

Preface

Our Lingering Farewell describes the experiences of my wife, Helen, and I over the last two decades. During these years Helen's capabilities were being continuously reduced by the progression of Alzheimer's disease and I was learning to acquire the skills needed to serve as her caregiver. I've actually been married for many years to two different Helens. The *Real Helen* and the *Alzheimer Helen*. *Real Helen* existed vibrantly during the first forty years of our life together, with *Alzheimer Helen* slowly beginning to appear in the late 1990s.

I have decided to record this summary of our journey to share our story with others facing a similar path with their loved one. I want to record the outstanding lifetime contributions that Helen has made, and relish in my own satisfaction in recalling the many great times we have enjoyed in spite of our Alzheimer limitations. I find that Juliette's words from Shakespeare that "parting is such sweet sorrow" capture perfectly my present feelings. Our lingering farewell is made "sweet" by celebrating our continuing good fortune for having met, and for still sharing a highly successful and wonderful life together. "Sorrow" comes from the acceptance that so many of our past adventures and achievements will no longer be possible in the future.

I have developed the material for *Our Lingering Farewell* over several years leading up to the early part of 2020. Although Helen

is the leading player in the events described, she was unable to contribute to any of the text herself because of the limitations imposed by the advanced stage of her disease. As a result, all the words are mine based on my own recollections and provide an overview of the highlights of our senior lives together throughout a totally unanticipated lifestyle.

Since Alzheimer's disease is such a slowly developing affliction, I find that the designation of caregiver does not really provide an accurate description of my situation during this time. Since our marriage, Helen and I have shared our family, social, and business responsibilities as a loving, congenial, and collaborative team of equal "Sharers." Throughout our Alzheimer years our sharing has been transformed. I have increasingly assumed the role of "Carer" as Helen's capabilities have steadily diminished.

Looking back, I realize that our relationship has been continually evolving from a relatively carefree and happy lifestyle to a much more highly constrained one as we encountered an array of new and unexpected events and challenges. Thus, I would more appropriately classify my experience as a transition from a "Sharer" to a "Carer" through a series of stages which have involved widely differing demands and responsibilities for both of us.

These stages of caregiving reflect the progression of Alzheimer's disease, broadly described in compilations such as the seven-stage Global Deterioration Scale, ranging from Stage 1 of no impairment through to Stage 7 and severe dementia. In this final stage speech becomes severely limited, and total support around the clock is needed for all functions of daily living. Progression through these

stages typically lasts from eight to ten years but can sometimes stretch out as far as twenty years. Duration is impacted by quality of care. The average length in Stage 7 is generally one to two-and-a-half years. Helen has now been in Stage 7 for almost eight years.