As the balance of duty shifts from parent to child, both generations reap unexpected rewards

The Care Dividend

Growing old is mandatory; growing up is optional.
—CHILI DAVIS

It was the moment I had been dreading for years, the one that had haunted me a thousand times ever since I'd learned that my father had Parkinson's disease. It was the moment of the death talk.

A few weeks earlier he had fallen and hit his head late at night in his room at the assisted living facility and nearly died en route to the hospital. Dad was so malnourished the doctors inserted a feeding tube. Within a week he was shuffling around again, charming everyone in sight, but it didn't last. Shortly after he left the hospital and moved to a nursing home, he started ripping out the feeding tube whenever the nurses were looking the other way. The head nurse called and told me that the tube had to be either reinserted surgically or removed. Without the feeding tube, Dad would die in a matter of weeks.

After conferring with my two brothers, I called Joan, a social worker I knew who specialized in end-of-life care. Dad had made it clear in his living will that he didn't want to be kept alive artificially, but I wasn't certain how he wanted to die.

By Hugh Delehanty
Illustrations by David M. Brinley

My father, a puckish, white-haired man in his 80s with the mischievous charm of a leprechaun, had been raised as a Roman Catholic but was not particularly religious. He was not philosophical either. He had seen a lot of death in World War II as an artillery officer in North Africa and Italy, but he never talked about it. Nor did he have much to say about his brother, James, who fell off a bridge at age five and drowned. This tragedy, which caused his mother to have a nervous breakdown, must have had an enormous impact on my father, who was three then. Yet when I asked him once what it felt like to lose his brother at such a young age, he stared at me blankly and

said he was too little at the time to remember. Nobody in his family ever talked about the drowning. Death was not a subject for polite conversation.

Joan ran into a wall of silence at first. Dad wasn't about to get into a serious discussion about such a personal matter with a stranger. When she asked him whether he believed in an afterlife, he recited something he had memorized in catechism class. I figured he was toying with her. As the conversation developed, however, he became more relaxed and matter-of-fact. At heart, Dad was a pragmatist. He knew his time had come; he just wanted to do it his own way.

"Your son tells me that you want us to take out your feeding tube," said Joan.

"Yes, that's right," he said.

"And if they take out that tube, you're probably going to die. Not today, not tomorrow, but soon."

He nodded.

"You may get to a point in the next few weeks or so when you're not going to be able to make decisions for yourself. Important decisions. Life-and-death decisions. You're going to have to rely on your son. Are you ready for that?"

Another nod.

"I need to hear you say it. Do you trust your son to make those decisions for you?"

"Yes, of course."

At that moment I realized the profound shift that had occurred between my father and me.

For most of human history, our elders could expect to spend their final years as respected members of multigenerational households. North American Indians speak with reverence of older people, who, they say, "are the link with our past, our present, and our future." Fijians advise one another to "listen to the wisdom of the toothless ones." Muslims often consult their elders on major decisions and view their care as a religious duty because, as one saying goes, "Heaven lies under the feet of one's mother."

Of course, this is the 21st century, and recent trends in the United States and elsewhere have put a strain on this time-honored tradition. In an increasingly mobile world, adult children often live hundreds, even thousands, of miles from their parents, while women—who provide more than half of unpaid caregiving—have entered the work force in large numbers. Almost half of the so-called sandwich generation—the cohort of Americans between 45 and 55—have children under 21 as well as aging parents or in-laws. It's a tight squeeze.

But the rewards of caregiving are many and profound. Not only does the experience give you an opportunity to repay someone who gave you life and nurtured you when you were a child; it can also bring you closer to estranged loved ones and resolve long-standing emotional conflicts. As author Beth Witrogen McLeod writes, caregiving "has the potential to alter us at the core of our being, opening our heart's capacity to live fully even in the midst of loss." In a recent survey, researchers asked caregivers to describe their feelings. "Worry," "sadness," and "frustration" came up a lot, but the words they used most frequently were "loving," "appreciated," and "proud."

Many caregivers start out thinking they're embarking on a fix-it project, says clinical psychologist and Buddhist meditation teacher Tara Brach, author of *Radical Acceptance: Embracing Your Life With the Heart of a Buddha*. "But if you think you're just doing a job, there will always be a wall between the two of you. Instead, if you approach it with the point of view that the person you're taking care of is going through a natural process, a profound connection begins to grow."

Sometimes this shift happens when the stress gets unbearable, but more often than not it emerges slowly because, in the process of doing all the day-to-day tasks of caregiving, a kind of intimacy develops that you've never before experienced. As soon as you realize that your parent isn't going to be around forever, says Brach, "you stop holding back expressions of love, because you know there's not much time."

There's also another dynamic at work. All your life you've envisioned your parent as strong and powerful, so as he or she gets weaker and more dependent, barriers begin to fall away. Parents—particularly those who survived the Depression—often resist acknowledging weakness. But when they do, it becomes the ground for a much deeper level of trust. "Trust occurs when somebody's vulnerable and lets you in—and you show up," says Brach. "It often isn't until we're sick and dying that we open up and let that happen."

For the caregiver, one of the most important tools is self-forgiveness. Caregivers often punish themselves for not being perfect. But what does "perfect" mean in this situation? No matter how angelic you are, you're not going to save your parent's life or completely ease his or her suffering. "All you can do is love that person," says Brach. "And the deepest expression of love is paying attention."

That means paying attention not only to what's happening with your parent but also to what's happening to you. When feelings of anger or fear or guilt arise, it's important to be forgiving toward yourself; otherwise, unacknowledged emotions diminish your ability to be fully present. "The more you're just being with the person, not trying to fix him or her," says Brach, "the more you'll be able to see them as what Thomas Merton describes as the divine that comes through all life."

Brach's friend Susan Stone had an awakening of this kind several years ago when her mother, Blanche, was diagnosed with terminal non-Hodgkin's lymphoma. As Susan relates in *At the Eleventh Hour: Caring for My Dying Mother,* Blanche surprised her one day by showing her some poems she'd written. Susan, who had taught poetry, said a few encouraging words. But that didn't satisfy her mother.

"You keep saying you like my poems, but you don't say anything else," said Blanche. "I don't want nice words. I want real criticism. Like the kind of things you talk about in your classes."

So for the next few weeks, until Blanche grew too feeble, mother and daughter talked about adjectives and line breaks and

"the fact that good poetry isn't just about pretty things but about real things." At one point Blanche declared, "Where've you been all these years? I never knew this before. You're the only one who could have taught me this, and I really need it now."

As he neared the end of his life, American novelist William Saroyan quipped, "Everybody has got to die, but I always believed an exception would be made in my case. Now what?" Saroyan was being lighthearted, but his question—"Now what?"—is an important one.

The journey through the later years is likely to bring moments of uncertainty and even bafflement, not just for those making the passage but also for the caregivers helping them down that mysterious road. Along the way many difficulties will arise. Caregiving can tear you apart. After all, this is your mother or your father. And you are their child.

I think of my friend Rosemary. She spent much of her adult life trying to create a close relationship with her mother, Arlene, a tough-minded, fiercely independent woman who raised five children on her own after her husband died in a plane crash. Then, when Rosemary was in her 40s, Arlene was diagnosed with early-stage Alzheimer's. Rosemary volunteered to become the primary caregiver.

It has been a wrenching experience. Rosemary moved Arlene to an assisted living facility a few blocks from her apartment in Manhattan. At times, Arlene would start yelling and lash out at Rosemary for no discernible reason. But with the help of an Alzheimer's support group and a lot of persistence, Rosemary slowly learned new ways to interact with her mother, and their relationship changed. "I had to drop what I wanted to do and step into her world," Rosemary recalls. "When I finally did that, the opportunity for love and gentleness grew by leaps and bounds.

"When you're a caregiver, a lot of what you do goes unrecognized. Then there are times when the eternal mother-daughter roles dissolve. She's softened and I've softened. She's become the loving mother I've always wanted, and I've become the daughter I always wanted to be."

Tears start to well in her eyes.

"I've finally learned what it really means to love someone."

A similar transformation happened between my father and me. When I started caregiving, splitting the duties with my brothers, I thought the generational divide between us was unbridgeable. Dad was a product of the Depression; I was a wide-eyed Baby Boomer who had spent a good part of my life creating as much distance as I could from him.

A therapist I knew suggested that I spend time hanging out with Dad—nothing special, just sitting around the kitchen table gabbing, as he called it. We talked about my mother, who was Dad's childhood sweetheart, and the 830 letters she wrote him during the war, one for every day that he was away. We talked about his father, a trolley man and a union leader in New Haven, and the lessons he taught Dad about his favorite subject: Irish history. In the course of those conversations we both changed. Dad allowed himself to become more open and vulnerable, and I became less of a smart-ass and began to allow myself to feel the depth of his love for me.

Then, that day in the hospital, when Joan, the social worker, asked her question and my father answered, I knew there was no going back. Yes, my father was going to die and I was going to have to give the order to pull the plug. All my life I had been the renegade, the one who tested the rules. That was my role. But with three words—"Yes, of course"—my father liberated me from my past. He trusted me with his life—and death.

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Excerpted from *Caring for Your Parents: The Complete AARP Guide* by Hugh Delehanty and Elinor Ginzler, published by AARP Books/Sterling, 2005. To order online, go to www.aarp.org/books or www.bn.com.

Visit www.aarpmagazine.org for additional caregiving resources. To order black-and-white reprints, call 866-888-3723.

HELP

Where to turn...

GENERAL INFO

AARP www.aarp.org/caregiving; 888-OUR-AARP (687-2277). A multifaceted resource for caregivers that offers information in many forms.

LOCAL CARING

Eldercare Locator
www.eldercare.gov; 800-677-1116. Sponsored by the U.S. Administration on Aging. Specializes in putting caregivers in touch with resources located in their own communities.

ADVOCACY

National Family Caregivers Association
www.nfcacares.org; 800-896-3650. An activist organization that supports, educates, and represents those caring for chronically ill, aged, or disabled loved ones.

MEDICARE

The official government contact for all questions about Medicare and Medicaid eligibility and coverage: www.cms.gov; 800-MEDICARE (633-4227).

BOOKS

Caring for Your Parents: The Complete AARP Guide by Hugh Delehanty and Elinor Ginzler (AARP Books/Sterling Publishing Co., Inc., 2005). Strategies from those who've been there; contacts for help lines, websites, books, brochures, and consumer resources; work sheets and checklists.

Always on Call: When Illness Turns Families Into Caregivers edited by Carol Levine (Vanderbilt University Press, 2004). A collection of helpful narratives by caregivers and noted health-care professionals.

The Merck Manual of Health and Aging edited by Mark H. Beers, M.D., and Thomas V. Jones, M.D., M.P.H. (Merck Research Laboratories, 2004). How to understand medical conditions and navigate the health-care system.

Being There

Caring for my mother was the greatest gift she could ever have given me

By Jane Adams

Early in the morning hours of what would be the last day of my mother's life, my 21-year-old daughter, who'd been shuttling back and forth to the hospital as I kept vigil, urged me to take a break. "Don't worry, I'll be here for Bubbe. I won't leave her alone." Holding out my coat, she put her arms around me, hugged me close, and whispered, "And when it's your turn, I'll be here for you too."

My heart, which had been so heavy, lifted at her words. At that moment I knew my daughter would someday accept from me the same gift I had received from my mother: the privilege of caring for a parent and of sharing in her last days.

Of course, when most of us had children, the last thought in our minds was that they'd take care of us at the end of our lives. But the question of who will be there for us becomes increasingly important as years go by. When the time comes, your children may see it as their last gift to you. But you'll know better.

It may be that your kids are long grown, and perhaps their kids are too. On birthdays, at weddings, and at funerals, you occupy the role of family elder. Such ritual occasions can leave you, in the quiet times between them, to dwell on how much being a parent has defined your life. Of all your roles, parenthood is the one that counts the most.

The last stage of parenting—when we turn responsibility for our children's lives over to them—comes at different ages for all of us. It is at this point when we realize that whatever we forgot to give, teach, show, honor, or forgive—well, they'll just have to do without. It's a critical point in our psychological development as adults. As for the children, it's a ready-or-not deal. They may take years to accept responsibility for their own lives and also stop blaming us if those lives aren't perfect.

Years go by, and long after we've resigned ourselves to knowing there's nothing else we can give our children, something comes up: the opportunity for that one last gift.

Some people call this "reversal of roles," but it is actually something much more profound than that. Our children can never become our parents, regardless of what caretaking tasks they assume. Rather, it's a shift in our shared emotional lives. For them, it is an important stage of their adulthood and an opportunity for psychological growth. For us, it's our last "teachable moment" as parents—and grandparents. Allowing our children to truly be our friends in all the ways that matter as we near the end of our lives creates a model of love, caring, and sharing for both our children and their own offspring.

I cared for my mother during the last four years of her life. I know that some of my friends, those who'd never "settled business" with their parents, undertook the responsibility of the final years out of a sense of duty rather than love. As one told me, "She wasn't a very good mother and maybe I wasn't the best daughter either. But at the end of the day, I want to be able to look myself in the mirror and say, 'You did what you were supposed to.' "

It wasn't that way for me. My mother and I had resolved our difficulties, accepted that we were both right, each in our own way. My mother was 71 when my father died. Gradually she allowed us to modify, though not reverse, our traditional roles. She turned to me as a source of information and a resource for learning to manage her own affairs, from finances to taxes to real estate. She let me be a friend with whom she could gossip or complain about her other friends. She knew I could and would understand, empathize, and accept.

She shared her long-buried anger at my father for "dying just when we had our best years ahead." She confided her guilts, justified or not; her fears about her health; her concern for her children and grandchildren; and her worries about the future of the world, the stock market, and the Mets.

I feel sorry for parents who begrudge their children that gift. I learned many valuable lessons in the last years of my mother's life. Most important, I came away from the experience feeling confirmed as an adult, aware that I'd fulfilled my obligations as a daughter—obligations of love, care, and commitment, like those she'd fulfilled for so long for me. That was her final gift to me, and of all the things she gave me, that's the one I'm most grateful for. ■

Social psychologist Jane Adams's latest book is Boundary Issues: Using Boundary Intelligence to Get the Intimacy You Want and the Independence You Need in Life, Love, and Work *(John Wiley & Sons, September 2005).*