

Staring at Dementia

Lessons from Mother

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© 2021

Published in the United States by Nurturing Faith, Macon, GA.
Nurturing Faith is a book imprint of Good Faith Media (goodfaithmedia.org).
Library of Congress Cataloging-in-Publication Data is available.

ISBN: 978-1-63528-138-5

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All Scripture citations are from the New Revised Standard Version (NRSV)
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Cover photo by Rebecca C. Akin.

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Acknowledgments

Becky, my wife and constant companion during this time, was immensely helpful in keeping me on track and providing wise counsel throughout the journaling and writing of *Staring at Dementia*. Becky and I were married just a few years before Mother moved about three miles from us to live at her retirement center. So, we all three were together for a long time.

Nurses, staff, directors, doctors, and chaplains were pleased to share stories that further defined Mother during her sixteen years in three units at the retirement center. Certain people were particularly noteworthy: Nurse Alicia was very close to Mother, especially near the end, perhaps partly because both women had three sons. Judy cared for and dressed Mother for some time and let me know when she needed more and larger clothes. Gina spent many hours talking to Mother, comforting her, and being a friend. All three of these women provided insights into Mother's character and enriched my description of her as she aged.

While I gratefully acknowledge the above persons for their stories and insights about Mother, the writings in this book come from Mother herself—stories shared during our visits and my continuous learning from her counsel and life experiences. What I learned in caring for Mother, including my anxieties and fears for her, my occasional anger at her, and my search to see her *self* as she aged, all came about because of the woman she was.



Mother and Dan: Best buds.

Preface

Mother retired. That was the word she used when she left her home and moved into a retirement center at age 82. Prior to starting this new life, Mother had looked after everyone else, so this move really was, in a way, retirement for her. She moved into a place where folks looked after her. Well, that is not exactly true. Mother continued to look after everyone—or tried to—*even when* she lived in the retirement center. She just did it in a different way. She was still Mother, but her address changed and gradually her life changed. So did mine.

I began a journal on Mother when she moved to be near me and my wife. As I kept up the journal, I noted how Mother changed and transitioned into her new life, first in an independent living apartment and later—as more assistance was needed—to a Personal Care setting and then a final move to Memory Care. The journal reminded me of her sayings, mannerisms, and philosophy of life. As I wrote, I thought about Mother's new life and realized that her transitions also involved my own.

When Mother began to suffer from dementia, she moved into what was officially called the Center for Alzheimer's and Dementia Care. Memory Care was the name used by staff and was the name printed on the front door of this new building. No one said "Alzheimer's" or "dementia." In the Memory Care center, Mother received around-the-clock care for all her needs. She was behind secure doors, and there was not much left of her independence—nor could there be.

I journaled many of our visits to try and capture the rapid and extreme changes occurring in her slowed-down life, with her memory and recollections shifting not only from day to day, but also at times from hour to hour. The journal became full of events, Mother's pronouncements, and the myriad of changes taking place in her life and mine. This once competent, "could do it all" woman began to depend upon me for her decisions. While her living experiences of the past held true, her recollection of events became faulty. Our roles changed, and eventually I became the parent.

While some of Mother's changes were uniquely her own, there were some general declines in her health that aligned with a diagnosis of dementia. Everyone involved in Mother's care tried to be cognizant of these declines and plan her moves accordingly. And with Mother's uncanny knowledge of herself, I think we were generally successful.

Writing about these times, particularly during the most stressful episodes, gave me a sense of purpose even as I struggled to make sense of difficult situations and decisions. As I look back and remember my feelings of frustration, there are times when I regret my anger—even when I tried to see the humor. Wise advice from other writers prompted me to look for the *self*, the person that remained of the mother I loved. Often, I found it in her kindness and even, at times, in her words.

Caregivers—particularly if they are family members—go through transitions with the person being cared for. While Mother’s transitions were of interest to me, being the youngest of her three sons, her experiences also have meaning for others who are traveling this road. My life changed immeasurably, and her care was more than just a part of my life, it was my job. As I became more involved with this new job, I realized I was transitioning from my role as son to that of primary outside caregiver.

So, why did I write this book? I did so mostly because I want to share the legacy of Mother, a woman who, without fame, wealth, or status—at least as the world defines it—deeply influenced the lives of her sons, grandchildren, great-grandchildren, extended family, church, neighbors, friends, and retirement home staff. I want to recall the *self* still present in this selfless saint. However, I also want to relate Mother’s transition to dependence and mine to caregiver and confess those feelings—joy, anger, frustration, love, humor, and amazement—that a caregiver experiences during these transitions.

It is my hope that this book will give others who must travel this road some hope, practical advice, a feeling of camaraderie with fellow caregivers, humor, and the encouragement to write down the stories of their parents before the stories are lost forever.