A Survival Guide for Alzheimer's Caregivers

The highest reward for a person's toil is not what they get for it, but what they become by it.
~John Ruskin

It started innocently enough. A widower for more than forty years, my father began to struggle to find the right words and express himself. In time, he started repeating sentences and telling stories over and over again.

He was often confused and feared getting lost in the grocery store. Soon he did not recognize his favorite cereal box on the grocery store shelf, so he couldn't place it in his cart. He started to wear his pajamas over his clothes. He neglected to bathe and groom himself. His days and nights were mixed up. He would call me by the wrong name.

One night, while my father was still living alone, he called me.

"Jim, I'm so glad I reached you," he said. "I don't know where I am." I could hear the fear in his voice and it moved me.

"You're at home Dad—and you're safe," I assured him.

"No, I'm not in my house," he insisted.

"Dad, look at the address on the front of the house above the door. If it says 911, then you're in your home."

He set the phone down, picked up a flashlight and went out into the darkness to look at the house number. This was a weekly occurrence I had learned to solve.

He returned to the phone. "It says 911, but this is not my house. Will you please come over and give me a ride home?"

It was late and his home was on the other side of town. I tried my backup plan.

"Dad, look at the family pictures on the coffee table," I suggested. This technique worked every time. The photos reoriented him.

He set the phone down again and walked to the coffee table in the living room. When he returned to the phone I knew he had transitioned to the next stage of this disease.

"Did you look at the family pictures, Dad?"

"Yes."

"Well?"

"Jim, I don't know any of those people. Will you please come and take me home now?" I could hear the fear in his voice and remembered how he quelled my fear at age 11 when my mother died. He was an image of strength then. I needed to be that for him now.

"I'll be right over, Dad."

When I walked in the living room, he was waiting for me. "Please take me home, Jim."

"Okay, let's get you home."

Before I left the house, I turned on the front porch light. I backed out of the driveway and we drove to the corner. I turned right. I made three more right turns as I slowly drove around the block in the darkness. When we approached his house I asked him to look for his house number, 9-1-1.

When I pulled up in front of his house the front porch light was on.

"Can you see that house number, Dad?"

"9-1-1. That's it!" he said. I could sense his relief.

I walked him in to reorient him. He thanked me profusely; relieved to know he was home again.

As I started to return home I knew the time had come to admit him to an assisted living center.

My father spent several years in an assisted living facility for people with Alzheimer's. My siblings and I visited him nearly every day.

Alzheimer's is a long road for both the person with the disease and the family. Yet, I learned there is no higher honor than to serve a loved one during their time of greatest need. My father raised his six children alone. He did it with unconditional love, enviable patience, quiet strength, and an enduring sense of duty. It was our privilege to return the favor.

To care for someone with Alzheimer's you must be ready for the long haul. My five siblings and I learned how to cope and find hope in this arduous journey. Here is what we learned. I call them "The Ten R's." I think of them as a survival guide for Alzheimer's caregivers, and they may help you.

1. Reach out. After an Alzheimer's diagnosis, fear and uncertainty overwhelm you. To combat both, you need to reach out and get more information. Learn as much as you can, because knowledge is power. A deeper understanding of what you're up against not only helps you cope, but it also helps conquer fear. Contact the Alzheimer's Association in your area for seminars that will teach you valuable information to prepare you for this journey.

2. Rotate responsibility. Divide and conquer. If possible, share responsibility for caregiving with siblings or extended family members. The point is, don't carry this burden alone. If there are no siblings nearby, consider hiring a visiting nurse or senior's organization that specializes in home care for seniors. Two of my five siblings, Kathii and Joanie, along with her husband Ron, provided vital emotional support from their home across the country. Avoid isolation. You will need help, if not physically, emotionally.

3. Roll with the punches. People with Alzheimer's often make inaccurate statements as they draw from malfunctioning memory banks. Don't make the mistake I made and correct them. They will wear you out correcting you. Instead, roll with the punches.

4. Release your frustrations. Confide in a friend or another loved one. Alzheimer's is frustrating for everyone involved. Vent. Lean on a friend. It's been said that friends multiply our joy and divide our sorrow. Share your pain.

5. Restore your perspective. Take a vacation. Find a way to get away from your caregiving routine. Easier said than done, but at least take a mini-vacation so you can restore your perspective, recalibrate your life, and come back refreshed and recommitted to the journey.

6. Remember who they "were." During the emotional strain and long course of care you can lose sight of who you're caring for. When I became exhausted, I could see my father as a needy old man. An angry old man. A forgetful and combative old man. If I could feel this way under duress, how would the caregivers at the Alzheimer's facility feel about him?

When his disease advanced to the stage where he had to be admitted to a specialized care facility, my five siblings and I set up a meeting with the entire staff of caregivers. The goal was to paint a picture of who my father "was" so they could appreciate who he "is." We shared photographs and stories of how he was the single parent of six children, a decorated Marine in World War II who fought at Iwo Jima, a cost accountant for the Chrysler Corporation, and a man so devoted to his wife and children that he never gave himself permission to remarry.

All six of his children painted a picture of who our father was—and who he is now. At the end of our presentation, the entire staff was in tears. Facility management later recommended that families admitting new residents introduce their loved ones to the staff in a similar way so they would "make a deep emotional connection with each new resident."

7. Rest. You must rest. This journey is long, hard, emotional, and exhausting. Find quiet moments to retreat and rest. Rest will restore your energy and, more importantly, your courage to tackle the next day. Listen to music, watch TV, or read. Reading a book like this one can help you recharge, relax, and feel less alone.

8. Rebound. If you make a mistake, learn to rebound. You are in uncharted waters. Your mistakes may irritate a loved one who is now prone to anger or combativeness. Accept mistakes and move on. Don't live with guilt if you admit your loved one to specialized nursing care before he or she is ready to go. They are never ready. And although they depend on you to make this call on their behalf, they may severely criticize you when you do.

When my father had to be admitted to an Alzheimer's facility, we decorated his room with familiar things and brought him there to visit for a few weeks. We told him this was his new apartment. Our hope was he would become comfortable and familiar with his room so when we moved him permanently it would not be traumatic for him and he would adjust quickly.

Our family selected the moving day together. We all had a role to play. My brother, Bob, took him out to lunch. Mary, Chris and his wife Sue, and I pulled up with a trailer and loaded his bedroom furniture and enough belongings to fit in the single room. We hung his pictures and set up his furniture. Bob brought him to the facility a few hours later.

My father's reaction? He was furious. He looked at me, insinuated that he had been deceived and accused me of being the "ringleader." My throat tightened when he suggested that I betrayed him.

My father and I were very close all my life so for him to feel I betrayed him cut me to the core. It was times like these I reminded myself that my father's accusations were "the disease talking." During this journey it is important to know the difference between when your loved one is talking and the disease is talking.

My father was a wise man and put his end-of-life instructions to me in writing when he was of sound mind so I would never second-guess myself if his verbal instructions contradicted his written instructions.

9. Rejoice. This is the most important "R." Rejoice in the privilege of serving your loved ones in their hours of greatest need. Abraham Lincoln once said of those who died in the Civil War, "…they gave the last full measure of their devotion…." My father has been gone for five years and I can say with confidence that the six children he raised alone "gave the last full measure of their devotion" in caring for him as he faded from this life. Even when he took his last breath, Bob held his right hand and I held his left. And Bob's wife Patti, and my wife Karen, stood by us until the end.

10. Reflect. When your loved ones pass, take time to reflect on their lives. Even if you did not have a great relationship with them, reflect on the good times and how you faithfully served them.

Along with my siblings, we consider it a joy to have served our father until his death and we enjoy reflecting on his life of integrity and its impact on our children and us.

And isn't having a powerful and positive impact on others what life and legacy are all about?

~James C. Magruder