

## FEATURE ARTICLE FROM ALWAYS BEST CARE



## **The Caregiver Chronicles**

The mother: Still glamorous and flirty in her nineties. The daughter: Loving but conflicted, convinced she'd been a lifelong disappointment. What happens when the two women say goodbye?

by Barbara Graham

Irene Graham at her 95th birthday Party with her daughter, Barbara Graham. Photograph: Courtesy of Barbara Graham

"You don't have to get all gussied up," I told her. "He's a *hospice* rabbi. He's used to seeing people in their bathrobes."

"I'm not people," my mother said, propped up on the hospital bed that had just replaced the single bed in her apartment. "And I don't parade around in a bathrobe when company comes." Even now, at 95, impossibly frail and tethered to an oxygen tank, Irene looked glamorous in her blue silk nightie with the ivory lace trim.

"He's not company," I protested halfheartedly, though really there was no point in arguing. My mother, the former belle of Pittsburgh, would die before she let any man see her undressed without her "face" on.

Which is exactly what would happen, but we didn't know that yet.

Two weeks earlier—before the buildup of fluid in her lungs started squeezing the breath out of her— Irene had called me on the phone sounding frantic. Hearing the wheezy panic in her voice, I panicked, too. Could this possibly be *it*? I wondered. After years of serial near-death experiences, could my mother—the woman who joked that she was too mean to die—be on the brink of disproving her point?

No, she was not. The lady had more important things on her mind than life and death.

"Barb, help me, please," she implored over the phone. "I'm absolutely going out of my mind. You've got to tell me: the bronze silk or the leopard chiffon?"

The retirement home where she lived was holding its annual black-tie ball that night, and Irene was in knots over what to wear. Forget that she was wobbly on her feet, even with the walker. Forget that she had lung cancer. The lady was a coquette—adored by men, envied by women—a flirty knockout with a

smart mouth. I counseled the leopard chiffon.

Irene's cancer diagnosis had seemed to come out of nowhere two years earlier. She'd been admitted to the hospital for chronic, unremitting back pain when a routine chest X-ray revealed a few suspicious-looking spots on her right lung. The biopsy confirmed adenocarcinoma.

My mother, then 93, chose not to treat the disease—or think about it. The tumors were small, and she didn't have a cough or any other symptoms. "I'm going to put it out of my mind," she announced, taking the Scarlett O'Hara approach. "Then it won't bother me."

Other family members—doctors—were less optimistic. "Chances are, she won't make it to 94," her first cousin, a Boston internist, told me privately. This man, along with Irene's nephew, a Pittsburgh doctor, was devoted to my mother. Both men had been making pilgrimages to her "deathbed" for years. They came rushing to her side after the emergency colostomy, the bleed on her brain, the hip fracture— and always left astonished by her ability to bounce back.

"I'm afraid this time it's for real," Jerry, the Boston cousin, predicted sadly.

"She doesn't have long," Ken, the Pittsburgh nephew, agreed.

They should have known better. This was my mother they were talking about.

A CT scan taken six months after the initial diagnosis revealed no change in the size of the tumors. Another scan taken six months after that was even more striking.

"I've never seen this before, and I'll be damned if I can explain it," the oncologist said. "The tumors appear to be *shrinking*."

I was stunned. Boston and Pittsburgh were stunned. Irene seemed relieved, but not as surprised as the rest of us.

Most people—except for certain family members and service professionals trying to please her—found Irene charming.

It wasn't her fault, really, that I was impervious to her charms. Or that she, for most of my life, seemed unimpressed by mine. We were so different, both products of our times, as well as our singular quirks and talents. I often felt as though we were mismatched, like two landmasses that don't fit together—say, Greenland and New Jersey. Irene longed for a daughter who would be just like her: a princess to her glamour queen. But I was an arty, waifish girl who rejected the whole package. I shacked up with a stoned cowboy in hippie outposts from Boulder to British Columbia. When my man and I stayed in one place long enough to have a phone, I kept the number unlisted so she couldn't call and tell me I was ruining my life.

That was in my twenties. By my midthirties, I had dumped the cowboy, had relocated from the woods to San Francisco with my young son, was earning a living (more or less) by my pen and had married Hugh, a man my mother approved of only grudgingly but later grew to adore. My parents were living in Florida then, and we saw one another infrequently. Within a day or two, Irene and I would start to drive each other crazy, so I kept our visits brief.

I never dreamed I would become my mother's caregiver. My mother never dreamed that she would need a caregiver, or that my father would die and leave her to fend for herself—or, worse, leave me to fend for her.

Taking care of a sick, aging parent is not a job you can train for. The training happens on the job, by the seat of your pants, and you are always one step behind, playing catch-up to the latest crisis. The only predictable thing about the job is its unpredictability. And in my case, the stubborn resistance of the caretakee.

Irene hollered and called me a bully. She accused me of turning her into an invalid and fought me over everything: the aides, the walker, the grab bars in the shower, the little alarm button she promised to wear around her neck but left in the bathroom the night she fell and broke her hip. The clincher was when she moved, at my insistence, from Florida to a retirement place in Washington, D.C., where I live now, so that Hugh and I could look after her. Once she arrived, Irene started addressing me as Mother in a tone so sarcastic, she sounded like me dissing her when I was a teenager.

My friend Mary Pipher, the author and psychologist, once told me it's human nature to love what—and who—we care for, but Irene? I was skeptical, to say the least. Although I never doubted that I would be a dutiful daughter, I wasn't so sure I could let go of the defenses that since childhood had been hardening inside me like bad arteries. Compassion, yes, but *love*? I was determined to ease my mother's suffering, but could I unblock my heart? I worried that I'd be an outlier, the rare exception to Mary's Law of Human Nature.

My mother was a party animal and had been a celebrated hostess among her set in Pittsburgh, New York and Palm Beach. Although for years she'd been threatening supernatural retaliation if I dared to include her age in her obituary—*if* she died—I'd thrown a bash for her 93rd birthday. She hadn't been doing well (this was shortly before the cancer diagnosis), and I was afraid that she might not see 94. But by the time 94 rolled around, her force of will seemed to have driven the cancer into retreat, so I decided to hold off on giving another party until the Big 95.

Plans were under way when the cancer finally caught up with her. Her right lung filled with fluid, and she was having trouble breathing. The pulmonologist recommended draining the fluid so she could make it to the party. The procedure nearly killed her. She begged me to cancel the event, but I refused. Family members, including my son, Clay, were flying in from around the country. Anyhow, this was Herself. The smart money said she'd rally, and sure enough, on the night of the party, the Belle of Pittsburgh showed up looking like a million bucks in the bronze silk.

I think my mother had the time of her life at that party. After the toasts, she confessed that she'd always been jealous of her own mother, envious of how much everyone who'd known Bessie had adored her. If Irene had the looks, my grandmother—also a beauty—had the charisma.

"I finally know how my mother felt, and it's wonderful," Irene said, glowing, her paper-thin skin practically translucent. "Because tonight I feel that way, too."

It occurred to me that this might be the first time in her life that my mother felt worthy. Good. Deserving of love, just for herself—not for her appearance, her zip code, her fine antiques, the rich and famous people she met, the five-star hotels she stayed in, her Chanel suit or any of the rest of it.

I'm pretty sure Irene knew there would be no 96th birthday fête. Still, she went right on as before: getting her hair done, complaining about the food at the retirement home, barking at the help for multiple offenses, agonizing over what to wear to the home's annual gala. She called me for advice, and this time she actually took it. She went with the leopard chiffon.

The real clue that she knew she was dying came in the form of a card she gave me on Mother's Day. On the front was a watercolor of children in old-fashioned bathing costumes splashing in the ocean. Inside, she wrote, "Happy Mother's Day! I know why Clay has turned out to be such a wonderful

person. You have been a great mother. I know this is true because you have been a good mother to me. I thank you for your caring and helping me in every way. Thank you, dear Mother."

This was the first time my mother had addressed me as *Mother* without a soupçon of sarcasm. It made me wonder if she'd been expressing gratitude, in her backhanded, wisecracking style, all those other times. Or if somewhere along the way, her tone had shifted, and I simply hadn't noticed.

Six weeks after the debilitating lung procedure—and two days after I'd asked the nurse if they were going to kick my mother out of home hospice care because she was doing so well—the phone rang early one evening. It was Irene, sounding scared. "Can you please come over and help me," she said. "I can't stand up."

From that moment on, everything happened so fast. Stepped-up visits by the hospice team, delivery of the hospital bed, the start of morphine. Irene hated it all, except when Boston Jerry, Pittsburgh Ken and Gary, the hospice rabbi, appeared at her bedside.

My mother had met with Gary several times before, and she'd grown to rely on him to help soothe her restless, fearful mind. (Plus, Gary was young, handsome and Jewish, so she also liked flirting with him.) One day I sat in with the two of them for the first time. When Gary asked her what it was about me that she was most proud of, she paused. "Who she is," she said finally. "Just. Who. She. Is."

A dear friend once wrote, "You learn the world from your mother's face." That day I learned my goodness from my mother's face. I told her that I loved her and that I would miss her. This time there was no holding back, no going through the motions, no saying the words *I love you* with half a heart.

Each day a little more of my mother disappeared. First her sight, then her hearing. She started reaching into space for things that weren't there, and one afternoon she fell into my arms, weeping.

"I can't see. I can't hear. This is no way to live," she sobbed as I held her and tried to comfort her. As if in that moment she really was my child and I was her mother.

Except, in point of fact, she was still my mother. Still Irene. Still the Belle of Pittsburgh. As soon as the tears had dried, she began fretting over what to wear the following morning when Rabbi Gary was due for his next visit.

"He's a *hospice* rabbi," I told her again. "You don't need to worry about putting on makeup or getting dressed."

But as long as she had a shred of consciousness left, my mother could not let herself go. What's more, I think she secretly believed that if she had the wherewithal to pull herself together, she would be able to, if not outfox (in her case, outdress) death, then at least delay it.

And so the next morning, instead of greeting the rabbi in her bathrobe, Irene insisted on getting dolled up. She couldn't stand or walk on her own, so Dawn, her Jamaican angel aide, carried her to the bathroom and helped her with her makeup. But that was as far as my mother got before her energy simply gave out. She toppled over into the easy chair by the hospital bed, her mouth slack, eyes shut, softly snoring.

I knew how much she wanted to see Gary again, so I tried to rouse her, without success. The rabbi talked to her, too, and said a blessing, but she didn't respond to him either. My mother seemed to have slipped into a realm that was beyond sleep but this side of death. After several minutes, Hugh, together with Dawn and Gary, lifted her onto the hospital bed. She never awoke again.

In a way, her retreat could not have been more perfectly Irene. My mother used up every last atom of her awe-inspiring, superhuman energy reserves to make herself look pretty for the rabbi.

As I kept vigil at her bedside over the next week, I realized that it didn't matter anymore what she and I called each other. Mother or daughter, those roles were done. Finished.

She was just Irene, a woman being swept away by the current that sooner or later takes us all. This was her story, her passage, and I was her witness. It was the first time I really saw her as a separate person—rather than one who existed only in relation to me—and somehow, during the hours I spent by her side not trying to do anything except be present, something came unhooked. All the things we fought over—my ripped jeans and wild hair, her ridiculous pretensions, my bad boyfriends and so-called irresponsible ways, her yearning for a daughter who would reflect her back to herself, my longing for a mother who would see me as I really am—seemed as insubstantial as a wisp of smoke.

Gone.

I buried her in the leopard chiffon.

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