(Not So) Golden Years

Category: Stories
written by Madge Kaplan | March 7, 2014

Madge Kaplan

When I read news articles about caring for elderly parents at a distance, I sometimes shake my head. There’s a tendency to put the best spin on the experience: as long as you contact the right people, get the right information and treat the ups and downs as just part of life’s challenges, you’ll be fine. *You can do this!*

I find myself wondering when the author last talked to a caregiver at her wits’ end—emotions and finances drained, logistics spiraling out of control.

I was a long-distance caregiver for twelve years. I believe it’s best to resist a formulaic approach in favor of one informed by the details—and always, always, humbled by the truth.

Because the truth—and real life—can be humbling indeed.

When my father was in his eighties, he engaged in many activities, from local politics to observing at the UN for an international human-rights organization. He often organized public discussions about our nation’s aging population and how unprepared we were, as a society, to care for their needs.

Then, in 1998, between Christmas and the New Year, he had a stroke.

Suddenly, he was exhibit A.

When I got the call about my father’s stroke, I was working as a national healthcare correspondent for public radio. I lived four hours away from him, and my sister a bit closer; together, we swung into action to help in every way we could. But nothing was easy.

After acute-care hospitalization and rehab, my father returned home dramatically less independent. He relied on a walker to get about a cramped and cluttered apartment—and relied on his wife, ten years younger, to help with pretty much everything else.

Fortunately, he had a computer with which he could search the Internet and keep up with things; he wrote long emails to family members, discussing whatever he was thinking about or had read.

Because the computer was his link to the outside world, when it malfunctioned my father was beside himself with frustration. I’d try to troubleshoot over the phone, and my sister and I installed safeguards, but these weren’t always successful.

My father’s homebound status revealed the limitations of Medicare and of his supplemental insurance coverage for long-term care. Medicare, for instance, covered only a limited number of home visits by nurses and aides, and then only after a hospitalization. Once those days were up, you had to pay out of pocket. My father’s finances consisted of a fixed income (mostly Social Security) and meager savings; he wasn’t poor enough to qualify for the Medicaid that would have covered a home aide.

My sister and I helped pay for the aides, but none of our efforts helped my father to adjust psychologically. Though he knew he was an elderly man, the idea that he’d probably never again be able to walk without assistance or lead an active, independent life made him feel cheated and disappointed.

These complexities were worsened by my father’s marital situation. My mother and father had divorced twenty-five years earlier, and my father’s second wife had serious mental-health problems, most notably paranoia. She viewed helpful outsiders—including her husband’s daughters—with suspicion. Though intrigued by my knowledge of health care and my knack for navigating the system, she also felt resentful, and this played out in disruptive ways.

For instance, although my father appreciated the aides we paid for, his wife accepted them only grudgingly. If she didn’t like an aide, she unhesitatingly found an excuse to get rid of her.

This led to periods during which my father and she had no home help. Some days she’d go out and leave him alone. If he fell, as he sometimes did, and remained on the floor for hours until she returned, that was just the way it was.

My father covered for her lapses, reluctant to have us interfere. In fact, we usually didn’t learn of these episodes until much later.

As I look back on this now, it’s hard to imagine how my sister and I managed to ride the roller coaster of our emotions—surprise, distress, frustration, resentment, helplessness. It was like a bad dream that just went on and on.

At times I found the situation too embarrassing to discuss with anyone but my sister and my closest friends. But I learned that other long-distance caregivers had their own hair-raising tales.

I discovered that we all lost sleep over the same things:

- the presence in our parents’ homes of a series of home aides, most of whom we’d never met;
- ringing phones that didn’t get answered although someone had to be home;
- newly purchased, lifesaving medical-alert buttons that we hoped would work as promised;
- walkers that tended to get caught in rugs, slippers and sidewalk cracks;
- unopened mail, missing bills, checkbooks, eyeglasses, hearing aids or (fill in the blank);
- refrigerators and cupboards that always seemed insufficiently stocked;
- doctor’s appointments we weren’t there for;
- long days alone we weren’t there for;

- medication lists that were out of date;
- lack of adequate funds for long-term care; and
- the inability to start planning ahead for our own long-term needs.

We did share one positive: a deep gratitude for the handful of social workers, hired from a distance, who said things like: “You’re doing all you can. It’s important that you live your life, too.”

Even years later, this list still feels relevant. There have been improvements in long-term care coverage, but not nearly enough; most families have to dig deep into their own pockets to obtain the necessary help.

In 2010 my father died of congestive heart failure while living in a nursing home (the roller coaster of institutional care was another long-distance challenge for my sister and me). Once he was buried in a veteran’s cemetery, we never saw or spoke to his wife again.

Our mother, who’s in good health and lives near me, turns ninety this year. At some point she’ll need more help—and when that time comes, I will try to remember that family caregiving, long-distance or otherwise, is hard and imperfect.

It can also be gratifying. But when it isn’t, that’s not because we forgot to review the playbook or aren’t clever enough. And being honest about that is where we all need to start.

I’m glad that there’s now a lot more public discussion about the ups and downs of family caregiving, including long-distance care. What still saddens me is how the challenges (including dealing with difficult spouses or family members) pretty much take over your interactions with your parent—sometimes for years.

The quality of your time together, the quality of conversation, is never quite the same. And then one day this person you’ve been constantly worrying about is gone—and you never did get to sit and read together or listen to classical music or tell funny stories from the past.

I’d like to believe that we as a society can figure out something better than this.

Until that happens, my sister and I continue to learn from our experience with my dad. Our hearts especially go out to everyone caring for older family members, whether near or far. We all are trying to do our best under challenging circumstances.

About the author:

Madge Kaplan is director of communications at the Institute for Healthcare Improvement (IHI), in Cambridge, MA. She hosts and produces WIHI, IHI’s online audio “talk show” about innovative, evidence-based approaches to health and patient care. She spent twenty years as a public-radio broadcast journalist, most recently at National Public Radio, and was a 1989/99 Kaiser Media Fellow in Health. Her reporting has been recognized by American Women in Radio and Television and by the Pew Charitable Trusts, among others. She’s also written short plays, including one recently staged by The Vineyard Playhouse.

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