

# LOVE, LOSS, AND LAUGHTER

SEEING ALZHEIMER'S DIFFERENTLY



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NOT FOR SALE • MARCH 2012

Cathy Greenblat, PhD  
Foreword by Princess Yasmin Aga Khan





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*Denise and Signe - France*

## FOREWORD

I am sure you will agree that this book offers so much more than the beautiful pictures it displays. Through Cathy Greenblat's camera lens and her great ability to describe real stories, we are welcomed into a world that is familiar to many and yet unknown by the world's population in general. We must not forget that dementia knows no geographic boundaries and that behind every case of dementia there is a story and a real person.

This book is not about the difficulties dementia can cause, as some might expect. It is about the lives that continue in spite of it. It really is about seeing Alzheimer's differently.

We have met so many individuals from across the world who are touched in some way by the same issue: dementia. We have been introduced to Maria, who is coming to terms with her impending move, and Len, who struggled to cope with losing his wife to Alzheimer's disease. We have also encountered some great success stories: Mrs. Morimoto, who enjoys singing although she is no longer able to speak clearly; and Anu, who continues to support other caregivers while caring for her own husband.

I hope that you have been as inspired by this book as I have. I know from personal experience that it is easy to feel alone when a close friend or family member is diagnosed with dementia, and this book offers proof that nobody is in this alone. For every person living with dementia there is, or should be, a network of support. This book shows that regardless of where and how you live, there are ways to maintain a good quality of life surrounded by people who care.

On behalf of Alzheimer's Disease International, I am grateful to Cathy for sharing her vision with us and helping to remind us that there are real people behind this disease who continue to live, and often thrive, with dementia.

—PRINCESS YASMIN AGA KHAN,  
PRESIDENT, ALZHEIMER'S DISEASE INTERNATIONAL, AND  
HONORARY VICE CHAIR OF THE ALZHEIMER'S ASSOCIATION (USA)

The human spirit in each and every one of us serves as a common bond, uniting us regardless of our ethnic origins, nationality, gender, age, economic status, or religious beliefs. It is also always present regardless of our physical condition or stage in life. That spirit may have been repressed due to circumstances such as overmedication, neglect, or simply a lack of understanding that this is a real person who still feels, loves, and wants to be loved.

All too often people believe that someone with Alzheimer's disease is only an empty shell waiting to die and that the situation is hopeless. We know and must help others to understand that even if the person is unresponsive due to the disease, the flame of their spirit is still intact, waiting to be fanned by the winds of love. We have seen many examples of people responding again, sometimes speaking again after a long silence, when caregivers, pets, and children shower love and affection on them in home care, residential communities, or hospice. We know that without igniting the spirit, medical science alone cannot make the difference. However, when medical science and igniting the spirit work together, the result is akin to magic and the results are irrefutable.

—LOREN SHOOK, FOUNDER AND CEO OF  
A GROUP OF ALZHEIMER'S RESIDENTIAL  
COMMUNITIES AND HOME CARE SERVICES



## CHAPTER 1

# “FACING” ALZHEIMER’S

If you’ve known one person with Alzheimer’s disease . . . you’ve known one person with Alzheimer’s disease. You will meet many here and in subsequent chapters. No one is immune. Women and men, rich and poor, people working in varied positions in industry, the military, academia, and cultural life, as well as those who work at home—all can experience serious neurocognitive disorders. While most are in their sixties or older, early-onset Alzheimer’s also affects those in their forties and fifties.

We risk generalizing far too broadly from the one or two people we know or know about. Knowing more than one person with Alzheimer’s is important, because there is such variety in background and experience. A richer understanding of this complexity can help us to respond more appropriately, individually and as members of communities.

The common emphasis on the fading of minds and memories—and by implication the fading of identity and personhood—reinforces the association of dementia with permanent tragedy. It also increases feelings of impotence, despair, and defeat—the erroneous conclusion that all we can do is await medical breakthroughs. Recognizing that there is still a person present, though more difficult to reach, we can “face” Alzheimer’s differently and more successfully.

As you look at the portraits in this chapter, what questions do you have about the people? What would you ask them if you had the chance? If there is a difference in those two answers, is it something

about them or something about *you* that accounts for the difference? Subsequent chapters explore how you can help create a more dementia-friendly world for them . . . and for all. You can kindle the spirit of a loved one, patient, client, or friend.

Julian Hughes, a psychiatrist with North Tyneside General Hospital in Newcastle, England, points to the ethical dimensions involved:

Thinking light-headedly about people with dementia is not without significance. To think of them as “shells” or simply as “cognitively impaired” is to fail to grasp what it is to be a person at all. People with dementia live in a context. We (on the outside) can situate them in that context in a way that undermines their personhood—for example, by regarding them as infants or as objects—or we can enhance their sense of self by our interactions.

Indeed, to fail to use our interactions to enhance the standing of the situated self of the person with dementia is exceptionally light-headed, for we are all situated. We are not (after all) on the “outside.” As persons we live in the same complex landscape of biology, psychology, history, social intercourse, moral discourse, spiritual concerns, and so on. Their standing as persons is enmeshed with ours; and, if theirs is deficient, ours is deficient, too.

Enhancing selfhood in dementia is a moral imperative.





## WHAT CARE DO WE WANT TO SEE FOR PEOPLE WITH DEMENTIA?

Care that is directed at the person as a complex and full human being, with human needs and rights, likes and dislikes, different from and similar to ourselves. A person who . . .

- *has had a long full life*
- *has experienced joy and sorrow, ups and downs, and continues to do so*
- *likes to remember the life he's led, who is proud of his life*
- *has regrets but doesn't want to be full of regret*
- *retains a sense of belonging to her family; wants to belong; knows what it is like to belong*
- *likes to be reminded of the good things he has done in life*
- *likes to be reminded that she will be cared for in the way she herself would have cared for others*
- *likes to be reminded that he will be cared for in a way consistent with who he knows himself to be*
- *wants to be seen as a person*
- *wants to engage with the world in a variety of ways—by watching and by doing*
- *is playful and enjoys having a laugh*

—MURNA DOWNS, PROFESSOR OF DEMENTIA STUDIES



### Elsa - Dominican Republic

*Elsa left school after fourth grade and stayed home helping her mother, not dating and never marrying. Another of her ten siblings was also diagnosed with Alzheimer's, a sister who was outgoing, a professional, married with several children.*

*Elsa was chosen as the main "face of dementia" on the 2011 World Alzheimer's Day poster and flyer, shown on page xi.*



#### **“The Luncheon” at Silverado, Kingwood – USA**

*Six women at this residential Alzheimer’s community in Texas were taken by staff members to a flea market to select and purchase hats. The next day, a special table was set for them in the dining room. Each woman arrived sporting her new hat.*

*At one point Jerre asked if I liked her black hat. When I said that I did, she replied, “It’s a little crazy and off balance, just like me!” We both laughed.*

*At the end of the luncheon, Lois charmed Sabrina, the daughter of a staff member, by placing her hat on Sabrina’s head. Everyone had a good time.*





## MARKETING CAMPAIGN

- National broadcast media campaign
- Major print media campaign
- Website with book trailer
- Social media campaign through Facebook and Twitter
- NYC-area and Washington, D.C., events

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## A BOOK THAT SHIFTS THE FOCUS ON ALZHEIMER'S FROM DESPAIR TO HOPE

"Through powerful images and empowering messages, *Love, Loss, and Laughter: Seeing Alzheimer's Differently* offers a glimpse of the disease through an important new lens. This groundbreaking book provides honor, respect, and dignity to people living with dementia and delivers comfort, support, and understanding to their caregivers. Equal parts inspiring and informative, this book will go a long way in enhancing the quality of care, and the quality of life, of everyone touched by this disease." —**Maria Shriver, journalist, activist, and best-selling author of six books, including *What's Happening to Grandpa?***

*Love, Loss, and Laughter* challenges the typical perception of people with Alzheimer's as "empty shells," lost to themselves and others. Endorsed by Alzheimer's Disease International (ADI), this important work melds uplifting photographs with thoughtful text by the author, care partners, researchers, medical practitioners, social care providers, activists, and people living with dementia diagnoses. While research for a cure will one day bring an end to the problem, this inspirational book shows and tells how today we can achieve ADI's vision of a better life for people with dementia and their caregivers.

More than one hundred touching photographs—taken in homes, memory clinics, day programs, and residential centers around the world—are interwoven with insightful commentaries from contributors whose personal experiences and statements about good practices reinforce the author's message: People with dementia retain vital capacities.

**Cathy Greenblat, PhD**, has engaged in a cross-cultural photographic project on aging, dementia, and end-of-life care since 2001. She has authored more than 100 professional articles and 14 books and has visited and photographed high-quality Alzheimer's care in many countries, while exhibiting and lecturing.

"This remarkable collection of photographs and commentaries creates an eye-opening perspective on persons with Alzheimer's disease—still human, still loved, and still capable of joy. It will inspire anyone—professional or lay person—who has been touched by Alzheimer's." —**Dr. Harvey Fineberg, President of the Institute of Medicine, National Academy of Sciences**