

A Memoir of Love, Alzheimer's and Joy

Marie Marley, PhD Foreword by Gregg Warshaw, MD

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By Marie Marley, PhD



am a professional medical grant writer and over the years I acquired a keen understanding of many topics, including geriatric dementia, but none of that could have prepared me for the sometimes heartbreaking demands of loving and caring for a person with Alzheimer's disease. Come Back Early Today is my first foray into creative nonfiction, where I describe remarkable my relationship with Edward Theodoru, PhD, the love of my life. I have been a grant writer at both the University of Cincinnati Department of Family Medicine and the American Academy of Family Physicians. I live in Olathe, Kansas with my Shih Tzu, Peter, whom Ed loved dearly, and my younger pup, Joey, whom Ed would have been so delighted to meet.

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#### **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

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### 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 another-what 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





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#### Introduction to the Book

Come Back Early Today: A Memoir of Love, Alzheimer's and Joy tells my story — that of an amazing 30-year relationship between a young American girl and a delightfully colorful, wickedly eccentric and considerably older Romanian gentleman. As the narrative begins in 1975 we meet, fall in love and have a three-year 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. When the romance ends our love endures and we develop a new relationship. We become best friends. Then we become inseparable. Our closeness deepens as the years go by until we become steadfast life partners - true soul mates.

Then around 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 any more. 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.

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#### **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.





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# Excerpt from the Book The Day Ed's Vodka Froze

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!*"

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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.





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# Excerpt from the Book Ah... She Loved Me

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.

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# **Suggested Interview Questions for Marie Marley**

- 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. You were introduced to Ed by your Italian professor, Guido, with whom you'd had a seven-year passionate relationship. Whatever happened to Guido?
- 5. What would you say is the one thing you admired the most about Ed?
- 6. What would you say is something Ed admired most about you?
- 7. Looking back, what were the first signs something was wrong with Ed?
- 8. Taking care of Ed began to consume a significant amount of your time. Were you able to balance taking care of your personal needs with your commitment to care for Ed, especially before he went to live at the Alois Center?
- 9. Caring for Ed was a very demanding role, how did you maintain your sanity before Ed went to the Alois Center?
- 10. What was the most distressing aspect of caring for Ed?
- 11. What was the most rewarding part of taking care of him?
- 12. Did there ever seem to be moments of mental clarity for Ed, when he revealed somehow that he knew something was wrong and he knew you were taking care of him?
- 13. 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?
- 14. What was the hardest, most painful decision you ever had to make on Ed's behalf?
- 15. How did you finally come to accept Ed's dementia?
- 16. If you had it all to do over again would you do anything differently?
- 17. How has life been for you since Ed died?
- 18. Why did you write this book?
- 19. Is there more of this story to tell, or are you working on any other books?
- 20. Do you worry about getting Alzheimer's Disease yourself?
- 21. Is there a question about Ed you always wanted to answer but no one ever asked?





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### **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**

- Please visit www.ComeBackEarlyToday.com
  - Paperback is \$14.95 \*Free Shipping\*
  - PDFs is \$1.95
- Or visit Amazon.com
  - Paperback is \$14.95
  - Kindle format is \$4.95

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Marie Marley, PhD c/o Joseph Peterson Books 15022 W. 123rd Terrace Olathe, KS 66062 816.876.8653

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www.ComeBackEarlyToday.com





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#### **Articles Published**

"How I Got My Beloved, Stubborn and Demented Romanian Soul Mate to Stop Driving." was published on the following websites:

Alzheimer's Reading Room | 4/20/2011

http://alzheimersreadingroom.com

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

Medpedia.com | 4/20/2011

http://www.medpedia.com

Medpedia is an open platform connecting people and information to advance medicine.

The Times of India | 4/21/2011

http://timesofindia.indiatimes.com

Regator.com | 4/21/2011

http://www.regator.com

This website brands itself as an online destination where you can "Discover new stuff you'll love from the best blogs."

"The Little Yellow One: My Secret to Relating to My Beloved, Demented Romanian Soul Mate." was published on the following websites:

Alzheimer's Reading Room | 8/16/2011

http://www.alzheimersreadingroom.com/2011/08/little-yellow-one-my-secret-to-relating.html The Alzheimer's Reading Room is the number one source of life news for the entire Alzheimer's community.