



Loving Someone Who Has Dementia: How to Find Hope while Coping with Stress and Grief

Pauline Boss

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Research-based advice for people who care for someone with dementia

Nearly half of U.S. citizens over the age of 85 are suffering from some kind of dementia and require care. *Loving Someone Who Has Dementia* 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 professionals—anyone touched by the epidemic of dementia. Dr. Boss helps caregivers find hope in "ambiguous loss"—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-giving

Boss'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 name—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 life—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, “Mr. Keen, Tracer of Lost Persons.” And my interest has never stopped. **Is it possible—and ethical—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 “no more sex” 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 “sex.” 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 awareness—and acceptance—of what is going on. Neither person can feel entitled to sex just because he or she is married or simply has desire.

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