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National Center on Caregiving

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Caregiving and Ambiguous Loss

By Family Caregiver Alliance and written by Pauline Boss

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—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 extremes of “either/or.” Instead of thinking the care recipient has to be either here or gone, think of him or her as both here and gone. This means balancing two different ideas at the same time—present, and also absent. Both/and thinking is less stressful than continuing to search for an absolutely perfect solution.

Here are some examples:

- “I am both a caregiver—and a person with my own needs.”
- “I take care of both him—and myself.”
- “I both wish it was over—and that my loved one could keep on living.”
- “I am both sad at my loved one’s illness—and joyful with my new grandchild.”
- “I am both sad about my lost hopes and dreams—and happy about some new plans and goals.”

Now add your own examples. “Both/and” thinking may come faster if you practice with another person.

3. Know your “family” and community information and support systems.

You need predictability (not ambiguity) about whom you can talk to and count on for help. Have some other people become “like family” to you? Does your community offer help and social support? Spiritual support? Recreation and respite? Information support? Talk with your Caregiver Resource Center about what help is available to you. Check the web—a quick online search for “caregiver” offers a wealth of information and online communities. If your biological family offers no help, perhaps you can create a “psychological family” that will be there for you when you need help. Talk about how to divide up the work among a “care team.” Make a written plan to know who will do what and when. Who will come once a week so that you can take some time off to do as you wish? Who will come for a week twice a year so that you can take a vacation from caregiving? Several websites can help you establish your caregiving community (see Resources list below).

4. Continue—but revise—family holidays, celebrations, and rituals.

Do not cancel, but rather, simplify the gatherings with the people you care about to celebrate birthdays, holidays, and religious events and rituals. Families, friends, and communities connect to celebrate life's transitions. Human connection can help lower your stress in times of sadness. It can help you and a person with dementia feel the spirit of life around you. This is essential to staying strong when the person you care for is not able to connect fully with you. Think and talk about this: what family rituals did you celebrate as a couple or family before the memory loss? Now? How can you simplify your family rituals and celebrations to fit the circumstances now? Young people can be especially helpful in answering these questions, because of their strong imaginations and new perspectives.

5. Revise family roles.

To manage the stress of caring for someone with severe memory loss, alterations are needed in what you and other family members previously did. There are changes in family roles as a result of the memory loss. What tasks are you now responsible for? What tasks have you lost? How do you manage these changes? What would help? Is there agreement in the family about who should do the caregiving? Are you resilient enough to change or do you feel you have to do it all as before? Talk about who plays what roles in the family.

Finally, based on roles, think about how you see yourself now. You might ask: Is it right for me to take time off to go out with friends when my spouse is suffering from Alzheimer's disease? Do I still feel like a son or daughter or more like a parent to my parent? If my spouse has memory loss, do I still feel married? How should I act?

6. Be aware of family rules.

Who is allowed to do what in your family? Is there a team approach or are you expected to do all the work alone? Become aware of your family's rules and question them. They can change. Do your family's rules about race, religion, class, age, or gender get talked about? For example, is there an unspoken rule in your family that only females can be caregivers? Are certain people excused from helping? Why are they excused? There may need to be a new family rule about "teamwork" so that caregiving does not fall to one person alone. Include children and teenagers in the circle of information about the illness, its effects, its unclear prognosis, and your need for help and teamwork.

7. Understand that anger and guilt are normal, but avoid harmful actions.

While mixed emotions are an understandable outcome of memory loss, the negative feelings can come out as anger or, worse yet, abuse—and that is not acceptable. Talk with someone—a professional or another caregiver—about your negative feelings to prevent acting out your anger. Remember, feeling angry about the ambiguity in memory loss is normal, but acting out that anger against the patient or yourself is not.

8. It seems contradictory, but imagine something new to hope for.

To stay healthy, everyone needs hope. When your loved one is ill, and you are tied to caregiving, you must discover new hope. It helps to talk about this with other people—and

again, with young people. They might help you imagine new dreams for your future—new connections, new hobbies, new travel plans, new skills, new relationships.

Given the stress from caregiving and the ambiguity of memory loss, what can you plan for the future that is clear and certain? How about an outing, a firm date for dinner with a friend, a hobby that has clear outcomes, a TV program that you clearly enjoy? New hopes and dreams will emerge when you can balance the ambiguity with some activities that have clear outcomes, no matter how small.

9. Check on your own health.

Seek professional help if you:

- Feel depressed, physically sick, or hopeless.
- Feel like hurting yourself or hurting or yelling at the person you care for.
- Depend too heavily on alcohol or recreational drugs.
- Fight with your spouse, children, stepchildren, or other family members and friends.
- No longer take care of yourself.

When you are a caregiver for someone with memory loss, the stress of ambiguity adds to the usual pressures of caregiving. You have a duty and a right to take care of yourself.

Summary

This fact sheet is a caregiver's guide to managing the extra stress from ambiguous loss. To sum it up, think of managing the ambiguity as learning to walk in the fog. Keep moving forward, despite the stress of not knowing what lies ahead. But at the same time, reach out for support and human connections to stay resilient and strong.

Resources

Family Caregiver Alliance

National Alliance on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

E-mail: info@caregiver.org

FCA CareJourney: www.caregiver.org/carejourney

Family Care Navigator: www.caregiver.org/family-care-navigator

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues, provides assistance in the development of public and private programs for caregivers, and assists caregivers nationwide in locating resources in their communities. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for

caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating health conditions that strike adults.

FCA Fact and Tip Sheets

A listing of all facts and tips is available online at www.caregiver.org/fact-sheets.

Depression and Caregiving

Caregiver Health

Caring for Adults with Cognitive and Memory Impairments

Dementia: Is This Dementia and What Does it Mean?

Grief and Loss

Taking Care of YOU: Self-Care for Family Caregivers

Other Organizations and Links

Lotsa Helping Hands

<https://lotsahelpinghands.com/>

Lotsa Helping Hands is a free online tool for caregivers to organize care and communicate with other family members, friends, and neighbors.

AgingCare.com

<https://www.agingcare.com/topics/60/caregiver-support>

This fact sheet was prepared by Family Caregiver Alliance and written by Pauline Boss and based on her books, Ambiguous Loss (Harvard University Press, 2000), Family Stress Management (Sage, 2002), and Loss, Trauma, and Resilience (W. W. Norton, 2006). ©2008 Family Caregiver Alliance. All rights reserved.

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