And Those Who Care for a Loved One with Alzheimer's





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And Those Who Care for a Loved One with Alzheimer's

ore than 65 million people, a full 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend¹. Those caring for a loved one with Alzheimer's disease total more than 14 million².

Marie Marley was an Alzheimer's caregiver for more than seven years. As a long-time medical grant writer, she had acquired a keen understanding of many geriatric topics, including dementia. But none of that could have prepared her for the emotional and sometimes heartbreaking demands of loving and caring for a person with Alzheimer's disease.

Because of her many years as an Alzheimer's caregiver, Marie recently began publishing a blog, a monthly newsletter, and a website, and has even published a memoir about her experiences. Connecting with other caregivers to share her personal story and learn about their's has been an effective way for her to find peace and inspire others who are caring for a loved one with Alzheimer's.



Her first foray into creative nonfiction, Marie's book, *Come Back Early Today*, describes her remarkable relationship with Edward Theodoru, PhD, a delightfully colorful and eccentric Romanian gentleman who was the love of her life. It's a memoir of love, Alzheimer's and joy. It will make you laugh. It will make you cry. If you're caring for a loved one with Alzheimer's it will give you information and advice. But mostly it will give you hope.

To contact Marie Marley, or learn more about her personal experiences as an Alzheimer's caregiver, please visit her website: http://www.ComeBackEarlyToday.com or call her at 913.633.9080





And Those Who Care for a Loved One with Alzheimer's

For interviews and other media inquiries, please contact:

Marie Marley, PhD (913) 633-9080 Marie@ComeBackEarlyToday.com

Suggested Interview Questions

Questions about Alzheimer's Disease and Caregiving

- 1. What are some of the typical early warning signs that something is wrong?
- 2. People are often in denial that there's anything wrong. What does it usually take for someone to realize their loved one may have dementia?
- 3. How much time typically passes between the earliest signs and the "defining event?"
- 4. Do you have any tips for getting along with verbally abusive or otherwise difficult Alzheimer's patients?
- 5. What are some of the signs it's time for your loved one to stop driving?
- 6. What are some strategies to get them to stop driving?
- 7. What advice do you have for family members who are compromising their own health in order to avoid putting their loved on in a nursing home?
- 8. How can people cope when their loved one doesn't recognize them anymore?
- 9. How do you know when it's time to start talking to the patient's doctor about hospice care?
- 10. What do you think are the most difficult aspects of caregiving for an Alzheimer's caregiver?
- 11. What do you think is the single most important thing caregivers can do for their loved ones?
- 12. What other advice do you have for caregivers?
- 13. Are there some resources you would recommend for caregivers?

About Marie's Relationship with Ed

- 1. What is your favorite memory from the early years of your romantic relationship with Ed?
- 2. Why do you think your relationship with Ed was so powerful and lasted so long?
- 3. Were there any issues or challenges because of the age difference between you and Ed?
- 4. What would you say is the one thing you admired the most about Ed?
- 5. What would you say is something Ed admired most about you?
- 6. Looking back, what were the first signs something was wrong with Ed?
- 7. What was the most distressing aspect of caring for Ed?
- 8. What was the most rewarding part of taking care of him?
- 9. Did Ed have any moments of mental clarity when he had Alzheimer's?
- 10. While Alzheimer's is a very serious condition and your role in caring for Ed was all-consuming, can you reflect on any humorous or funny moments?
- 11. What was the hardest, most painful decision you ever had to make on Ed's behalf?
- 12. How did you finally come to accept Ed's dementia?
- 13. If you had it all to do over again would you do anything differently?
- 14. Why did you write this book?
- 15. Do you worry about getting Alzheimer's disease yourself?
- 16. Is there a question about Ed you always wanted to answer but no one ever asked?

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Selected Caregiving and Related Publications by Marie Marley, PhD

www.AlzheimersReadingRoom.com

The Alzheimer's Reading Room is the number one source of life news for the entire Alzheimer's community.

- "Alzheimer's and Music: How a Classical Violinist Brought Great Joy to My Demented Romanian Soul Mate" 9/17/2011 http://www.alzheimersreadingroom.com/2011/09/alzheimers-and-music-how-classical.html
- "The Little Yellow One: My Secret to Relating to My Beloved, Demented Romanian Soul Mate" 8/16/2011 http://www.alzheimersreadingroom.com/2011/08/little-yellow-one-my-secret-to-relating.html
- "How I Got My Beloved, Stubborn and Demented Romanian Soul Mate to Stop Driving" 4/20/2011

http://www.alzheimersreadingroom.com/2011/04/how-i-got-my-beloved-stubborn-and.html

www.EzineArticles.com

- Alzheimer's Disease and Antipsychotic Drugs A Controversial and Difficult Issue for Caregivers
- Grandma Has Alzheimer's: 10 Ways to Help Your Child Cope When a Grandparent Has Alzheimer's Disease.
- Alzheimer's and Driving: 8 Tips to Getting Your Loved One to Stop Driving Before it's Too Late.
- Alzheimer's and Family Strife: 3 Tips for Dealing with Relatives Who Criticize Your Caregiving.
- Alzheimer's Family Members: 5 Proven Ways to Handle Your Loved One's Negative Changes.
- Hospice Care for Alzheimer's Patients Near the End of Life: Answers to Top 10 Questions.
- Alzheimer's Caregivers: 10 Things Friends and Family Members Can Do to Lighten Your Load.

Media Coverage

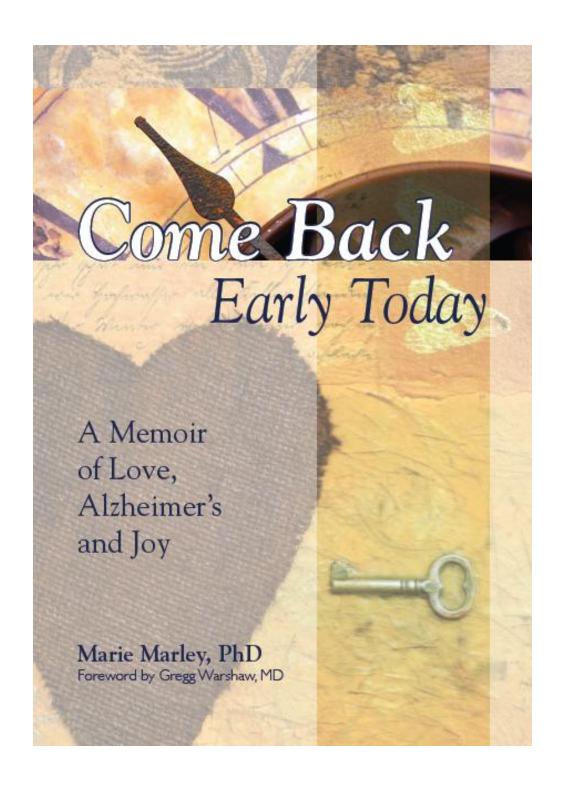
Interviews & Media Coverage

- "Alzheimer's Rising Tide of New Cases Floods Caregivers." CNBC. September 14, 2011. http://www.CNBC.com/id/44515486.
- "Author Tells Unique Tale of Alzheimer's Experience." Cincinnati Alzheimer's Association Cornerstone. Summer 2011.
- "Memoir Holds Advice for Alzheimer's Caregivers." Kansas City Nursing News. August 29, 2011.



For a full listing of articles and media coverage, please visit: www.ComeBackEarlyToday.com





THE MEMOIR



A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Open Letter to Readers

Dear Reader,

I initially began writing this memoir as part of a personal effort to help me honor, and process the loss of, the most significant relationship of my life. But while writing it, I also found it helpful to read books by other Alzheimer's caregivers. One day, it occurred to me that my story might be helpful to others just like others' stories had been helpful to me. So I decided to publish my memoir.

Come Back Early Today: A Memoir of Love, Alzheimer's and Joy tells the story of my amazing 30-year relationship with a delightfully colorful, wickedly eccentric and considerably older Romanian gentleman. As the narrative begins in 1975 we meet, fall in love and have a whirlwind romance. I'm 25; he says he's 52. Despite the gaping difference in our ages (which later turns out to be even greater than I thought), life is happy and carefree, and we frolic about like a couple of love-struck teenagers. While the romance itself comes to an end, our love for each other grows stronger and endures. We develop a new, more enriched relationship. We become absolute best friends and we become inseparable. Our closeness deepens as the years go by and we grow into steadfast life partners - true soul mates.

Then in the year 2000, something starts to change. Little by little Ed's mental capacity and functioning begin to decline. He begins drinking to excess and he becomes hostile, belligerent and verbally abusive toward me. Our relationship goes awry. I don't know if I can take it anymore. I'm not aware he's developing dementia, I just think he's become incredibly mean and hateful. I desperately need to end the relationship, but love him too much to abandon him. Great struggles, tragedy and – ultimately - joy ensue.

I hope you enjoy this memoir and that it will be meaningful to you in some way.

Sincerely,

Marie





A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Edward Theodoru, PhD (1912 – 2007)

Come Back Early Today is the powerful love story of a young American woman and a delightfully colorful, wickedly eccentric Romanian gentleman and scholar. Brilliant, compassionate, generous, courageous, honorable and fiercely patriotic are just a few of the words that describe Dr. Edward Theodoru.



Born in Bucharest, Romania's center of culture, Ed became a dazzling defense attorney at a young age, attracting clients from all parts of the country and racking up an amazing list of acquittals.

After being divorced by his wife, when he wasn't in court he was out and about courting the ladies. He was particularly drawn to young women, and over his lifetime captured the love and affection of numerous women, many of whom were only half his age.

Ed was persecuted by the Communist regime in Romania, which sent people to prison for up to five years just for telling jokes about the government. He fought tirelessly to gain permission to leave the country and suffered further persecution just for doing that. Finally, after many years he was allowed to go, but the conditions were harsh. He was only allowed to take one suitcase, the clothes on his back and today's equivalent of \$100 plus his elderly mother, her suitcase and her \$100.

They went first to Rome, where they were penniless political refugees, living in a cramped apartment with no hot water and eating only spaghetti for nearly every meal. After that they came to the US and settled in Cincinnati, where Ed saved up enough money from doing menial jobs to attend the University of Cincinnati and earn a PhD in Romance Languages. Then he became a distinguished professor of French at Northern Kentucky University, just across the river from Cincinnati.



He had liaisons with several Cincinnati ladies, but eventually settled down with Dr. Marie Marley. They were deeply committed life partners for the next 30 years, and Marie cared for him during the last seven years of his life, when Alzheimer's slowly ravaged his once brilliant memory. He was so incredibly lucky to have her, but she always said she received far more from this remarkable and unforgettable man than she gave to him.

A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Praise for the Book

"In the world of Alzheimer's memoirs, a rarity--not, strictly speaking, a "happy ending," but a different tale from the usual bleak, grinding, downward spiral into unalloyed misery. Edward Theodoru, magnificent Roumanian gentleman, scholar, adventurer and lover extraordinaire, not quite like anyone else you've ever known, did life his way. And when Alzheimer's came along, he did it his way, too. Marie Marley tells the epic story of their decades-long association--which itself defies description--with humor, honesty, detail, and great love."

Eleanor Cooney, Author of *Death in Slow Motion: A Memoir of a Daughter,* Her Mother, and the Beast Called Alzheimer's

"Here's a memoir that lights up dementia with humor, with compassion, with a loving eye. The story is inherently fascinating: how a woman starts a romance with a man 38 years older, how they become the deepest friends, and how she looks after him when, in his nineties, Alzheimer's overwhelms him. It's not an easy story—but like a gathering storm, you can't look away from it. Marley has written a powerful, detailed, often lyrical book about love, and where it leads us."

John Thorndike, Author of *The Last of His Mind: A Year in the Shadow of Alzheimer's*

"Come Back Early Today . . . reads like a novel as the author tells the story of her life, the life of her once lover, and their thirty years of life together as best friends. Marley uses a lot of dialogue which makes the reading easy and exciting and often humorous and entertaining despite the devastation of the disease. Marley also uses suspense in her writing which keeps the reader always wanting to know what happens next in Come Back Early Today."

Lela Shanks, Author of Your Name Is Hughes Hannibal Shanks.

"A unique Alzheimer's story, passionately told. Vivid scenes of the chaos dementia brings. Then we see this transformed, and concluded with insight and grace."

Ann Davidson, author of *Alzheimer's: A Love Story* and *A Curious Kind of Widow*

"Marie writes so poignantly of caregiving for her soulmate and life partner, Ed. Despite his cognitive and functional decline, Marie was able to maintain the essence of her beloved friend...Her story is a lesson for all who take on the caregiving role."

Clarissa Rentz, APRN, Executive Director, Alzheimer's Association of Greater Cincinnati





A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Praise for the Book, continued

"I could feel the pain and the joy. I laughed and cried reading this book, which clearly expresses the pain and torment a loved one goes through as they lose someone they love to Alzheimer's disease. This book captures the subtle, daily disease progression all too often missed, ignored, or misinterpreted by families. Marie shares the experience of making the decision and moving a loved one to a facility in a real and loving way. Her story will allow families to learn from the experience of anotherwhat does and does not matter to a person with dementia."

Susan Gilster, PhD, Executive Director, Alois Alzheimer Center, Cincinnati, Ohio

"I had the privilege of knowing Dr. Marley while she was caring for Ed. Even after his death, her resilience and humor have continued and she is open to the lessons he taught her. I feel grateful that she has shared her story, which will inspire other caregivers and helping professionals to also be open to learning from individuals with Alzheimer's disease."

Irene Moore, MSW, Chair, American Geriatric Society Social Work Section

"This memoir is admirable – a wonderful story, so beautifully written and so alive with Marie's love for Ed and his for her. Reading this book on the fading of life in one so close resonated with me deeply. So many of Marie's personal qualities emerged as she provided unstinting care for Ed based on the long love she describes that continued to the end and beyond, and which not even dementia could extinguish."

Robert Smith, MD, Professor Emeritus and Founder, Department of Family Medicine, University of Cincinnati

A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Foreword

By Gregg Warshaw, MD
Past President, American Geriatrics Society
Professor and Director of Geriatric Medicine, University of Cincinnati

In this fast-paced engaging memoir, Dr. Marie Marley relates vividly and honestly the challenges faced by caregivers of loved ones with Alzheimer's disease, a condition that currently afflicts 5.4 million Americans. The statistics for these patients' caregivers are even more alarming. The Alzheimer's Association estimates that nearly 15 million family members, friends and neighbors are currently providing care to patients with Alzheimer's and other dementias. The toll on caregivers is great. Their experience significantly increases their emotional stress, jeopardizes their physical and mental health, and can negatively impact their employment and finances. There is a critical need for information about how to approach the daunting problems these committed individuals face.

This compelling love story offers hope and help to those moving along the path of what can be an overwhelming journey. The author chronicles her struggle with the complex problems that arose as her life partner, Dr. Edward Theodoru, became evermore demented. These are the challenges all caregivers of Alzheimer's patients typically face, usually beginning with a fierce denial that there even is a problem. Following that other issues typically arise, including dealing with the loved one's personality changes (which can be negative or even abusive), suspending driving privileges, managing assisted living and/or nursing home placement, engaging hospice services, and making end-of-life care decisions. Two of the most trying problems for caregivers - problems some never solve - are simply coming to terms with their loved one's condition and finding new ways of relating. Dr. Marley shows us how she overcame her denial, depression and despair and ever so slowly rose to the challenge. In the final chapters she shares the intimate details of her last visits with Ed, during which he was sometimes entirely lucid and freely expressed love, affection and even joy.

I strongly recommend this memoir to caregivers of dementia patients. It will show them it's possible to find new and creative ways to communicate and interact with their loved ones. It will bring comfort to those going through the same experience, letting them know they are not alone, and it will help validate both their positive and negative feelings about the difficult situation in which they find themselves. This work will also be valuable to health care professionals, giving primary care physicians, nurses, social workers and others a detailed, comprehensive view into a caregiver's life that will provide insights as they care for dementia patients and caregivers in their offices or long-term care settings.

As a family physician and geriatrician who has provided care to hundreds of dementia patients and their caregivers, I found the book's information illustrating approaches to caregiving problems to be practical, insightful, and inspiring. Equally important, *Come Back Early Today* is a true testament to love, devotion and perseverance.





A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Excerpt from the Book

The Day Ed's Vodka Froze (Before he had Alzheimer's)

Ed and his vodka had often posed a problem for me, one I'd tried to solve in various more or less successful ways over the years. Way back when Ed was 63 and I was only 26, and we'd been together for about a year, Freddie came down from Toledo for a long weekend. We were gabbing away and giggling as sisters often do while we drove through Eden Park on our way to Ed's place. The air conditioner was blasting on high, trying to overcome the fierce August heat that had been making everyone miserable for several days.

On the drive I mentioned to her my concerns about Ed's drinking. Even back then I thought he drank too much, although in retrospect, his consumption at the time was moderate by comparison.

"You know, Freddie," I said, turning slightly toward her, "I've started keeping track of the amount in the bottle. Sure enough, the levels are going down a lot faster than I think reasonable."

Freddie looked at me with an expression that conveyed disapproval, so I tried to justify my snooping.

"I've talked to him about it, Freddie, but every time he insists that he drinks 'little – very little.' Talk alone isn't going to help, and so I've been watering down his vodka."

She looked at me sternly and shouted, half serious and half joking, "Marie, that's horrible! You shouldn't trick him like that!"

She was right, of course, but that's what I was doing anyway.

Shortly after my confession we arrived at the Edgecliff. Freddie, wearing pink Capri pants, a matching pink tank top, white bejeweled flip-flops, dainty earrings and assorted other jewelry, and I, dressed in my usual uniform of worn jeans, a tee shirt, and old tennis shoes, went up to the ninth floor, where Ed welcomed us. Our dress was but a symbol of the enormous difference between us. Freddie was concerned about her appearance. I cared very little about mine. I loved intellectual banter; Freddie wanted to socialize and preferred small talk. But over the years we had figured out a way to remain close despite our differences.

Once Ed had let us in, I plopped down on the sofa, Freddie daintily sat down beside me, and Ed took a seat in his fake leather recliner. We began making light conversation and somehow the issue of vodka arose.

"I have to tell you an *unbelievable event* that happened the day before yesterday," Ed announced. "I got out of the fr-r-reezer my vodka to pour a drink and guess what? It was *f-r-r-rozen!*"

A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Excerpt from the Book The Day Ed's Vodka Froze

Freddie and I immediately figured out why. We stole a quick glance at each other and each saw the other was struggling to keep from bursting into laughter. After all, how would we explain to Ed why we were laughing so hard? We didn't dare look at each other.

Ed continued, his voice becoming more energetic, "I have kept in the fr-r-reezer my vodka *all my life* and it has *never* fr-r-rozen."

To hear him tell it, it was as though hell itself had frozen over.

"So I just put it in the 'oh-ven' to 'taw' it out!" he said with an air of finality.

This made us want to laugh even harder, but somehow we managed to hold it in.

A little while later we left to go back to my house. When we reached my car, we let loose and laughed so hard tears were streaming down our faces and we were literally doubled over. Every time we managed to stop laughing one of us would start again and then the other would, too.

For many years after, Freddie and I would laugh at the memory. Ed never did figure out why his Popov froze, but after that I put in less water, and as far as I know it never happened again.





A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

Excerpt from the Book

Ah... She Loved Me (When Ed Had Alzheimer's)

That day I'd decided to show Ed the cards and photos I'd found in his storage unit. It was Rosa's idea – I never would have thought of doing that myself. I got up and turned on the black pole lamps at each end of the sofa. The one on the left didn't come on. Reminds me – I have to get a new bulb. So I went to get the white lamp from the other corner of the room and put it at the left end of the sofa. Having illuminated the room as much as possible to compensate for Ed's poor eyesight, I was ready to start the show.

"Kitty!" he exclaimed, coming out of the bathroom. "I'm so happy to see you. You are *so* beautiful!"

Then he sat down, careful not to disturb the little animals.

"Hi, Kitty. I found some old photos and cards I sent you many years ago and I'm going to show them to you today."

"Marvelous! Superb!" he answered, using the words he always used when he was happy about something.

I decided to start with the cards. Although he was no longer able to read books or the newspaper, I hoped he'd still be capable of reading the cards. He was, and he even seemed to understand what he read. He laughed at the funny ones and responded more seriously to the others.

After he'd seen them all he looked up at me and said in a reverent tone of voice, "Kitty, I am so touched that you kept these cards all these years."

I didn't even try explaining that he was the one who had kept them.

Next we looked at the photographs. Some were from his childhood. There was one of him around age six wearing a sailor suit and posing with his father, and another with his grandparents, sitting on a bench in a beautiful park. I was awestruck when I suddenly realized some of those photographs were more than eighty years old. Then there were several pictures of us from the '80s and '90s. There were also photos of him with a whole variety of people I didn't know. I guessed they were different Romanian friends and relatives. Probably some previous lovers, too.

He was drawn to the photos just as much as he was to the cards, studying each with interest. The last one was a picture of him with a woman standing behind him. She had her hands on his shoulders and her head was peeking around his, facing the camera.

"Ah . . . She loved me," he murmured, an affectionate expression on his face. He kept looking at the photo.

"What are you thinking?" I asked when he didn't say anything more.

"I'm thinking of love," he whispered.

"That woman is me and I still love you."

He looked up and gazed into my eyes the way he did when we were lovers. I couldn't tell if he was in the past or the present. I decided it didn't matter.

A Memoir of Love, Alzheimer's and Joy

By Marie Marley, PhD

How to Get the Book

For the Press/Media

•A complementary PDF of the book is available at: www.ComeBackEarlyToday.com/press

For General Audiences

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