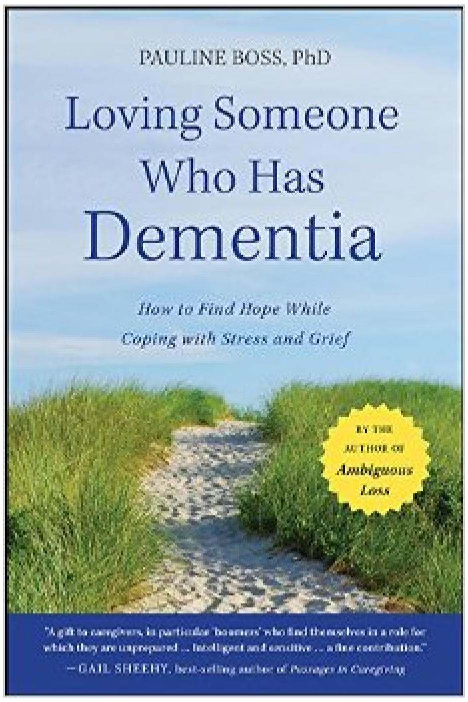
Loving Someone Who Has Dementia: How To Find Hope While Coping With Stress And Grief



Synopsis

Research-based advice for people who care for someone with dementiaNearly half of U.S. citizens over the age of 85 are suffering from some kind of dementia and require care.Â Loving Someone Who Has DementiaÂ is a new kind of caregiving book. It’s not about the usual techniques, but about how to manage on-going stress and grief. The book is for caregivers, family members, friends, neighbors as well as educators and professionalsâ ”anyone touched by the epidemic of dementia. Dr. Boss helps caregivers find hope in "ambiguous loss"â ”having a loved one both here and not here, physically present but psychologically absent.Outlines seven guidelines to stay resilient while caring for someone who has dementia Discusses the meaning of relationships with individuals who are cognitively impaired and no longer as they used to be Offers approaches to understand and cope with the emotional strain of care-givingBoss’s book builds on research and clinical experience, yet the material is presented as a conversation. She shows you a way to embrace rather than resist the ambiguity in your relationship with someone who has dementia. Q&A with the Author Author Pauline Boss What is meant by the term "ambiguous loss"? Ambiguous loss is simply an unclear loss. It is a term I coined in the 1970’s to label the all too common experience of having a loved one disappear without evidence of whereabouts or being dead or alive. Such disappearance can be physical, as in the case of a loved one gone missing, or psychological, as in the case of dementia when memory and emotion fade away. Ambiguous loss ruptures meaning, that is, it is immensely distressing to make sense of this kind of loss. In order to cope one has to know what the problem is, so I gave it a nameâ ”ambiguous loss. Knowing what the problem is the first step to managing it. In the case of dementia, the ambiguity will likely not lessen, but in this book, I tell you how to increase your tolerance for it. How did you come to be interested in the concept of ambiguous loss? I came to be interested in the idea of ambiguous loss early in my lifeâ ”living in a Swiss immigrant community where everyone seemed to be pining for the homeland across the sea. I grew up living with a Swiss grandmother (maternal) and a father, both of whom were homesick for the families they left behind. In our farm home in New Glarus, Wisconsin, she was the oldest and I the youngest, so we spent a lot of time together, doing the lesser tasks such as setting the table and shucking peas. Later on, that grandmother, Elsbeth Hammerlie-Elmer, to whom I dedicate this book, suffered from what was then called senile dementia. I felt I lost her in yet another way. She, like my father, was often dreaming of another family across the sea, and now she had dementia on top of the melancholy of homesickness. Because I lived with ambiguous loss, I became curious early in my life about the mystery of loved ones being gone psychologically. My favorite radio program back then was, â œMr. Keen, Tracer of Lost Persons.â • And my interest has never stopped. Is it possibleâ ”and ethicalâ ”to continue to have a sex life with a loved one who has dementia? For couples who already have diminishing pleasure in life, automatically saying â œno more sexâ • is unfair. First, individuals and couples vary widely in their desire to continue or stop having sexual relations. However it is viewed, stopping sex is one more loss in the midst of so many other losses. Second, there are vast differences in what couples consider â œsex.â • Third, there are vast differences in dementia, ranging from mild to severe, and this may be the most important decider for whether or not sex should continue after dementia. While research is slim, and more is surely needed to break the no-talk taboo, clinicians know that many couples affected by dementia continue to be intimate. But how they do this varies. Their sex life may still be what it was in their younger years, before dementia set in. Or it may be spooning in bed, or tender touching and hugging during the day before going to separate bedrooms. The bottom line is that there must be no exploitation, no forcing, no intimidation, no coercion, and no abuse. There must be some awarenessâ ”and acceptanceâ ”of what is going on. Neither person can feel entitled to sex just because he or she is married or simply has desire.

Book Information

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Customer Reviews

This is a fantastic book. I wish that it had been available when my mother was diagnosed with Alzheimer’s disease several years ago. I am giving my copy to a friend who, after reading it immediately, will mail it to another friend whose mother has just been diagnosed with this horrendous disease. Dr. Boss’ emphasis is on the caregiver rather than the patient and what the caregiver can do in order to be both more effective ("isolation leads to higher burden and depression for caregivers--and in turn, this leads to more behavioral problems in the person who has dementia") and survive with his/her own life intact. The author gives a sobering statistic: "caregivers die at a rate 3 percent higher than people the same age who are not caring for someone with dementia."Dr. Boss uses the words "ambiguous loss," over and over to describe when your loved one is here but isn't here and you are faced with an imperfect relationship that is not the way it once was, it never will be that way again and it will get even worse. One thing you can do to make things better for everyone involved is to continue with family rituals: celebrating birthdays, weddings, graduations, Thanksgiving and religious holidays as well. She also discusses the difference between depression and grief, reminding us that all too often professionals see a caregiver as being depressed she/he is actually experiencing extended grieving and is sad, a perfectly normal phenomenon for someone whose loved one is slipping away with dementia.The author, to her everlasting credit, debunks the myth of that awful word "closure," which she points out has been done to death by pop psychologists and television reporters.

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