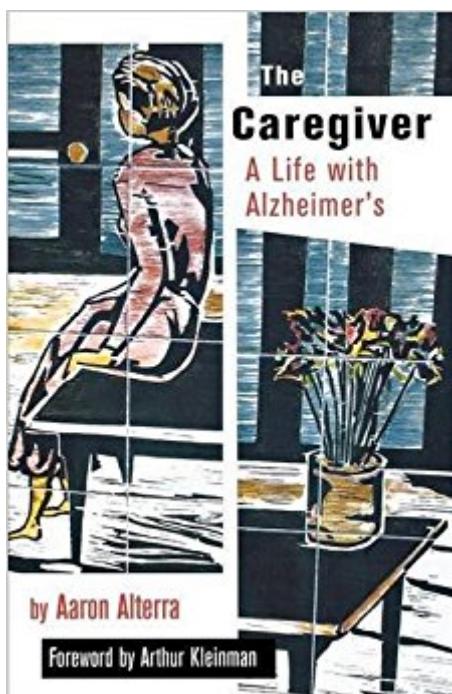


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# The Caregiver: A Life With Alzheimer's, With New Material (The Culture And Politics Of Health Care Work)



## **Synopsis**

Aaron and Stella Alterra had been married for more than sixty years when Aaron began to notice puzzling lapses in his wife's memory. Innocuous at first, they became more severe and more alarming. After a series of appointments and tests, the Altermas were informed that Stella was one of the more than 4.5 million Americans with Alzheimer's disease. Combining medical research on the disease and often-painful anecdotes of memory loss, deteriorating motor functions, personality shifts, support-group and daycare experiences, and drug trials, Alterra chronicles his transformation from husband to caregiver after his wife's diagnosis. More than a chronology of one family's experience of Alzheimer's disease, *The Caregiver* is an intelligent, beautifully reflective testimony to how family members turned caregivers become the ultimate advocates for their loved ones in the face of a disease with no cure.

## **Book Information**

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## **Customer Reviews**

Despite promising research, Alzheimer's disease cannot be arrested by medical intervention. So it has fallen to Alterra to monitor and care for his wife, Stella (a pseudonym, as is the author's name), who was formerly an accomplished cellist and is now almost completely dependent on her husband. He first became aware that Stella might have Alzheimer's when she lost some short-term memory and had difficulty driving and cooking. He had a good relationship with their primary care physician but, once Stella was diagnosed, Alterra quickly learned that the best place to get help was through the Alzheimer's Association. In this thoughtful and honest memoir, Alterra effectively impresses on

the reader that the "primary physician" is not the doctor but the caregiver who lives with the patient. Through a drug trial, he obtained medication that slowed his wife's decline; he also followed up on the association's recommendations of caregiver and patient support groups. Alterra offers a touching account of how he still makes an effort to engage his wife in conversation. Anyone going through the same experience will benefit from his description of how he has coped with problems such as Stella's seeming inability to eat and her incontinence. He also provides a vivid depiction of the tortuous health care labyrinth he was forced to navigate by Medicare, which, in effect, provides almost no coverage for Alzheimer's. Although Alterra is committed to care for his wife as long as possible, as her condition worsens, he is currently weighing the possibility of moving into a nursing home with her. Copyright 1999 Reed Business Information, Inc. --This text refers to an out of print or unavailable edition of this title.

Alterra is the pseudonym of a prolific and award-winning short story writer and novelist who wishes to protect his wife's privacy. Like many a spouse of an Alzheimer's patient, he realizes that he missed the early warnings of this disease, which slowly robs victims of memory and ultimately all intellectual and physical functions. Alterra, who made the decision to become the primary caregiver, writes of his experiences here. As he discovers, life with an Alzheimer's patient is an ever-changing series of challenges; for instance, Alterra's wife lost her ability to walk but not to dance, so husband and wife dance from bed to chair or room to room. Alterra's book will strike a chord with anyone who has a family member with Alzheimer's: the search for understanding, the hallucinations, mood changes, loss of mental and physical functioning, and unpredictable nature of the disease. For most health collections. AJodith Janes, Cleveland Clinic Foundation Copyright 1999 Reed Business Information, Inc. --This text refers to an out of print or unavailable edition of this title.

I read every personal book I can find about Alzheimer's and dementia, and have reviewed more than 25 of them here on . Among many excellent books (by Mary Gordon, John Bayley, Sue Miller and Virginia Owens, among others), I found this the very best. My father died in 2005, after descending into Alzheimer's. During the year I took care of him, I started reading memoirs on the subject--but somehow failed to come across Aaron Alterra's book until this year. From the first paragraph I knew I was in good hands. On page five I noted in the margin, "Every paragraph is perfect." And so it continued, one rich page after the next. I'm always swayed, pro and con, by a book's writing, and Alterra (a pseudonym for the novelist and short story writer, E.S. Goldman) is a gorgeous writer: observant, deft, succinct and original. He would never heap on the adjectives this

way, but I will, about him. The characters are spry, the dialog subtle, the descriptions powerful, his observations pierce like a quill. What can I say? I love how he writes. My father would never mark a book. I do though, so after I finish I can find felicitous passages or points worth remembering. I use checks, brackets and occasional exclamation points--and after reading "The Caregiver" I went back through the entire book, counting them up. I found over 130 pencilled marks. Alterra's scenes, of which there are many, are the lifeblood of the book. I ticked the opening of this one on page 63: "Ina Krillman's office decoration consisted of shelves of books and pamphlets and a row of folding metal chairs arranged for a small meeting in front of a small desk that she dominated like an adult on a pony." I checked this, as well, about how many of the elderly will suffer from dementia: "People are living longer. If you expect to make it to eighty-five, expect also that you or your spouse will have Alzheimer's, the other will be a caregiver. Stella and I did not beat the odds." His chapter on how the caregiver becomes the de facto primary care physician for anyone with dementia is particularly astute. How I wish I'd found this book when my father was still alive, and I was coping with several physicians. There is so little that doctors can do for Alzheimer's, Alterra points out: "Diagnosis and prescription are professionally satisfying, but a disease that is all downhill with not even pain to mitigate by prescription offers little professional reward." There are guidebooks which discuss all features of dementia. For me, emotionally, I learn more from a book like this one. Take this passage, in which Alterra, with perfect economy, covers the entire prognosis of the disease: "What are the odds? For recovery, none. For living with it comfortably, we'll have to see. You may just lose a little more memory from time to time. You can live with that. It may be more severe. You may become incontinent, wheelchair-bound, forget how to chew or swallow, want to sleep all the time, be unable to speak. You may take it in stride, step-by-step. Or you may become profoundly unhappy, depressed, suicidal, and need drugs to even want to get up in the morning. Whatever it is, you can't do a thing about it." The caregiver, however, can read this book--and what a pleasure it is to do so.

Thank you, Aaron Alterra, for sharing your very insightful experiences while giving such loving care to your dear wife, Stella. Your touching recount of Stella's final days as a cellist and your countless successful efforts at preserving her dignity brought tears as I (a sexagenerian) empathized with your many dilemmas. I would certainly recommend this book to anyone with elderly parents or who themselves have become caregivers.

This is a most thoughtful insight from both the point of view of the Caretaker and the one for whom care is given. Many of your own thoughts, questions, fears, victories, frustrations and actual

experiences are seen and lovingly, yet honestly, shared by a gifted writer. Thought provoking, calming, and a real companion for a Caretaker who feels alone -- as we all do from time to time. Well worth the read!

I was very touched by the way he cared and loved his wife. He did a lot of trial and error and gave 110%.

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