

# Suggestions for Coping with Caregiver Grief

## What is Grief and how is it related to Aphasia?

According to the Mayo Clinic, “Grief is **the natural reaction to loss**. Grief is both a universal and a personal experience. Individual experiences of grief vary and are influenced by the nature of the loss.”

I think we often associate grief with death...we grieve for those who leave us physically, and are no longer here. However, grief is experienced in many forms. In the Aphasia world, I feel it is quite common for caregivers to experience grief...a lot of it.

There is actually a word for this type of loss that is often experienced by our caregivers. The term has been coined “**ambiguous loss**,” which is any loss that’s sort of unclear and lacks a resolution. It can be physical or psychological. Dr. Pauline Boss, a pioneer in interdisciplinary study of family stress, has written several novels on this topic. “These are all things we were attached to and fond of, and they’re gone right now, so the loss is ambiguous. It’s not a death, but it’s a major, major loss,” says Boss. “What we used to have has been taken away from us.”

## Our Recommendations to Caregivers:

Here are some of the suggestions that are at the top of my list:

- Do one thing each day that is for YOU. Just you. Make a commitment to focus on yourself one time a day, as this will also help to optimize your capabilities as a caretaker, and will also honor the fact that you, too, deserve to be taken care of.
- Identify those remaining important relationships in your life and focus on maintaining and strengthening those. Friends and relationships with relatives will undoubtedly change – find those connections you truly value and work on keeping those strong. Consider creating a new network and joining a support group.
- Accept help when it is offered. This may feel like a tough one, because you have your routine, you know what works and what doesn’t, and even though someone is trying to help you feel they may cause one of those many balls you are juggling to drop. However, it’s important to lean on others for support once in a while, even if it is something as simple as having them go grocery shopping for you or picking up your clothes at the dry cleaners. One less errand to complete, one more chunk of time you can focus on you.



- Accept that your life has changed, it is different now, and will be. Once this new life is accepted, it will likely be easier to embrace the changes and find ways to rebuild a new life.
- Discover activities that fulfill you and your new life, both new and old. Think about it...these activities are what we seek out because they are what helps to define who we are. We don't always get to choose relationships with people or our family members, or our careers or even where we live, but those hobbies of ours are what define our enjoyments in life, are a part of who we really want to be and how we want to live our lives.
- Finally, consider expecting a little less out of yourself than you once did. You have A LOT on your plate. You may have once been that person who always had your house clean, closets organized, you never had an issue remembering appointments, and you always had a homemade meal on the table at dinner time. This is likely no longer going to be the case...and that is OK. Let your house be cluttered for a few days. If you forgot an appointment, it's not surprising given how many things are on your mind and how many different things you are responsible for remembering in one day. Apologize to the staff and reschedule. No big deal.

It's time to let go of who you were and what situation was possible before and embrace the new hand you've been dealt and discover what is now possible.

