

A Role You Did Not Choose

WE SPEND MOST OF OUR LIVES PREPARING FOR THE future we envisioned for ourselves. We might work hard to get into a good college or train to excel in a sport we choose. We prepare as diligently as we can for the profession we seek. We read books on marriage and parenting.

Then, sometimes right at the time when we feel we have achieved our life's goals, when we have fulfilled our responsibilities to children and profession and are looking forward to winding down and savoring the time to pursue other interests, we are caught off guard with a doctor's proclamation: "You have Alzheimer's"—or Parkinson's, or a cancer, or a critical heart or lung condition, or another life-threatening disease; a brief sentence that brings our carefully crafted world crashing down and changes our lives forever.

When we first received the diagnosis of Alzheimer's, my husband was about to retire. Our children were well-established in their careers and each of our grandchildren seemed solid and full of potential. We had hoped to have the leisure time to travel and enjoy each other. The years ahead were ones we had worked a lifetime to enjoy. Now three words had changed everything.

Too often, no matter how conscientious we have been in previous roles in our lives, we slide into what may be our most challenging responsibility yet with no plan or direction, unprepared and ill-equipped for this unanticipated transition. This verdict was not in our life's plan. We dread going through this new doorway. We don't have confidence in ourselves. We fear being in a place where we have no command and no control.

Most of us tumble into this new caregiving role without acknowledging to ourselves what a momentous transformation has just taken place, not only for our afflicted mate or loved one but for ourselves. Faced with the need for immediate action, we shoot from the hip. We try to handle the change without reevaluating, without a plan, without knowing our options. Our world has just taken a major turn, one we are woefully unprepared to deal with, yet we don't understand what a steep and crucial learning curve lies before us. So it is vital here, too, just as in our younger days, to educate ourselves about this new and unanticipated reality. Too often, by the time we begin to learn what might have worked, the negative consequences of this unwelcome sentence have become so entrenched that they are difficult or impossible to change.

In this book, I describe all that I learned during my husband's last six years, in the hope that it will make others' paths easier, calmer, less stressful—and, yes, happier. I knew I was not prepared for what I was facing, but it took me several years to comprehend the enormity of the transition I had to make. Gradually, I understood that I could no longer get by on instinct, that this was not the time to merely react in the moment to day-to-day challenges. That this was another life opportunity to learn and to grow—to learn that we *always* have options, even if it's only the attitude we bring to conditions that we would do anything to change.

I realized that I could not just continue to react in a haphazard way. I had to consciously change my world and that of my husband. I had to become the manager of a huge new enterprise, tackling

my new role as if I had just been hired to run a major company. I set out to observe and learn all that I could to make our lives as fulfilling as possible, for as long as possible, given our new constraints. As the years went on, I began to pay constant attention to what worked and what did not. In the process, I discovered many positive techniques that I write about in these pages.

For example, I began to include Ady in all the decision-making that affected him. Instead of telling him what had to be done, I asked him—often giving several choices, each of which was acceptable. He made the decisions, he owned the decisions, and, most importantly, he accepted them without argument or frustration. In more difficult situations, when Ady expressed genuine opposition, we worked out the differences together, trying to avoid confrontation. Increasingly, he was the one to come up with the solution. Instead of bucking each other, pulling in opposite directions, we became a team working towards a common goal.

Perhaps the most essential change that I consciously made was in my perspective. If we, our loved ones' caregivers, feel frustrated, disappointed, sad, or angry about the new role foisted upon us, those feelings are magnified many times over for our patients. They didn't choose this either. The more compassion, kindness, tenderness, and love we can offer, the easier life will be for both. A brain blocked by anger and frustration cannot function at an optimal level. A peaceful, predictable, non-combative environment creates the opportunity for inner calm and healing. At first, I had to remind myself constantly of this approach, but over time it became easier and eventually almost instinctive. The more I gave genuine praise and encouragement, the more the typical frustration vanished.

The success Ady and I achieved together was far beyond anything that I could have envisioned. My life became easier, and his flourished. It was a classic win-win situation. Our lives evolved from bearable to pleasurable. So simple, once one develops the habit, and so marvelously productive!

This totally unanticipated outcome is what motivated me to gather all of the notes I had scribbled on the back of envelopes and on the blank pages of concert programs to try to understand what we did together that worked successfully. My goal is to give hope and offer concrete suggestions to others who have received that devastating pronouncement. While much of what I suggest are concrete ways to deal with medications, doctors, aides, time management, and decisions, the greater part of this book emphasizes the attitude that we bring to our spouse or loved one. No matter what the relationship was before the onset of any decline, the more we bring large doses of compassion, kindness, tenderness, support, and encouragement, the easier the path will be for both caregiver and patient. *Even if your past relationship was not ideal*, it's not too late to build a more supportive one.

Though the personal experience on which this book is based was with a loved one with Alzheimer's, it became clear as I wrote that many of the lessons learned and the insights gained could apply to a family member or patient who is declining for any reason—whether the affliction is Alzheimer's, Parkinson's, cancer, a chronic case of sciatica or back pain, or any other debilitating condition. In each case, the awareness of loss of function, dignity, health, self-respect, or zest for life can be devastating. The theme that echoes throughout this book is that our role as caregivers can have a profound impact—on the patient's psyche and willingness to cooperate, on their physical health and well-being, and on the life that patient and caregiver have together.

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Important Caveat: I in no way wish to imply that a caregiver who follows the course of action suggested here will have similar success. Every person, every case, is unique. Countless deeply caring spouses have given love and devotion beyond measure and still ended up with a loved one who doesn't recognize them or becomes angry and abusive. I cannot offer any guarantee of a

different outcome. Relationships come with a history—a history that shapes reactions to each other and to difficult situations. Regardless of your relationship, however, I believe that the evolving methodology described throughout this book has the potential to benefit both patient and caregiver, especially if introduced before unwanted behavior becomes habit.

This book attempts to suggest a path that might make the journey more tolerable for both patient and caregiver. I hope to inspire and empower you, the caregiver, with the knowledge that you are not helpless. You *can* make a difference. You can continue to open doors, rather than just witness them closing. You can increase the chances of success by providing mental stimulation; by encouraging creativity; by refraining from judgment or criticism; by giving support, appreciation, praise, and respect; and by remembering always the person your loved one once was and giving him or her the dignity they have earned throughout their lives. I hope to demonstrate that even during this overwhelmingly sad time, you and your loved one can choose to live with JOY.