

Negotiating Life's Turns

Are you ready to be a family caregiver?

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Let's say you're about to hit 50. Your children are out of the nest. Your parents are enjoying their golden years. Free at last! You have a whole second adulthood ahead of you. This is the time to find your passion, maybe go back to school or start your own business. Then you get the call that changes everything. Your mom's had a fall and broken her femur. Or your dad's driven through a red light and had an accident, but he doesn't remember how it happened—is it his eyes or his mind? Or your husband's doctor calls you with shocking news: “It's cancer.” That call came to me. I froze. The shock plunges you into a whirlpool of fear, denial and feverish action. You search out doctors. They disagree on the diagnosis. You scavenge the Internet. The treatment options and side effects freak you out. You call your brother or sister, hoping for help. Old rivalries flare up. You haunt the corridors of the hospital, always on duty to prevent mistakes. It begins to dawn on you that your life is also radically changing. You have a new role: family caregiver. It's a role nobody applies for. You don't expect it. You won't be prepared. You probably won't even identify yourself as a caregiver. So many women tell me, “It's just what we do.” But family caregiving has become a predictable crisis for Americans in middle and later life.

The average family caregiver today is a 48-year-old woman who holds down a paying job and still has at least one child at home. Half of family caregivers work full time. There are nearly 50 million of us taking care of adults who used to be independent. Will you approach this role as an honor or a burden? Will you stumble through it in chaos or find a path? I found and walked this path for 17 years with my husband. And in my role as AARP Ambassador for Caregiving, I have interviewed hundreds of caregivers and learned about useful tools and techniques from them. In my experience, I discovered eight universal turns caregivers go through. It begins with *Shock and Mobilization*. Once the immediate crisis is resolved, you enter The New Normal and begin to think, “OK, I can handle this.” This reprieve may go on for months or years. Eventually there is a third turn—Boomerang, another crisis. But this time you are a little smarter about how to galvanize. You need to call a family meeting. You cannot do this alone. If you begin to think you are responsible for keeping your loved one alive and safe, you will eventually find yourself at the next turn: *Playing God*. This can become an unhealthy, co-dependent relationship. Eventually you will reach the next and most dangerous turn: *I Can't Do This Anymore!* You must take care of yourself. The sixth turn is *Coming Back*. You have reached the center of the labyrinth of caregiving. Here, you must appreciate all you have done and begin to acknowledge that your loved one is not going to return to the independent person he or she once was. You are on a different path. You need to replenish your lifelines—friends, music, work, nature—whatever are your transports to joy.

The *In-Between Stage* is a momentous turning point for those who care for the chronically ill. Your loved one cannot be cured in an acute-care hospital, but he or she is not ready to die—and may live on for years. But our health-care system has little to offer at this stage, except round trips to the emergency room and readmissions to the hospital. Most slow-aging adults today develop chronic illnesses. They are sent home quicker and sicker to you, the family caregiver, who has no professional training, no financial support and rarely any respite. I found a solution in palliative care—which is an entirely different strategy. The final turn is *The Long Goodbye*. This is a true gift. You now have time for end-of-life conversations and some kind of closure. The passage to caregiver may well be the most memorable in your life. How you usher your mom or dad or spouse or sibling out of this world has so much impact on how you think about yourself: Am I a good person? Did I do everything I could? Did I let my siblings do the heavy lifting? Did I hold on too long? Let go too soon? Or did I share precious moments of full presence right up to the end?

About the author: Gail Sheehy is the author of 15 bestselling books, including the revolutionary *Passages*, which remained on The New York Times bestseller list for more than three years and has been reprinted in 28 languages. Her new book, *Passages in Caregiving*, deals with the challenge that people will most likely encounter later in their lives—taking on the role of caregiver.

