

Facing Loss & the End of Your Caregiving Role



Because of the nature of progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA), people living with the diagnosis and others close to them alike experience a variety of changes and losses over time. These can be small or big, and they are often a combination of emotional and existential responses (such as loss to your sense of self or to the person as you once knew them) as well as tangible losses (such as no longer being able to drive a car). For those living with a neurodegenerative diagnosis, anticipatory grief over what is to come is also common. Members of our community have shared with us that these experiences are not always understood or validated by others and, as a result, can feel ambiguous. Feeling grief over the course of an illness is normal and real.

The big loss, of course, is the death of a person. Despite having already grieved along the way and having emotionally, and sometimes logistically, planned ahead for the person's death, death can still bring about many raw and unanticipated thoughts and feelings. While all grief experiences are personal, grieving someone who died with PSP, CBD or MSA is often described by our community members as unique. A lot changed—from diagnosis through death—in a relatively short period of time. For many, days and energy in that time were spent attending to their loved one's care and needs. One PSP care partner once described it to us as “a fast-moving train” that she “could not get off of,” and said she had to spend a lot of time wrapping her head around that after her husband passed away. Additionally, there is the element of not many people having heard of the illness someone's loved one lived and died with. These facets are layered on top of how the death of the person you were caring for brings with it an additional loss—the end of your caregiving role. This transition marks the beginning of yet another new and uncharted path in your own life.

CurePSP recognizes that grief is individual and dynamic, and we want to be here for you in this new chapter. Through this resource, it is our hope to offer information and support as you understand your grieving process and map a new course for yourself. Every person moves through these stages at their own pace. The information and suggestions contained here are meant to be general guidelines.

CurePSP also offers a bereavement support group and a bereavement journal. We invite you to visit www.psp.org/bereavement-resources to learn more.

Moving Through Grief

The grieving process is unique to each person and depends on many factors, including how a person died, cultural and religious beliefs, a person's support system and how they reflect on and make meaning from their experience.

Grief progresses in ways that are not necessarily sequential or linear. Nevertheless, each person is likely to pass through similar phases of grief and to experience common thoughts, questions, challenges and emotions. Perhaps most well-known for her work in this field, 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 called The Grief Cycle suggests grief is experienced in a more dynamic circle (rather than in stages), which can include:

- **Shock:** This phase can be experienced as numbness or the inability to think straight. For the care partner of a person with PSP, CBD or MSA, it is often described as a sense of disbelief that after months or years of adapting to life with the diagnosis and providing care, the person died. This emotion is often contrary to the logic that they knew the person would eventually pass away.
- **Protest:** This phase is characterized by acknowledging the deep sorrow of the loss and consequently feeling anger, guilt, sadness and fear of what's next.
- **Feeling of Disorganization:** This feeling can be experienced as depression, loneliness, confusion, loss of identity and uncertainty of how to move forward. A care partner may feel relief that their loved one no longer has to live with the symptoms and challenges of PSP, CBD or MSA as well as relief that they no longer have to provide care. There can then be guilt over this relief. Many people describe experiencing seemingly opposite emotions—and trying to make sense of them. No matter what, this phase can be a very vulnerable space.
- **Reorganization and Redefining of Self:** In this phase of the grief cycle, a person experiences a gradual discovery or rediscovery of routines as well as a new sense of self. This does not mean they are no longer grieving and that everything feels right or OK, but rather that they are able to feel they are moving forward and finding grounding in a new normal.

Give yourself permission to experience and feel all of the emotions and thoughts that can arise in the grief process. Know that just as it can be hard to accept a diagnosis, it can be hard to arrive at a place of acceptance with the loss of someone you cared for and about. Expect for memories or important dates, such as holidays, birthdays and the anniversary of a person's passing, to be triggering and bring up renewed feelings of grief. Memorable occasions can equally be processed with fondness and gratitude. Grief is complex.

Making a New Life After the Caregiving Role

Inside the Grief Cycle is the resolution, which the theory calls Recovery. It means learning to live apart from and in spite of the loss. It does not mean that you are over the loss by any stretch, as it will likely always be something you carry and process. To help yourself arrive at this place of recovery, try to:

- **Take Care of Business:** Give yourself time before plunging into the tasks of sorting through belongings, settling finances and passing on personal items. You may want to delay making major life changes soon after the death, such as moving or leaving a job. At the same time, take the steps you need, which may be very practical, to make sense of your experience and move forward. How and when you take care of business, and what it means for you to take care of business, will be unique to your coping and needs.
- **Take Care of Yourself:** This step looks different for different people, but ultimately, it is a matter of intentionally attending to your own health and well-being. Nourish yourself, make sure you are hydrated, rest when you feel tired, exercise and meditate. It may have been difficult to find times to do these things when caring for your loved one. Accept offers of companionship and help from others. Rediscover what you enjoy and discover newfound joys.
- **Interact with People:** Maybe you want to or need to reconnect with people that you may not have seen frequently during your days and years of providing care for your loved one with PSP, CBD or MSA. As you move through the grief process, it is important to build and turn to your support system. Reach out to a person in your life 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 time now that you are no longer providing care to a person with PSP, CBD or MSA. Take small steps with the goal of establishing new routines and interests, or perhaps rediscovering those from before your caregiving role. Structure at least a few days a week around a particular activity, volunteer role or other responsibility. You may want to take up a new creative endeavor, such as writing, gardening or quilting, as an outlet for your energy.

- **Continue in Your Healing Journey:** If it helps to continue to process the experience you went through, talk about your loss as well as the life of your loved one. If you belonged to a support group for PSP/CBD/MSA or for care partners, consider returning to the group once to share the news, to reminisce, to impart lessons learned and to thank everyone for what the support group meant for you. Now may be a good time to try a bereavement support group. Reflect on what brings you strength and hope, and consider journaling to capture your thoughts as you move through your healing journey.

Think about whether you would gain solace or meaning through volunteer work for CurePSP or another organization related to the disease or experience you went through, or some other way to give back in memory of your loved one.

Keep alive the good memories of your loved one—sit with special mementos, look through photographs and share stories. These are important ways through which their love, light and legacy live on through you and others who were touched and shaped by them.

Reach out for professional help from a psychotherapist or bereavement counselor to process your experience and emotions around life with a diagnosis of PSP, CBD or MSA; your caregiving role; and the death of your loved one. This advice is particularly important if intense grief persists for many months, results in depression or anxiety that is difficult to cope with and move past, interferes with day-to-day life and functioning, or causes you to be preoccupied with thoughts of death or a desire to die.

Reflect on and embrace the personal rewards of having been a care partner of someone with PSP, CBD or MSA: Did you learn patience or the ability to adapt to uncertain circumstances? Did you discover strengths and skills you didn't know you had? Did you experience a new level of closeness with your loved one? Did you define and discover gratitude and hope in new and different ways?

The Takeaway Message

Grief is normal, complex and individual. It is a journey that can have many phases and forms. Give yourself the time, space and support that are right for you as you remember your loved one and make sense of your experience. We hope this information and these suggestions provide you with directions, options and affirmations as you process your loss. Please know that CurePSP, as well as others in your life, care about you and are here to support you in this next chapter.



Phone: 800-457-4777
Fax: 410-785-3777
info@curepsp.org
www.curepsp.org
Facebook.com/curepsp.foundation