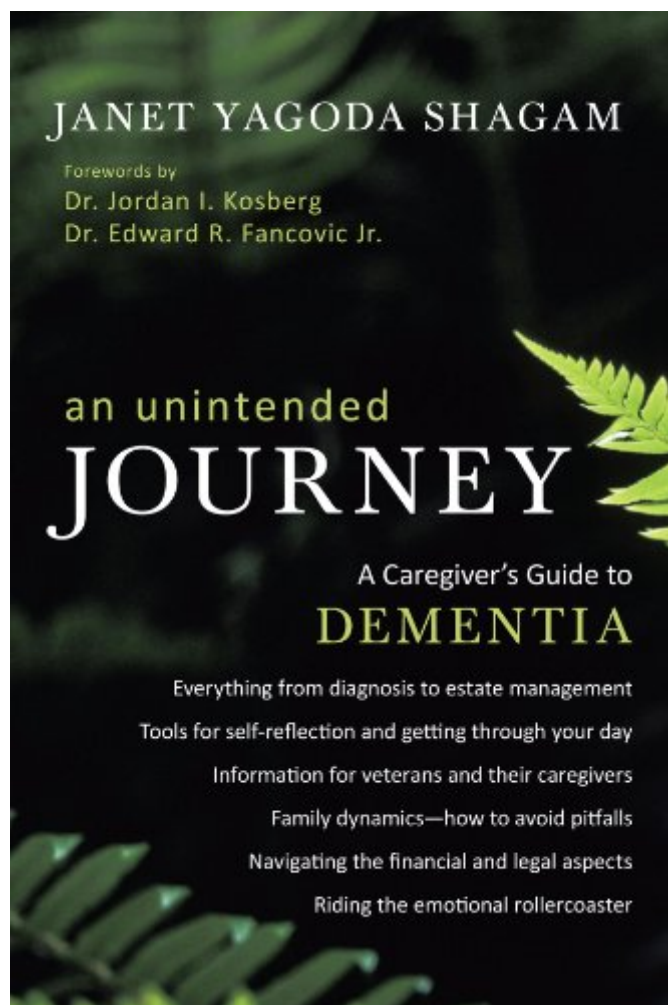


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# An Unintended Journey: A Caregiver's Guide To Dementia



## Synopsis

According to the 2009 census, more than five million people living in the United States have Alzheimer's disease or some other form of dementia. Not reported in these statistics are the fifteen million family caregivers who, in total, contribute seventeen billion hours of unpaid care each year. This book addresses the needs and challenges faced by adult children and other family members who are scrambling to make sense of what is happening to themselves and the loved ones in their care. The author, an experienced medical and science writer known for her ability to clearly explain complex and emotionally sensitive topics, is also a former family caregiver herself. Using both personal narrative and well-researched, expert-verified content, she guides readers through the often-confusing and challenging world of dementia care. She carefully escorts caregivers through the basics of dementia as a brain disorder, its accompanying behaviors, the procedures used to diagnose and stage the disease, and the legal aspects of providing care for an adult who is no longer competent. She also covers topics not usually included in other books on dementia: family dynamics, caregiver burnout, elder abuse, incontinence, finances and paying for care, the challenges same-sex families face, and coping with the eventuality of death and estate management. Each chapter begins with a real-life vignette taken from the author's personal experience and concludes with "Frequently Asked Questions" and "Worksheets" sections. The FAQs tackle specific issues and situations that often make caregiving such a challenge. The worksheets are a tool to help readers organize, evaluate, and self-reflect. A glossary of terms, an appendix, and references for further reading give readers a command of the vocabulary clinicians use and access to valuable resources. From the Trade Paperback edition.

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## **Customer Reviews**

This is a thoughtful, comfortably written and compassionate experiential and explanatory book that addresses the heart breaking condition we call dementia - a condition suffered by millions of older Americans. Our perception and understanding of this degenerative disease at a societal level is at best limited. We usually associate it with advanced stage Alzheimer's by which time the sufferer has become unable to care for himself, incontinent and forgetful. But it turns out there are several types of dementia and the symptoms are far more far ranging and insidious. This is a must read regardless of whether you think you have a relative with dementia or not, because there are so many people in this country over 65 with the potential of having some form/stage of dementia. It might help everyone view older people with more compassion and not just dismiss them with such phrases as "he's just become more difficult as he gets older", or "that's just what old people are like", or any number of other condescending statements that enable them to not deal with what is standing in front of them - a person with a degenerative disease. If people were simply more aware, the behaviors that evidence early decline might be addressed and alleviated in many cases. This is why I consider this book a "must read". If more people were aware of the symptoms, cases of dementia might be discovered earlier and it turns out there are some medications that can be helpful if the disease is caught in its early stages. Reading this book, I realized I knew nothing about dementia other than some anecdotal information from people who had experience with parents who had succumbed to the disease. Had this book been available in 2005, I would have realized that the aggressive and odd behaviors exhibited by my father who died of cancer that year, were in fact evidence of dementia which he'd probably had for about 10 years. Like the author's mother though, he had always been difficult and was a highly intelligent, educated and accomplished person. And, he had a lucid wife to cover for him. I would particularly recommend this book for families with dependents with Down syndrome - although the condition is not specifically addressed. Some

genetic propensity for dementia is found on the 21st chromosome. Since people with Down syndrome have trisomy 21, they have a tendency to develop early onset dementia. My 19 year old daughter falls into this category. Reading this book has given me some practical tools for cataloging and following her decline for the purposes of planning, reporting to medical professionals, and maintaining a safe environment for her. It's also been helpful in realigning my expectations of what she is still able to do. There is a plethora of useful and informative information in this book and it's written with deep compassion. Everyone should read it.

An Unintended Journey is a book that can help you prepare for what could happen to yourself or someone that you love. It is a good book for those who are caregivers as a paying job. In any form a caregiver's roll is a hard one and the more knowledge and understanding they have the better they can be a better caregiver. This book provides inside look at what dementia can do to the person and those around them. The fact that Janet takes you to the end which no one wants to think about but is better off being more prepared for is a wonderful thing. Thank you Janet for putting it in plain words to help us all understand better.

I recently bought this book because my parents and my father in law are suffering from "old age". Trying to figure out when it is normal and when to worry is a common question. This book helped me to focus on what signs to look for and what to do if I see them. It is a book written for the layman- a help guide on where to begin, the different diagnosis and how to cope. The personal stories are touching. And for anyone going through the care giving stage a plethora of tips and and- more importantly- knowledge that you are not alone. I would highly recommend this book to anyone starting the "unintended" journey or someone who is in the depths of the care-giving role.

I was hoping for a practical guide to help my mother deal with my father's Alzheimer's. What I got was a dry, clinical description aimed at adult children who live across the country. I did not see any tips or pointers for how to interact with someone who is confused, depressed, or difficult. After struggling through the first 50 pages, I put the book away and will not pass it on to my mother. I found what I was looking for in two other books: "Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers" by Jolene Brackey and "Being Mortal: Medicine and What Matters in the End" by Atul Gawande.

Dr. Shagam has a unique command of the sensible- what's practical, do-able and helpful. She

thoroughly explains the various forms, stages, and spectrum aspects of Dementia in lay terms. In addition, through the journey with her mother, she shares her inner thoughts, often including the background of a situation, to deliver an accurate portrayal of what life can often be like as a caregiver/care partner. Living with Dementia oneself, or living with and caring for someone else that has Dementia, should be a shared experience that hopefully reveals the deeper aspects of one's "story," and allows for a special opportunity of connectedness with those you love, even within the sadness and loss.

I spent close to two years managing the care for my father who was afflicted with Dementia leading to Alzheimer's, and after losing him to complications of the disease; my mother was diagnosed with it. I wish I had found this book while I was a novice at caregiving issues and while I was learning about the progression of the disease, but even with my experience - this book is invaluable to me. I can attest to many of the challenges Janet Yogoda Shagam discusses and the toll it takes on the person who is ill as well as the caregiver, and while reading this I am thankful to be learning so many new things about coping and caregiving; things I wish I had known during my first experience with Dementia, and ultimately, Alzheimer's. I am actually only halfway through the book as I write this - it is that good - and would give it 6 stars if I could. I am recommending it to everyone and especially to those who would immediately benefit from reading it: the agency that supplies my mother's day companions, the social worker for elderly services, her doctors, and my friends and family. Thank you Janet Yogoda Shagam, this is an excellent book and wonderful tool!

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