sat down in his recliner. He was worn out.

After his fall on the way to the mailbox, Daddy told us his final wishes. He had a cemetery plot and wanted a graveside service with no flowers and a medium-priced "outfit," by which he meant a casket. He clearly thought he was about to die. We moved Mama and Daddy into a Decatur assisted-living facility in 2001. Mama needed their highest level of care, so Daddy paid about \$6,000 a month for both of them.

After Mama died three years later, he moved to a floor with less care and paid \$2,500 per month. During that decade, he lost most of his vision, most of his teeth, and more than a hundred pounds from his peak weight of 250 on his six-foot-three frame. Today all of the meat and muscle is gone.

Last May he fell in his bathroom and broke his shoulder. Doctors were afraid his heart wouldn't make it through surgery, but they operated anyway. We moved him to a nursing home for rehabilitation, where the aides dropped him, breaking the shoulder again. Unable to urinate, his body swelled up. He was rushed to a hospital, where the doctors inserted a catheter and sent him to a hospice. They figured he had suffered a stroke that interfered with his swallowing. They said he would last only a couple of weeks. Trisha and I cried again.

After a few weeks, the hospice administrator called and said, "We don't know what's going on, but he seems to have bounced back and we can't keep him here any longer." She added, "We've never seen anything like it." Later he was rushed to another in-house hospice facility after choking on his own mucus, with doctors again convinced he was at death's door. He got the boot from that place, too, like a bad boy making the rounds of prep schools. His Medicare HMO paid the bills from those facilities.

"He must be growing new organs, like a frog," I told Trisha.

The hospices had soft-spoken chaplains who talked to Trisha and me. One of them asked, "Has your dad talked about death?"

"Well," I said, "he has a burial plot next to my mother at Melwood Cemetery in Stone Mountain. He used to describe death as 'doing the Melwood mambo,' but he hasn't mentioned that lately."

For years when I was growing up, my maternal grandmother cared for her mother and sister, who each had been felled by strokes, in a one-bedroom apartment at Pershing Point. My grandmother ran the mail room at the state highway department. Her sister's former boss, Mayor William Hartsfield, paid for a nurse to watch over the invalids until my grandmother got home from work.

In those days, extended family cared for the oldest. Now, in an age when family members are separated by hundreds of miles, we leave it up to nursing homes and assisted-living facilities. And the need has never been greater. The fastest-growing age group in America is the eighty-five-and-older cohort. As the population ages, healthcare costs continue to outpace inflation. Many older people have seen a sharp decline in their retirement investments since the 2008 economic collapse and are rapidly losing value in their homes. American political leaders are not preparing adequately for the huge demographic shift caused by the aging of the boomers, who began turning sixty-five in 2011. Many of them are retiring at the same time they are dealing with parents who are still alive.

Costs for long-term care are skyrocketing because only 3 percent of adults carry long-term care insurance. As a result, middle-class people without Daddy's pension income are bankrupting themselves and then applying for Medicaid to pay for a nursing home in which they may languish for years. Medicaid now pays for some 28,000 Georgians to live in nursing homes. Another 2,200 apply each month, although many are rejected.

The long ordeal endured by my sister and me, juggling our father's care while still trying to scratch out a living for ourselves, will be experienced by virtually every middle-class boomer with an Immortal in the family. When I shared my situation with a fellow teacher, she said she had gone through a similar scenario with her mother, who died slowly, over a period of years, from what was supposed to be a fast-moving cancer.

"She wouldn't die. She just wouldn't die!" the teacher told me. "People used to tell me, 'Oh, you're so lucky!' But I wasn't lucky. It was a nightmare."

Trisha and I were lucky in one sense: Daddy has the type of retirement income that is becoming an anomaly. After all, how many of us will be able to fork out \$300,000 for assisted living? Pension plans like my father's have often been eliminated in favor of risky 401(k)s, vulnerable to the stock market's volatility. Politicians are champing at the bit to cut back on Social Security and Medicare at a time when so many of us will depend on them. The financial reality of old age—our parents' and our own, often at the same time—can feel overwhelming.

One thing you learn fast in dealing with navigating the fantastically complicated world of elder care is that it's a fat, unguarded treasure ship constantly under attack by pirates. I once took Daddy to his doctor, who told me that Daddy's Medicare HMO had changed his doctor on him. I called the HMO and they refused to talk to me. It seems an HMO representative had entered Daddy's assisted-living facility and signed him up, even though he was legally blind. The HMO, based in Florida, refused to recognize our Georgia medical power of attorney. I was furious and paid out of pocket for the doctor visit. Eventually I had to involve my lawyer son to get the HMO to communicate with us.

Last June we moved Daddy to a personal care home run by two Bosnian women. A visiting nurse from the most recent hospice sees Daddy several times a week. The Bosnian women keep Daddy sparkling clean. They change his diapers and catheter bag. They coat his bald head with lotion every day. They lift his skeletal frame out of bed, dress him, and put him in a high-back wheelchair that he scoots from room to room, propelling it with his size 12 feet. He grins at the other aging people who live there and watches Westerns on TV with a retired chicken farmer named Ernest.

The Bosnian women run Daddy's food through a blender and spoon-feed it to him. He doesn't gain weight, the nurse tells us, because of "adult failure to thrive." Still, he thrives, so to speak. I told one

of the nurses that you could drop a smart bomb in Daddy's lap and he wouldn't be late for lunch.

The personal care home costs \$4,100 a month, straight from his checkbook. A corporate-run nursing home would cost more than twice that much and would provide a much less personal level of care. Medicare pays for medically necessary skilled nursing facilities under certain conditions, but it wouldn't pay for Daddy's long-term nursing home care or assisted living.

Medicaid, on the other hand, does pay for nursing homes. Those costs are the fastest-growing piece of the Medicaid program. But qualifying for Medicaid, which is designed to help people with no assets, can be a complicated legal process, especially for an elderly person who still owns a house. Daddy has too much retirement income to qualify for Medicaid. He quitclaimed his small house in Collier Hills to Trisha and me, but that's not a guarantee of anything.

One of the toughest parts of dealing with the long-term aging of a parent is coping simultaneously with the crises of younger family members who are not immortal. After I moved to New York City to teach, Trisha had to deal with the fatal illness of her husband, Jack. He was diagnosed with brain cancer, the same kind that Ted Kennedy had. I told Daddy about it over the phone, not realizing the extent of his dementia. A few hours later, Trisha called me in tears. She had gotten a call that Daddy was disoriented and in a terrible panic, roaming the halls of the assisted-living facility in his wheelchair as fast as he could roll, crying, looking desperately for my mother. By that time, she had been dead for five years, but he thought she was lost in the facility and it was up to him to find her. He was confused, but he knew at a deep level that he needed to rescue somebody. He was trying to be the strong man who once caught an 80-mile-per-hour fastball with his bare hand to keep it from hitting my head.

We let Daddy have a shot of Jack Daniel's now and then. I put a fifth in his sock drawer. He sips part of a jigger at a time. He seems to have some sort of crisis every few months and has to be rushed to a hospital or doctor's office. It always turns out the same: "He's doing fine now! Never mind!" And back to the Bosnians he goes. So far, knock wood, those visits have been paid by the Medicare HMO and the backup policies. But the thing about medical bills is that you never know when a hospital will suddenly drop a six-figure bill in your mailbox. Trisha learned this the hard way when Jack was sick. The system is complicated and unpredictable, and giant debt always lurks on the horizon like a storm cloud.

The last time I saw Daddy was in October when I was driving my son and his wife, who live in Philadelphia, to the airport after my daughter's wedding. When the three of us went in, Daddy was sitting up in a chair and hardly seemed to recognize us. He kept wincing in pain, trying to get comfortable. He said the middle of his back hurt. His head is barely more than a skull now, with giant Gollum eyes and a black chasm where his lower teeth used to be. The scene was so stark I turned my head. I later left messages all around, demanding more OxyContin for my father and generally making an ass of myself. I calmed down after I talked with the nurse and my sister. The fact is, old people are often in pain. Trisha visits and reports he is clean and happy and doesn't complain about pain. I must have caught him on a bad day.

Trisha and I now have to consider what will happen if Daddy outlives us both. And, of course, we wonder what will happen as we age. Neither of us will have anything like Daddy's resources. We're both still working, making much less than we used to.

Frankly, I don't want to put my two children through an experience like this. What's so crazy is that medical science is keeping people alive longer. We just won't be able to *afford* to live—we'll be a nation full of immortal poor people.

I went through a serious illness a few years ago and slept through most of 2006, living on savings and credit cards. I describe myself now as “pre ruined.” I’ll never be able to retire, so I’ve downsized, simplified, and learned to live with much less than I used to.

I would rather kill myself than live like Daddy is living. I’m sure I’m not the only baby boomer who jokes about replacing his 401(k) with a .357. But I certainly haven’t given up yet. I will turn sixty-five in June, and I’m busily examining brochures about medical insurance policies that supplement Medicare. I checked with AARP about long-term care insurance. I can’t afford it.

A while back, I had a talk with my son, Matthew, about what was going on with my father. I said, “If I end up like your grandfather, I want you to take me out in the backyard and shoot me.”

Matt thought about it and then said quietly, “Dad, it’s time to go to the backyard.”

Doug Monroe was a senior editor, columnist, and blogger for Atlanta magazine. He lives in Brooklyn. On December 1, as this issue was going to press, his father, Augustus Monroe, passed away.

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