

*When My Mother
No Longer Knew
My Name*

A SON'S "COURSE" IN "RATIONAL" CAREGIVING

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WHEN MY MOTHER NO LONGER KNEW MY NAME
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To the memory of my mother,
Sylvia K. Goldstein,
who gave me life, devoted her life to me,
and let me care for her,
even when she no longer knew
who I was

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INTRODUCTION

*It is our choices, Harry, that show what we
truly are, far more than our abilities.*
—J.K. Rowling

There is already a caregiving crisis in the U.S. — too few family members willing and able to care for their parents in their home, too many aging parents in need — and it's only going to get worse. As the nation's population continues to age, more and more seniors will need help with daily living. Typically, they aren't acutely ill, but are frail and failing, limited in what they can do and where they can go. Slowly but surely, their condition gets worse, not better. Tens of millions of us will be affected because we will either need others to care for us or we will need to care for someone else.

Unfortunately, the nation is in denial. Family caregiving is low on the totem pole of priorities and never discussed publicly with the urgency it merits. It was barely mentioned during the months of debate over health system reform. The new law provided for only a voluntary, long-term care policy with minimal benefits and a token daily payout — but even that has been scrapped because it proved unworkable. We can't possibly build enough public or private facilities to accommodate the additional millions of Americans who soon will need care. Insurance companies will not be able to write enough affordable policies paying enough in benefits to defray all the costs we'll face as families and as a nation. And no government program or programs will be able to meet the demand for services.

The *only* solution to our eldercare crisis is obvious: We need to

become a nation of family caregivers. I want to urge others to open their hearts, their homes, and their wallets if necessary to their parents in their declining years, even though it is difficult, challenging, and at times depressing. I also want to show families how they can prepare for the roles and responsibilities of living with and caring for family members, especially their aging and frail relatives, many of whom will suffer from dementia, Alzheimer's, and similar conditions. I believe people should be institutionalized only as the absolute last resort—when they need round-the-clock, skilled care and caring for them at home would be detrimental to them. It's not about money; it's about *neshoma* (Yiddish for soul). Whatever you call them—assisted-living facilities being perhaps the most palatable—the unvarnished truth is even the most exclusive and expensive of them are human warehouses. Assuming there's good blood between family members, it really does run thicker than even the purest water of compassionate strangers. If home is where the heart is, it's surely where family members deserve to be when they need care, especially in the final years of their life.



Caregiving isn't just for women. Most people are shocked to learn about 34 percent of all caregivers in the U.S. are men. By one estimate that's 14.5 million men; by another, as high as 22 million. Make sure all the men in your family play a prominent role in your family caregiving.

I especially want to give hope to mothers and fathers whose sons are their likeliest caregiver. A commonly accepted misperception in America today is that if you want to be cared for in your old age, you'd better have a daughter. Traditionally, a son is thought to be lost to his own family, co-opted by his wife's. Even my mother believed it; at least, as a child, I recall her saying, in addition to my brother and me, she would have liked to have had at least one daughter to remain close to her.

Happily, I proved my mother wrong. In 1998, just before her 80th birthday, I invited her to move in with me. And during the 10-plus years we lived together, she discovered I cared about and for her at least as well as any two daughters combined. My brother was *always* “there” for her, too.

The saddest words I’ve ever heard were repeated to me when my mother was in the hospital, in a rehab facility, and under the care of private duty caregivers at our home. Again and again, shocked professionals told me when they contacted the relatives of people in their care to tell them they were in the hospital or in a nursing home, too often their response was, “Call me when they die.”

I realize every family is different, of course. Not everyone has had a “giving” parent or parents—or is on good terms with them. Caregiving at home is disruptive. I would be the last person to romanticize the experience or the commitment it takes to adjust to eldercare. Not everyone has the extra space I had to accommodate a parent or parents, let alone the emotional reserve. An elderly parent’s needs become greater, more complex, more costly, and more taxing over time.

But more than anything, I want to make America a nation of rational, responsible caregivers — people who plan ahead for the likely



Discover how caregiving can be a joy or you’ll never be able to bear the sorrow, especially as you watch the parent upon whom you depended during your whole life slip away from reality—and you.

day when they or someone in their family can no longer care for themselves, partially or totally. Successful and effective caregiving isn’t an emotional or knee-jerk reaction to crises. It’s the result of thinking through alternative scenarios to deal effectively with different circumstances, long before they arise.

Strange as it may sound, I also

want to make America a nation of joyful caregivers. But how can I possibly write joy and caregiving in the same phrase? How can I suggest there could be anything upbeat about caring for a parent who no longer knew my name? I experienced it.

It took me four-and-a-half years and the sadness of living with my mother who had dementia to discover the “joy” of “caregiving”, and it took me more than two years to write a book to relive it, tell my story, and share practical tips to show others how they too can become joyful in the most unlikely of circumstances. It isn’t the sudden joy of seeing a newborn baby or graduating from college or of taking an exotic trip or winning the lottery or of any of the experiences people typically think lift their spirits. However powerful it may be, that kind of upbeat feeling attached to a given experience fades. The joy from caregiving is more like bliss — a stereophonic, profound and lasting feeling, a unique emotion that comes from giving your all for someone else while expecting absolutely nothing in return.

Overwhelming positives outweigh any and all the negatives of caring for someone whose life is slipping away. For me, nothing is more gratifying than knowing I gave my mother the best care she could possibly have gotten in the last years of her life — absolutely nothing! I cannot imagine not having done this for her. You don’t know what love is until you’ve changed your mother’s or father’s diaper, survived the shock when they no longer know your name, or have spent time holding the hand of, and talking to, someone with dementia, whether they appear to understand what you’re saying or not. In the end, one of the rewards of caring for someone else is discovering a part of yourself you might never have known.

As personal as my observations and experiences are, they contain a total of 75 tips filled with valuable perspectives and practical advice from which everyone may benefit. There are lots of things I would have



The odds are unpaid family members will have to provide most in-home care. But, because there may come a time when paid professionals will need to assist them, it is never too early to weigh the pros and cons of taking out long-term, in-home care insurance. There's a case to be made for getting it — or not. The care someone needs may at first be minimal, lasting just a few hours, and the cost may be manageable. But the bill for 24/7 care can be astronomical. When my mother needed round-the-clock care, we paid \$400 per day out-of-pocket, just for home-health aides. She had decided against taking out an insurance policy. She only needed one-on-one, professional assistance for a matter of weeks. But it still added up quickly. If she had paid thousands of dollars in insurance premiums for years, it wouldn't have been cost-effective for us. In retrospect, we took a calculated risk and made the right choice. But we may have been more lucky than wise. We could have faced a major financial drain. The lesson is to be prepared: Research your options and plan ahead, especially for the unexpected, which can almost be guaranteed to occur. And most important of all, know where the money for long-term care is going to come from if it's needed.

wanted to know and might have done differently. There are many things I learned on-the-job and that could *only* be learned by trial-and-error. I've written my reflections and tips hoping they might help current and future caregivers avoid unnecessary mistakes.

My experiences of caring for and providing care for my mother were the defining moments of my life. They are written entirely from memory. While she was alive, I didn't want to keep a diary because I didn't want to treat her living with me like a laboratory experiment. And I didn't want to do anything, even subliminally, thinking it would make good copy for an eventual publication. Nonetheless, the writer in me knew the day would come when I would simply *have to* write something,

both for myself and others. I made mental notes.

Ten years is a long time in anyone's life. When I invited my mother to move in with me neither of us had any idea how long we would live together or which of us would die first. As the years progressed, she became more and more dependent upon me, and I gradually made adjustments to my personal and professional lives I never dreamed I'd have to: My whole life for four-and-a-half years revolved around taking care of her. Reliving those moments is my way of turning my abiding grief over her loss into a celebration of the unconditional love I found in myself for her — for love, pure and simple, trite as it may sound, is what *real* caregiving ultimately is. My decision to invite my mother to live with me was the best thing I've ever done in my life — an unqualified joy. A similar experience can be equally transforming and rewarding for everyone.