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Caregiving and Ambiguous Loss

Introduction

Caregiving for a loved one can cause stress in many ways. To manage the stress-which we know can be dangerous to a caregiver's health-we must first know what the problem is. Surprisingly, many caregivers of individuals with memory disorders or dementia report that the main problem is not the illness itself, but the ambiguity and uncertainty it causes.

It's a difficult challenge to care for someone who is here, but not here-physically, but gone mentally and psychologically. You feel alone, and in some ways, you are. For many caregivers, it's as if there's a stranger in the house.

Adding to the stress, disorders such as Alzheimer's disease or traumatic brain injury cause unpredictable memory loss that comes and goes-one moment here, the next moment gone. This roller coaster of absence and presence is a very stressful kind of loss-what author Pauline Boss calls ambiguous loss. Unlike death, there is no closure, no official validation, and sometimes little community or religious support. You feel you are left to cope on your own; even the strongest caregivers feel anxious and depressed. The challenge is to learn strategies to cope with this ambiguity that is so much a part of memory loss.

Symptoms of Overwhelming Stress

Caring for someone with a cognitive impairment-and the ambiguous feelings that arise-can create a constancy of sorrow that can immobilize caregivers. For example, decisions are put on hold, tasks pile up, chores delayed. Doubt, confusion, helplessness and hopelessness set in, and caregivers can feel anxious and depressed. Friendships are in limbo as caregiving takes more and more of your time. Conflict increases with spouse, children/stepchildren, siblings. Family gatherings and rituals that were the glue of enjoyable family life are cancelled or changed. When a caregiver feels increasingly isolated, the possibility of depression, anxiety, abuse, guilt, shame, lack of self-care, illness or substance abuse increases.

Tips for Coping with the Ambiguity of Memory Loss

To manage the stress of caregiving, try to connect with other people: if possible, join a support group either in person or on the Internet, attend a book club, social event, or faith-based group. Here are some ideas, questions and tips to help:

1. Name your problem.

Know that one real culprit causing your stress is the ambiguity from a loved one being here, but not here. Call it "ambiguous loss." It is neither your fault nor the patient's. It is caused by an illness.

2. Practice both/and thinking.

It helps to think "both/and" rather than in the ex-