

FACING LOSS AND THE END OF YOUR CAREGIVER ROLE

(A companion piece to the tri-fold pamphlet of the same title)

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INTRODUCTION

Throughout the course of one's life, every loss helps to prepare us for subsequent losses. Because of the progressive nature of PSP, CBD, MSA, and other prime-of-life neurodegenerative diseases, caregivers and others close to the patient have already experienced and grieved the step-by-step loss of the person they knew and loved. Yet, the death of the person you were caring for brings with it an additional loss and subsequent life transition, i.e. the end of your caregiver role and a period of mourning for that role, and the beginning of a new and uncharted path in your own life.

The purpose of this article is to help you with the grieving process and with mapping a new course for yourself. Grief is not necessarily predictable, nor is it the same for everyone. Every person moves through the series of steps at his or her own pace. Therefore, the suggestions contained here are meant to be general guidelines.

GRIEF

The grieving process is unique to each individual, and its so-called "stages" are not sequential or linear. Nevertheless, each person is likely to pass through similar phases of grief and to experience common issues and emotions. In 1969, Elisabeth Kubler Ross was the first of many subsequent theorists to posit a framework for the stages of grief. Her theory is comprised of five stages: **Denial, Anger, Bargaining, Depression, and Acceptance.**

A more recent theory, The Grief Cycle, posits the emotions of grief in a dynamic circle, rather than in "stages" (see Resources: Shelly O'Brian), as follows:

Shock – Numbness, disbelief, inability to "think straight"

Protest – Acknowledging the deep sorrow; consequently feeling anger, guilt, sadness, fear of what's next, yearning. Feelings such as anger at the person who died or at those who tried to help her are normal. Guilt is also normal: For example, guilt about the death of your loved one; guilt that you have survived; or guilt that you feel a sense of relief that your caregiving duties are over.

Feeling of Disorganization – Depression, loneliness, anxiety, confusion (perhaps because you feel relief that the suffering has ended not only for the one you cared for, but for yourself as well), loss of identity, vulnerability

Reorganization and Redefining of Self – A gradual return to “normal” functioning, new habits and routines, but still feeling “not quite right”

Give yourself permission to experience and feel these emotions, and their fluctuations. Expect “anniversary” grief reactions on the dates of memorable occasions and holidays. With that in mind, mentally allow yourself to grieve for at least one year of seasons, holidays, and anniversary events without your loved one. Even consider planning for anniversary reactions. For example, think about what would feel right for you on a particular occasion. Let your family and friends know this, and ask them to honor your wishes. Do as much, or as little, as you can handle, and allow yourself to be flexible and change plans if you feel you need to. Anniversary times are stressful enough as is, and grief can intensify that feeling of stress.

MOVING ON – MAKING A NEW LIFE AFTER CAREGIVING

Inside the circle of grief is the resolution, which the theory calls **Recovery**. Recovery means learning to live apart from and in spite of the loss. What can you do to help yourself arrive at this place of Recovery, or “Now what?”

Take Care of Business:

In view of the multiplicity of your losses – the loss of a dear loved one, the loss of your role and perhaps identity, the loss of much that filled your days and your mind – please, allow yourself time before plunging into the tasks of sorting through belongings, settling finances, passing on personal items, managing family business matters.

Delay making major life changes, such as selling a home, moving, or leaving a job.

Take Care of Yourself:

The basics: nourishment, hydration, rest, exercise, relaxation breathing or meditation, making and keeping doctor and dentist appointments.

Exercise: Regular exercise contributes to improved circulation, flexibility, sleep, and sense of well-being.

Breathing: Breathe in through your nose while counting to four; then exhale through your mouth to a count of four. Repeat 5 to 10 times.

Accept offers of companionship and help from others.

Rediscover what you enjoy.

Interact with People:

Perhaps you will want to/need to re-connect with people who you may not have seen frequently during your caregiving days and years.

Reach out to trusted friends who will listen to you and support you in your grieving process and in building a new life.

Develop Daily and Weekly Routines:

Take time to figure out how you might want to spend your newly found time.

Take small steps toward the goal of establishing new routines, activities, and interests.

Structure at least a few days a week around a particular activity, class, job, or volunteer responsibility that gives you purpose and meaning. Perhaps schedule an activity where others rely on your presence.

Volunteering: Many organizations offer volunteer opportunities on weekly schedules and also as one-time events. Consider how much time you might want to give. Decide whether you want to utilize your professional expertise or to try a new area of interest. Think about location: Is it important to you to volunteer in a particular neighborhood, e.g. close to home or work? If you choose, you can even find volunteer jobs that you can do from your own home, e.g. recording audio books, or making phone calls.

Continue Your Own Healing:

Talk about your loss. Face your thoughts and feelings about it.

If you belonged to a caregiver support group, consider returning to the group at least once for reminiscence, good-byes, and closure; or even for longer, if you are so inclined.

Think about whether you would gain solace through volunteer work for CurePSP or another organization related to the disease or particular issues you were dealing with.

Resume or start a creative endeavor such as painting, music, crafts, or writing.

Any of these enable self-expression and the possibility of seeing things from a new perspective.

Join a bereavement or grief support group, either in-person or online. If, in the past, you have been a member of support groups, you know firsthand some of the benefits: commonality among participants, feeling less alone, receiving understanding and feeling understood, the reward of reaching out to others, socialization and relationships, information and resources.

In addition to planned online groups, there is an app called Goodgrief. It asks you a few questions about your loss, offers additional filters, and then connects you on a one-to-one basis to people in similar situations.

Turn to your faith or faith group for guidance.

Keep alive the good memories of your loved one. Talk about him or her. Reminisce about the positive moments you and your loved one shared. Retain precious mementos. Enjoy special photographs with your friends and family members. Include children or grandchildren in conversations, and in general, in the processes of grieving and healing. Create a memory book. Throughout, bear in mind that, although death ends a life, it does not end a relationship or your feelings about the person.

Reflect on, and embrace, the personal rewards of having been a caregiver: Did you learn patience? Acceptance? Taking “one day at a time?” Did you discover inner strengths and resources you didn’t know you had? Do you have a sense of pride and contentment that you were “there” for your loved one?

Be aware that grief may re-appear even after you thought it might be over.

Reach out for professional help from a psychotherapist or bereavement counselor, particularly if grief persists for many months, interferes with your day-to-day life, causes you to lose (or not re-gain) interest and pleasure in life, and/or makes you preoccupied with thoughts of death or a desire to die.

THE TAKE-AWAY MESSAGE: *We hope that these ideas and suggestions provide you with directions, options, and affirmation as you grieve the loss of your loved one and map a new course for your life. Grief and “moving on” are processes that take time, are not necessarily linear, and are different for every individual. For many people, grief continues – in varying degrees and occasions – for a long time. Give yourself the time, the space, and the course that is right for you.*

RESOURCES FOR FURTHER INFORMATION

AARP

888/687-2277, aarp.org

Hospice Foundation of America

800/854-3402, info@hospicefoundation.org, www.hospicefoundation.org

National Library of Medicine

www.medlineplus.gov/bereavement

National Hospice and Palliative Care Organization

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3367>

Peaks and Valleys – Integrative Approaches for Recovering from Loss by Shelly L. O'Brian, LCSW, 2014.

Today's Caregiver Online Magazine

<https://caregiver.com>

<https://caregiver.com/topics/caregiving> - Series of articles under the heading: After Caregiving

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