CurePSP is the leading nonprofit organization working to improve awareness, education, care, and cure for devastating prime of life neurodegenerative diseases. These include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and others. They often strike when people have careers, family responsibilities, and active lives. Their symptoms are incapacitating and there are no known causes, treatments, or cures.

Research has shown that there are important links between prime of life diseases and more common neurodegenerative conditions, such as Alzheimer’s disease and Parkinson’s disease. Your support will help advance this research, provide resources for families and caregivers of patients, and better educate the healthcare community. Together we are unlocking the secrets of brain disease.

CurePSP is a not-for-profit 501(c)(3) organization. Gifts and pledges of support are encouraged and donations are tax deductible to the extent allowed by law.

Facing loss and the end of your caregiver role

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GRIEF

The grieving process is unique to each individual, and progresses in steps that are not necessarily 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 Kübler-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’Brien), 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
- 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 – Gradual return to “normal” functioning, new habits and routines, but still feeling “not quite right”

Give yourself permission to experience and feel these emotions.

Expect “anniversary” grief reactions on the dates of memorable occasions. Mentally allow yourself to grieve for at least one year of seasons, holidays, and anniversary events without your loved one.

MOVING ON

Making a new life after caregiving

Inside the circle of grief is the resolution, which the theory calls “Recovery.” It 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?

Take Care of Business:
Give yourself time before plunging into the tasks of sorting through belongings, settling finances, passing on personal items.
Delay making major life changes, such as moving or leaving a job.

Take Care of Yourself:
The basics: nourishment, hydration, rest, exercise, meditation.
Accept offers of companionship and help from others.
Rediscover what you enjoy.

Interact with People:
Maybe you want to/need to re-connect with people who you may not have seen frequently during your caregiving days and years.
Reach out to a friend who will listen to you and support you in this new stage of your life.

Develop Daily Routines:
Take time to figure out how you might want to spend your newfound time.
Take small steps with the goal of establishing new routines, activities, and interests.
Structure at least a few days a week around a particular activity, class, or volunteer responsibility.

Continue Your Own Healing:
Talk about your loss.

Throughout the course of one’s life, every loss helps to prepare you 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 the beginning of a new and uncharted path in your own life.

The purpose of this pamphlet is to help you with the grieving process and with mapping a new course for yourself. Every person moves through these stages at his or her own pace. The suggestions contained here are meant to be general guidelines.

If you belonged to a caregiver support group, consider returning to the group at least once for reminiscence, good-byes, and closure.

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

Take up a creative endeavor such as painting, music, crafts, or writing.

Join a grief support group.
Keep alive the good memories of your loved one. Talk about him or her. Share photographs with family members.
Retain special mementos.
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?
Reach out for professional help from a psychotherapist or bereavement counselor, particularly if grief persists for many months, interferes with day-to-day life, and/or causes the person to be preoccupied with thoughts of death or a desire to die.

The takeaway message: We hope that these ideas and suggestions provide you with directions, options, and affirmation as you go through 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. Give yourself the time, the space, and the course that is right for you.