



## The Phone Call

Ann was out with friends on the evening of February 21, 1996. I was sitting in my favorite chair, reading a book and listening to music, when the phone rang. I don't remember the book or the music, but I will never forget the call. With just a few words, my family was sent plummeting into a painful, mysterious, and all-consuming world for which we were completely unprepared.

A five-minute conversation turned an ordinary suburban couple into caregivers for an elderly parent—a role we would play without respite for the next year and a half. Within twenty-four hours, we would begin careening from crisis to crisis, grasping for solutions to problems we only half understood, all the while being undermined by a medical and financial system that was as woefully unprepared to manage long-term care as we were.

It would be, at once, the most difficult and the most rewarding thing I have done in my life.

What happened to us on that raw February evening is so common

that elder-care professionals simply call it The Phone Call. If you have not received one yet, chances are you will. Nearly 70 percent of our parents will require personal care sometime during their old age. A typical senior will need it for three long years, and one out of every five will depend on it for five years or more.<sup>1</sup> More often than not, it will all begin with the ring of a telephone.

For us, the caller was my father-in-law, Albert Kline, a quiet retired government worker. He was calling from a pay phone at a hospital in Ft. Lauderdale, Florida. In a broken voice, Al tried to explain that his wife, Ida—my mother-in-law—had suffered a massive stroke. Al couldn't get the words out. "I can't believe this is happening," he said again and again. But the message was clear enough.

When my wife returned a few hours later, I broke the news as best as I could. Ann first called her father, then her brother, Ron. We arranged to get the first plane to Florida the next morning, and when we arrived at the hospital, we found Ida on life support in the intensive care unit. She was, by any reasonable definition, already dead. Still, we needed to make the decision to remove her from the ventilator that was pumping oxygen through her body.

I stood frozen in the doorway of her room, unable to decide whether to go in or not. Entering felt like an invasion of her privacy. Ida, who was not a small woman, seemed lost in the large hospital bed, her breathing maintained only by a gray metal machine, a plastic tube in her mouth. I struggled to capture an image of the warm and gregarious woman who had persevered despite a very difficult life. Yet, at just seventy-two, that Ida was gone.

But seeing my mother-in-law was only the first shock of that day. While Ann, Ron, and I struggled to absorb what was happening, Al had more news. Standing in the corner of a soulless waiting room, he broke it simply and quietly: "I have a tumor."

What Al had was advanced melanoma. He had suffered a bout of this skin cancer a half decade before, but it had been successfully treated and was half-forgotten. On our recent visits to Florida, he had complained of back pain. But, deep in denial, we all convinced

ourselves that this was nothing more than normal discomfort for a seventy-four-year-old.

In fact, his melanoma had returned. It had gone undiagnosed for a long time, and now the cancer was aggressively attacking the rest of his body. Al and Ida had never told anyone that the disease was back—not their kids or their own brothers and sisters, who lived nearby. For months, Ida had been Al's sole caregiver. She'd done it with no one to talk to, or to help with rides or advice. She'd had no shoulder to cry on. The stress almost certainly had helped kill her.

Now that overwhelming responsibility was about to fall to Ann, a lawyer with the U.S. Environmental Protection Agency. Ron, a peripatetic college professor, couldn't do it. Besides, sons rarely care for aging parents.

The day Ida was removed from life support, we arranged her funeral. She'd be buried in her hometown of Wilkes-Barre, a grim little place in the coal country of central Pennsylvania. When Ida was a teenager, she couldn't wait to get out of Wilkes-Barre. But her parents were buried there, and Al felt this was where she should be laid to rest, too.

Al was much too sick to travel to the funeral, so Ron flew to Pennsylvania, where a brief graveside ceremony was held. Al, Ann, and I stayed in Florida and held a memorial service in Al and Ida's living room.

A few days later, we met with Al's oncologist, who talked about experimental treatments and drug trials. We listened, skeptical but too overwhelmed to ask him the probing questions we should have. We did ask if Al had much hope of survival, or if we should consider ending his debilitating chemotherapy and instead enroll him in hospice. An in-home hospice program would provide an aide for ten hours a week, a registered nurse who could check in on Al to be sure that his pain was being managed, and a social worker who could help us plan any additional care he might need.

But the oncologist rejected the idea out of hand. Government rules required that a doctor certify that a patient had less than six

months to live before Medicare paid for hospice, and he flatly refused. “Your father isn’t there yet,” he told Ann.

It took us a while to figure out that Al’s melanoma was going to kill him, and that all of this doctor’s grand plans were little more than a long-shot attempt to buy my father-in-law a couple of extra months. Perhaps this doctor, like many oncologists, saw hospice as a kind of surrender in his personal war with cancer. The doctor had no suggestions for what we *could* do, but whatever his reasons, hospice was, for now, out of the question.

Still in shock from her mother’s sudden death, Ann now had to find a way to care for her very sick father—from a thousand miles away. Al didn’t make it easy. He wanted to stay in the apartment he had shared with Ida for so many years, but he refused any help. He wouldn’t even consider a nursing home or assisted-living facility. He would not move to the Washington, D.C., area to be with us or to upstate New York, to be near Ron.

Yet Al was, in many ways, helpless. He could not cook. He had no idea how to use a microwave, and in any event was too weak to stand in the kitchen, so all his meals had to be made for him. He couldn’t do any housecleaning. The idea of his driving terrified us all. We had no idea what to do.

Ann needed to get back to her job, and Ron needed to return to his. So we decided to hire a part-time aide who would come in for four hours a day, three days a week, to cook and clean for Al. We’d try this while we attempted to return to our lives. Ann, feeling deeply guilty about how little she was doing for her dad but not sure what else she should do, flew back to Washington.

After a month, there was another phone call. This one was from Al’s brother, Jake, who had met Al for dinner and was stunned at how much he had deteriorated.

Ann was back on a plane the next day, taking more time off from work. She was not sure how sick Al was, but she knew she had to find better arrangements for him. Ann began to think about taking a leave from her job to stay in Florida with her dad.

She brought Al back to the doctor. This time, he concluded that further treatment was futile, so we turned to hospice to help keep Al comfortable in the days he had left. We all met with a hospice nurse in Al's living room. She explained how the program worked, how Medicare would pay for it, and how Al could remain at home. But this had to be Al's decision.

At first, he seemed comfortable with the plan.

The nurse took us through pages of numbingly routine forms until we got to the question of whether Al was likely to live for less than a half-year, as Medicare regulations required. And for the first time, Al heard his death sentence. No one had ever told him just how sick he was.

"So, I am going to die in six months," he said, in what was at once a question and a statement.

"This doesn't mean you're going to die in six months," I told my father-in-law. "It just means a doctor says so to make you eligible for hospice. They don't really know."

And so they don't. But Al was going to die soon, and this was the first time any of us said it out loud.

We enrolled him in the home hospice program, but by now Al was so unsteady on his feet that he needed assistance getting to the bathroom at night. He wouldn't let Ann help him, so we had to hire aides on two twelve-hour shifts. The overnight aide mostly slept or watched TV, but she had to be there for those few minutes Al needed her.

While Medicare paid for hospice, it did not pay for those extra aides. Al paid their fees out of his pension. Ann stayed with her father for the first two weeks of his hospice care. But she had a job, and a life, back in Maryland.

Even with the aides, hospice, and Ann's help, the toll of the melanoma was too much. Al was having trouble eating, was deeply depressed, and was visibly failing. Despite all of our wishes, he could not stay at home.

So, after just a few more weeks, Ann brought her dad to be near us. We had no idea where he could live, so we first arranged to

have him admitted to a large local nursing home until we could plan the next steps.

It is not always easy to get a patient into a good nursing home on such short notice. But we had one big advantage: We could “private-pay.” That is, we were willing to write very large checks without relying on government assistance. About half the total cost of long-term care is paid by Medicaid, the welfare-like government health program for the poor. But Medicaid pays about 15 percent less than the retail rate, so nursing homes are always happier to have private-pay patients like Al.

The official price—a decade ago—was \$5,000 a month. With add-ons, it was closer to \$6,000. We learned that in a nursing home, you pay extra for just about everything, from adult diapers to snacks.

After a harrowing flight, which left Al extremely weak and disoriented, we brought him to the facility, a large multistory building that was part of a huge seniors’ complex just a few miles from our house.

He was immediately taken to a small room. As I stood in a hallway watching the nurses struggle to stabilize him, I was convinced he would die within hours, and wondered if perhaps that might be a blessing.

But Al didn’t die—and once he recovered from the trip and got his bearings, he had one wish: to get out of that sterile and impersonal nursing home.

He was wheelchair-bound by then, and struggling to manage his steadily increasing pain. There were good days. One warm early spring afternoon, Al munched hot dogs, his favorite food, on our patio. And there were bad: late-night calls from the nursing home telling us that Al had fallen, or half-coherent calls from Al himself, as he tried to grasp what was happening to him.

After one of those falls, Al was X-rayed, and we learned how widely the cancer had spread through his body. Ann and I knew we would lose him soon, but those extra weeks were a gift.

Al’s goal of escaping the nursing home became ours, and after

three weeks we did get him out. He refused to live with us, so we found him an apartment in a nearby assisted-living facility. We rented furniture, put up family photos, and hired a live-in aide to care for him.

Al moved in, but said it still didn't feel like home. The apartment needed, he decided, more artwork on the walls. So we found some paintings at a furniture rental store. Once we hung those, Al smiled for the first time in months. He was, in some way, home.

He lived there for one week.

One morning, a few days after we finally got him settled, the phone rang again. This time it was my mother, Marilyn. My dad, Herb, had been admitted overnight to their local hospital in Delray, Florida.

This time Ann stayed in Washington with Al while I caught the next available flight to Florida. I found my father in the intensive care unit, alert but ashen. All my mother could tell me was that he had suffered a heart attack and that, at two A.M., the local rescue squad had taken him to a nearby hospital emergency room.

After I saw my dad, I tried to find out what was wrong with him. It was almost impossible to get answers, but I finally cornered a cardiologist in a hallway. My father had not had a heart attack. His problem was congestive heart failure, an extremely common ailment among the elderly. His heart was literally wearing out, and was no longer able to pump enough blood to the organs in his body.

His cardiac disease was very bad. After eighty-one years, my dad's heart was pumping at less than 15 percent of its normal strength. The doctors were amazed he was still alive. Age, a long-ago heart attack, and an old three-pack-a-day cigarette habit had finally caught up with him.

After a couple of days he somehow stabilized, and my mother and I started to think about what would happen next. Then the phone rang again.

It was Ann. Al's regular aide had taken the day off, so Ann had

gone to his apartment to check on things. When she arrived, she found Al barely responsive. She realized right away what was happening: Her father was about to die.

The fill-in aide was screaming and crying and clumsily trying to perform CPR. It was a nightmare. Ann tried to comfort her dad while hustling the hysterical aide out of the apartment. She kept thinking that she wanted her father, who even in the best of times loved the quiet, to die in peace and calmness.

While Ann and I were talking, Al stopped breathing. As he wished, Ann did not call 911. It was May 26, just three months after Ida's stroke.

Even today, it is hard for Ann to look back on the last months of her father's life without weeping. "Nothing," she says, "worked out the way I wanted it to."

Ann began making arrangements for her dad's funeral. I got a plane back to Washington and we prepared to bury Al next to his beloved Ida. Al's life had ended, but our long-term-care story was only beginning.