

The following is an excerpt from *Shared Stories from Daughters of Alzheimer's: Writing a Path to Peace*

xiii

Preface

It was May of 1996. I was on the way home, and I was frazzled. I had been visiting my stepmother, Ginny, at the graduated care facility where she teetered on the edge of what is referred to there as “independent living.” She was steadily descending into Alzheimer’s disease, and her “independence” was heavily dependent upon the attentiveness of wonderful friends, the dogged efforts of a “bookkeeper” named Sally (who found no task too menial or too daunting), and the invention of stickybacked memo paper.

My head was splitting, overstuffed with shoulda-dones and needtados. We hadn’t even left the driveway and were still waving goodbye to Ginny when I began the recital of woes, punctuated by my husband’s sympathetic grunts. “I cleaned out Ginny’s fridge, but it still needs defrosting, and there wasn’t time. I left her a note to remind her to go down to the nurse for her medication in the morning. She’ll never remember. I got all her bills caught up, and left a note stuck in her checkbook telling her to let Sally pay the new bills as they arrive. And I put a note on the desk reminding her to leave the bills in the desk cubbyhole for Sally, because I found an overdue insurance bill stuck in a stack of magazines. I don’t think she reads the notes. I put one on her dirty clothes to remind her to put them out for the cleaners on Thursday. Hope she doesn’t hang them back in her closet.” And on I went. I guess we were forty or fifty miles up the road before I gradually wound down, feeling the anxieties and frustrations of the preceding days ebb away. My brain slipped from overdrive to idle. It was always the same. Every time I visited I became suffocated in craziness like this. And yet, it wasn’t the worrisome details alone that were so stressful; I was overwhelmed by trying to second-guess how Alzheimer’s would next assault Ginny’s being.

Each time I thought I had it figured out.

Each time I thought I was prepared.

And each time I was blindsided by a new development of the disease.

It was driving me crazy. Was it just me? Or did everyone in my situation feel like this? And if not, how did *they* react?

Those were some of the questions that prompted me to pull together the stories in this book. With appalling ease I compiled a list of thirteen women who were dealing with or had dealt with Alzheimer's disease in a parent. Their names flew into mind from the ranks of my friends and family, and their friends and families. Just like that. I wrote to the women and proposed that each tell of her own experience. I told them they could handle the topic however they wished, but urged them to be excruciatingly honest about their feelings. I said we could help others cope with Alzheimer's in the family by letting them know that they are not alone in this sadness, and that the events and feelings they experience—some of which may be repugnant to them—fall well within normal limits. All but four of the women I contacted agreed enthusiastically to share the stories of what had happened to them and how they had reacted. To these women I owe heartfelt thanks for all the hours of work and painful self-examination they subjected themselves to in completing this project.

We began the arduous process of remembering, writing and revising. Slowly the chapters were chiseled and the book was built. The stories showed that, despite commonalties found in the Alzheimer's experience, each woman's experience had aspects that were unique. There was no single "right" way to respond to the challenge. Each woman's experience reflected her own individuality, her own life situation and the particulars of her relationship with the ill parent. The stories varied, too, according to the type of care that was selected for the parent. When it was done we had created a cross-section of the Alzheimer's experience, and that much had been predictable. That was what we had set out to do.

But something unexpected happened as well. One by one, the writers spoke to me of the serendipitous benefits the writing had effected in their lives. Initially there was the cathartic release of frustration, pain, guilt, anger, fear, and a host of other pent-up emotions as each writer poured out her first draft. Then, as the writer analyzed, sifted and sorted the material, she achieved a measure of perspective and understanding. Ultimately, as the story was finished, there came a sense of healing and peace.

When I reflected upon the benefits we had reaped from the writing process, I realized that our book should open that opportunity to the reader as well. In addition to telling a story, each chapter should *elicit* a story, enabling the reader to unburden herself and begin to effect her own healing. But how to do that?

I contacted Kathleen Adams, founder and director of the Center for Journal Therapy and author of many books on journaling, including

the best-selling *Journal to the Self: Twenty-Two Paths to Personal Growth* (Warner Books, 1990), and asked her to lend her expertise to our book. To my delight, she agreed to write an introduction that would introduce the uninitiated reader to the phenomenon of therapeutic journaling. Kathleen Adams' introduction to this book not only describes the value of journaling, but also offers some handy tips to help you, the reader, get started. Recognizing that each reader is unique, she suggests a variety of helpful approaches to journaling through the conflict and pain of Alzheimer's.

Building on Kathleen Adams' suggestions, I have listed after each chapter some "prompts" which may help jumpstart your journaling efforts. Some were provided by the chapter's author, and some were created by me. We have borrowed heavily from techniques suggested in *Journal to the Self*—"Springboards" (Adams 1990, 74—8), "Captured Moments" (Adams 1990, 94—95), "Journal Lists of 100" (Adams 1990, 124) and "Unsent Letters" (Adams 1990, 172). We recognize that how you go about journaling—or, indeed whether or not you even care to journal at all—is an intensely personal choice. It is not our intention to pressure you to journal; your life is too full of pressure already. We are here to say only that writing helped us and it may help you.

Let us be your support group in print. Use the stories here as tools to understand your own painful situation. Employ them to help you empower yourself, sort through your emotions and begin to heal. Seize upon that which makes sense to you and disregard that which seems irrelevant. Then, if you like, pick up your favorite pen and notebook and "talk" about what is going on in your journey with Alzheimer's disease.

We wish you well.
Persis R. Granger