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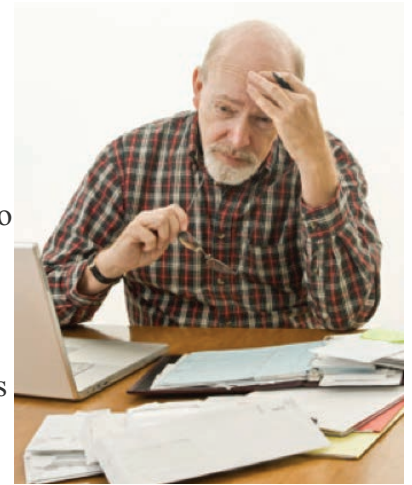
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Elder Care Guilt: Making Peace with Your Decisions

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“When I first asked my mother to move her answer was a definite ‘No!’” Lynn D. remembers. “To her, leaving her home meant abandoning her life, including the memory of her time with my father. Even though I believe the change was absolutely for the best, I couldn’t force her to leave that memory. After all, it’s been 15 years since my father died, and I still miss him every day. How could I do that to her?”

“Plus, my mother’s mind is starting to fail her. Would moving her into a new situation mean that she would lose all reminders of my father? Was being this cruel a risk I was willing to take? I even wrestled with whether I had my mother’s best interest in mind sometimes. I experienced constant confusion.”



MAKING THE SENIOR CARE DECISION

Lynn made the elder care decision to relocate her mother into senior housing after an incident at the hospital.

“My mother had fallen and broken her hip. She was sitting up in her bed when she made a fist and pulled her hand back suddenly, her target the unsuspecting medical aide who had called her “honey.” “Mother!” I said firmly. She struck me instead.

“Stop!” Lynn recalls yelling, treating her mother more like child than parent. “Just stop, mother. Now!”

Lynn held her mother’s fist within her hand, uncertain if she should let go.

“At this point,” says Lynn, “my emotions felt unbearable. My mother reacted physically to her frustrations with her situation, her helplessness, her vulnerability. Ultimately, as my mother’s only child, I am going to own the brunt of her anger when her world turns upside down. It is a role I’m used to but one that never abates.”

Lynn’s mother is strong-willed and independent. But Lynn has come to realize that her mother needs to be moved so that she can receive better care, so she is moving her from New York to Maine, where her mother will live next door and receive full-time professional home health care. Lynn knows that relocating her mother from her home of fifty years is the right thing to do, but it doesn’t alleviate her feelings of remorse.

COPING WITH ROLE REVERSAL

Every aspect of handling our aging parents’ futures can provoke tremendous ambivalence. We are often in denial about their increased vulnerability as well as their reduced decision-making abilities. We, as children,

are suddenly placed in the role of caring for our elderly parents, who for many until only recently were our caregivers. This exchange of roles not only intensifies our parents' feelings of helplessness but also our own confusion and guilt.

Marjorie W. feels that guilt every day. A self-proclaimed perfectionist who does not count patience among her traits, the University of Washington medical researcher never experienced a sense of calm when caring for her mother. Today, Marjorie looks after her father in the later stages of his life, an experience she enjoys.

“Dealing with my mother’s dementia, which came on so quickly, challenged every fiber of who I am,” Marjorie recalls. “My mother was a very sharp woman who made me promise, after having dinner with a demented family member, that I would never allow her to become like that. But I had no idea how to deal with this demand once the dementia actually started.

“Each time I would leave my mom, I was determined to be more patient the next time I saw her. Then I would fall back into frustration within minutes of seeing her again. This pattern would repeat itself throughout my visits.

“One positive result occurred, however-after experiencing all of the feelings of guilt with my mother’s situation, I was clear placing my father in an assisted-living situation was the right thing to do. Because I had bound myself in guilt with my mother, the questions surrounding my father’s relocation were mostly answered.”

Marjorie’s father first moved to an independent living retirement community after his wife passed away. Once he sustained multiple bone fractures in a fall, he moved into the adjacent nursing home.

“With my mother I felt like I was always failing, a concept that is, frankly, very foreign to me in my professional and personal worlds. I remember once, early on, I glanced over at her while I was cooking for her and noticed that she appeared really lost. I asked her what was wrong and she said, ‘I don’t have a role anymore.’

“I said, ‘of course you do, you’re my mother.’ But her comment really stung.”

Putting anyone into a new environment can be an uncomfortable and even distressing experience. Suddenly, while at their most vulnerable, we “ask” our parents to form new acquaintances, trust new professional caregivers, navigate new schedules, and acclimate to new environments. These demands will challenge them acutely, while we, as children thrust into primary decision-making roles, can only hope they’ll make the best of the new situation.

MOVING PAST GUILT

According to Dr. Stephan Quentzel, Medical Director for Psychiatry at the Institute for Urban Family Health in New York City, Marjorie’s and Lynn’s feelings are typical of caregivers who are faced with relocating their parents.

“There are plenty of factors that go into feeling guilty,” Quentzel explains. “Emotions range from feeling inadequate to feeling overly responsible.

“Most significantly, we want our parents to remain decision makers and to be omniscient, to regain the sense of normalcy. We’re upset when we have to take over their roles. We feel guilty about the role reversal. We assume moving them into assisted living declares loudly and clearly that we can’t handle taking care of them.

“One way to address this situation is to anticipate it,” he suggests. “Enter into it with emotional health, whether as a result of psychotherapy or some other methodology. Deal with issues before they encumber our ability to deal with our parents. The better our perspective, the better the outcome. Visiting assisted living facilities with your parents early is one definite method to keep them in the loop.”

The “could-a, would-a, should-a” moments further add to our guilty feelings, creating an emotional vicious cycle. We find ourselves rethinking our elder care decision, replaying conversations, wondering if we are doing the right thing. This second-guessing can turn the already finite time we have to spend with our parents into even more stressful and anxious experiences.

“I constantly thought I should be with my mother,” Marjorie remembers. “Returning to work after an extended visit with her felt like when I returned to my research after having a baby. My focus was shot, I was unsatisfied on both the work and the caregiver fronts.”

“In our society,” observes Quentzel, “we are used to making informed decisions about what we buy, where we live, etc. Medicine doesn’t always provide perfect answers, plus we are asked to make critical arrangements about someone other than ourselves.”

Quentzel believes that this issue can also be anticipated. “Make decisions with your parents while they are still at a place to make such decisions. A comprehensive Living Will and Health Care Proxy can ease the approaching situation for everyone. Proper health insurance and financial preparation also alleviates areas of common conflict.”

When the topic is relocation into an assisted living community or nursing home, an elder care decision with enormous financial and lifestyle consequences, the anxiety level is further heightened. Early planning can broaden the options, answer many of the initial questions, and clarify some of the ambiguity, but the doubt and uncertainty of how things will turn out remain.

“The paradox, of course, is that we want nothing more than to ease our parents’ pain and suffering, even to sacrifice our comfort temporarily to improve their overall lives,” Quentzel says. “And yet, by its very nature, the desired outcome remains uncertain.”

“Still, focusing on the small victories helps alleviate our guilt. Small victories include excellent palliative care, creating meaningful activities, even keeping our parents together for as long as possible. Making an informed decision about assisted living is a potentially huge step towards this goal.”

“I discuss most of my life with my father,” reflects Marjorie, enlightened with the wisdom that comes from having gone through this process once before. “I am much more patient with my father, who is less complex psychologically than my mom. I am also determined not to repeat the mistakes with him that I believe I made with her.”

“Empowering our parents is a priceless opportunity,” Quentzel agrees. “They remain keepers of the family, full of family history and cultural knowledge. We craft their legacy and add a bit of eternity when we communicate. They appreciate the longevity of their family and their fear (and our guilt) of being supplanted diminishes.”

Moving our parents is never easy. We are faced with an elder care decision that challenges our ideals of the parent-child relationship, and the often narrow window in which to make these decisions usually forces us to make momentous choices without having every resource available to us. But we do the best we can for them with what we have, and hopefully remember that our parents once did the same for us.

“I’m told I am a very empathetic person,” says Lynn, releasing a long sigh. “Even so, I often block the most difficult times with my mother. I try to maintain perspective about her condition and that my moving her conveys her best interest at heart. Still, it is never easy. In fact, I’d say it is extremely hard. But I know it is for the best.”