The Care Dividend

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

By Hugh Delehanty

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 and 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 we either had to reinsert the tube surgically or remove it. Without the feeding tube, he 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, to help me talk the situation over with my dad. Even though he had made it clear in his living will that he didn’t want to be kept alive artificially, I wasn’t certain how he wanted to die.

My father, a puckish, white-haired man in his 80s with the mischievous charm of a leprechaun, was not particularly religious. The son of Irish immigrants, he had been raised as a Roman Catholic in Fair Haven, Connecticut, and attended parochial school, which made him skeptical about religious dogma for the rest of his life. He went to Mass on Sundays when my brothers and I were kids, but he often fell asleep in the pew and I never once saw him go to confession or take Communion. For him, going to Mass was a familial duty, not an act of spiritual discovery.

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

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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 a profound shift had occurred between my father and me.

The generational divide between us used to seem unbridgeable. He was a product of the Depression; I was a wide-eyed baby boomer. I had spent a good part of my life creating as much distance as I could from him because he was stubborn, autocratic, and wanted us to fit into his conventional 1950s vision for the family. I needed the freedom to shape my own identity. So after college, I put 3,000 miles between us by moving to northern California. Sure we talked, but not about anything real. He wasn't interested in the demons I was wrestling with ("all that therapy stuff," as he called it); he just wanted to know how "the Job" was going. Most of our phone calls didn't last very long.

Years later, after I moved with my family to New York, Dad's illness got worse, and my brothers and I decided to split the caregiving duties. My older brother, John, took over the finances and legal matters; my younger brother, Dennis, coordinated the supporting cast of friends and neighbors; and I became my father's health advocate.

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 his 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.

En Español

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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.

The World's Greatest Gift

For most of human history, our elders could expect to spend their final years as respected members of multigenerational households. American Indians speak with reverence for older people, who, they say, "are the link with our past, our present, and our future." Fijians advise each other to "listen to the wisdom of the toothless ones." Arabs often consult their elders on major decisions and view their care as a religious duty because, as one saying goes, "Heaven would be found under the feet of one's mother." And the Chinese consider parental fealty a key to social harmony.

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 workforce in large numbers. The challenge of working outside the home while caring for an elderly parent—and often children as well—adds considerable stress to the lives of women and men alike. 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 aging in-laws. It's a tight squeeze.

But the rewards of caregiving are many and profound. Not only does it 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."
"Love Is Paying Attention"

If you're reading this, you're probably embarking on a caregiving journey of your own. What kind of caregiver will you be? Many people when they're starting out tend to think of caregiving as a fix-it project, says clinical psychologist and Buddhist meditation teacher Tara Brach, the author of *Radical Acceptance: Embracing Your Life with the Heart of a Buddha*, but that perspective has serious limitations. "If you think you're just doing a job, fixing a person who is weaker than you, there will always be a wall between the two of you," she says. "But 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 that shift happens when the stress gets unbearable, but, more often than not, it emerges slowly, as it did with my father and me, because 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, "the preciousness of their life becomes very immediate. 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. Our culture places such a high value on self-reliance that aging 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."

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Caregivers who have the easiest time shifting perspective, says Brach, are those who aren't locked into patterns of denial. "If you're in the habit of avoiding uncomfortable situations, you will probably take the position that something's wrong," she says. "But if you've developed a habit of honestly recognizing your own insecurities, then you'll probably find a place in yourself to tolerate it when someone else is experiencing pain and suffering."

The key 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. "Caregiving is painful," says Brach, "because you can't take away the other person's pain. You can't make everything okay. All you can do is love that person. And the deepest expression of love is paying attention."

That means not only paying attention to what's happening with your parent, but also 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 will diminish your ability to be fully present. "The more you're just being with the person, and not trying to fix him or her," says Brach, "the more you'll be able to see them as what Thomas Merton calls, 'the divine that comes through all life.' "

Brach's friend, Susan Stone, had an awakening of this kind several years ago when her mother was diagnosed with terminal non-Hodgkin's lymphoma. A poet and an expert in Asian history and culture, Susan was training at the time to be a Zen monk in California. When she returned to St. Louis to take care of her mother, Blanche, she had elaborate plans. "I thought that I was going to help teach her how to face death," says Susan. "But Mom didn't want any part of that. So I dropped my big mission and started focusing on little things, like folding the laundry together. I realized this was the greatest gift I could give her. Just being with someone—and doing it mindfully—is empowering because you're allowing that person to be who they really are."

Three months before her death, Blanche surprised Susan by writing a poem about the trees in the backyard. Susan said a few encouraging words, but that didn't satisfy her mother. A few days later, Susan relates in her book *At the Eleventh Hour: Caring for My Dying Mother*, Blanche announced, "You keep saying you like my poems, but you don't say anything else. I don't want nice words. I want real criticism. Like the kind of things you talk about in poetry 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. And I was satisfied with just my newspapers and my books. You're the only one who could have taught me this, and I really need it now."

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After Blanche died, Susan designed a workshop on mindful caregiving based on her experience with her mother. "When I started out as a caregiver, I didn't think I could do it," she says. "But I learned that I didn't have to have all the answers. I just did things step by step, and I found that if I made decisions based on what was needed at the moment, I didn't have to worry. That was very liberating."
In Search of a Second Adulthood

In his groundbreaking book *The Soul and Death*, psychologist Carl Jung argues that the task of midlife is to come to terms with death. "Natural life is the nourishing soil of the soul," he writes. "Anyone who fails to go along with life remains suspended, stiff and rigid in mid-air. That is why so many people get wooden in old age; they look back and cling to the past with a secret fear of death in their hearts. They withdraw from the life process, at least psychologically, and consequently remain fixed like nostalgic pillars of salt, with vivid recollections of youth but no living relation to the present. From the middle of life onward, only he remains vitally alive who is ready to die with life."

Contemporary Western culture doesn't reinforce this point of view. We have replaced the traditional mythic rites of passage with a Peter Pan-like obsession with youth. To cling to the past and remain stuck in the illusion of youthfulness, writes Jung, is as absurd as not being able to outgrow child-sized shoes. "An old man who does not know how to listen to the secrets of the brooks puts it, "When you're close to someone dying, you realize that you're a living-dying being yourself." They spend their last years living more consciously. Those who avoided the first death are haunted by the second, afraid their lives have not been meaningful.

Caregiving is a way to avoid that trap. The Jungian analyst James Hollis divides life into four psychological stages, each with the power to define a person's identity. The first stage is childhood, which is characterized by the dependency of the ego on the parents' world. The second stage is first adulthood, roughly from puberty to age 40 but it can last a lifetime, when the dependency of childhood is projected onto the roles of adulthood. The third stage is second adulthood, when those projections dissolve and one has a chance to become a true individual, beyond the determinism of parents and cultural conditioning. The fourth stage is mortality, which involves learning to live with the mystery of death.

In his work as a therapist, Hollis has noticed that the elderly generally fall into two categories: "There are those for whom the life remaining is still a challenge, still worthy of the good fight, and those for whom life is full of bitterness, regret and fear," he writes in his book *The Middle Passage: From Misery to Meaning in Midlife*. "The former are invariably those who have gone through some earlier struggle, experienced the death of the first adulthood and accepted greater responsibility for their lives. They spend their last years living more consciously. Those who avoided the first death are haunted by the second, afraid their lives have not been meaningful."

This transition doesn't come easily. It usually requires a major loss or disillusionsment that jolts you into consciousness and liberates you from old projections. Taking care of a dying parent can be such a catalyst if it's done consciously. As Tara Brach puts it, "When you're close to someone dying, you realize that you're a living-dying being yourself."

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Caregiving is a humbling experience. It forces you to move beyond narcissism to a more inclusive identity. "We spend so much of our time thinking 'How am I going to make myself comfortable?' 'How am I going to handle this future situation?' " says Brach. "But there's a tremendous amount of freedom that comes when you widen the circle of what you're paying attention to and include someone else." It's possible, of course, to find this kind of liberation in other ways. But the day-to-day rigors of caregiving give you direct experience of the alchemy of selflessness. It helps you see, says Brach, that "there's more reality in togetherness than any idea of a separate self."

Now What?

As he neared the end his life, the American novelist William Saroyan quipped, "Everybody has got to die, but I always believed an exception would be made in my case. Now what?"

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. The specifics may vary, but every adult child taking care of an aging parent faces some version of Saroyan's question. What is coming next? How should I get ready for it? How do I cope? 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 free herself from 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, one night when Rosemary was in her 40s, Arlene packed a suitcase and wandered away from her house in Brooklyn, hallucinating about a helicopter on her roof and men under her bed. She was later diagnosed with early stage Alzheimer's, and Rosemary, who is a gerontologist, volunteered to become Arlene's primary caregiver.

It has been a wrenching experience. Rosemary moved Arlene to an assisted living facility a few blocks from her apartment in Manhattan and tried desperately to communicate with her. At times Arlene would start screaming and lash out at her 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 dynamic changed. "I had to drop what I wanted to do and step into her world,"

http://www.aarpmagazine.org/family/caregiving/the_care_dividend.html/tools/print/?Title=The Car...
Rosemary recalls. "When I finally did that, the opportunity for love and gentleness grew by leaps and bounds."

Not long after things settled down, Rosemary had to cut back her time with her mother to two days a week to care for her husband, who was diagnosed with cancer. By then, though, Rosemary's connection with Arlene was strong enough to withstand the strain. "When you're a caregiver, a lot of what you do goes unrecognized," Rosemary says. "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 loving daughter I always wanted to be."

Tears start to well in her eyes. "I've finally learned what it really means to love someone."

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