

# Ambiguous Grief: Grieving Someone Who is Still Alive

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"Some stories don't have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious ambiguity..." Gilda Radner

The term "ambiguous loss" was first used in the 1970s by Pauline Boss, a researcher who studied families of soldiers who were Missing In Action. The term is often used to refer to the similar experience of the care partner/caregiver.

There are times in life when someone you love becomes someone you often don't recognize, especially if they have dementia. The person you love is still physically with you, but psychologically they seem gone.

This can happen because of dementia, addiction, traumatic brain injury, mental illness. The person you love may do things they never would have done, say things they never would have said or treat you in ways they never would have treated you. This is often referred to as "ambiguous loss" or "ambiguous grief." It may not always feel as "delicious" as in Gilda Radner's quote!

You still love the person but miss the person they used to be and the relationship you had. It's normal to feel sad and yearn for who your loved one used to be. It's also normal to feel angry, confused, helpless and sometimes hopeless. Even the strongest care partners/caregivers sometimes feel anxious and depressed!

## Tips for when you are grieving someone who is still alive:

### ❖ Name it "ambiguous loss."

Know that you are experiencing the loss from a loved one being here, but not here. It is not your fault, nor your loved one's fault. You can learn to manage the normal experiences of ambiguous loss when you name it and accept it.

### ❖ Practice "both/and" thinking.

When you notice yourself thinking in the extremes of "either/or", move to "both/and" thinking. Think of your loved one as both here and gone.

Practice balancing the two different ideas at the same time.

A couple of examples of "both/and" thinking:

"I am both a care partner AND a person with my own needs."

"I am both sad about my loved one's illness AND joyful with other parts of my life."

"I both wish it were over AND that my loved one could keep on living."

Both/and thoughts will come more quickly with practice.

❖ **Know that the present doesn't override the past.**

Remember that the person your loved one is now doesn't change the person they were and the relationship you had. You can cherish those memories, write them down, or even create a memory book with photos and words. You might even be able to share that with your loved one.

❖ **Understand that the illness isn't the person.**

You can learn about your loved one's illness. When you notice yourself feeling angry or frustrated, you can remind yourself that understanding the illness can help manage some of those feelings.

❖ **Be open to a new type of relationship with your person.**

This many feel very difficult, but it can be practiced. You may discover humor that can be shared, old memories and gentle touches that can also be shared. You can notice yourself feeling grateful for small moments that now seem more significant.

❖ **Imagine new hopes and dreams.**

You might want to talk with others or write without editing to discover dreams for your future.

Perhaps new hobbies, travel plans, skills or relationships.

What can you plan for NOW that is clear and certain?

Perhaps a lunch date with a friend or a TV show you've wanted to watch.

When you balance the ambiguity with small activities that have clear outcomes, hopes and dreams can be imagined.

❖ **Connect with others who can relate.**

Your friends and family may not be able to relate to ambiguous loss.

In a support group like Pima Council on Aging's Family Caregiver Support Groups, you can be heard and supported. You will connect with others dealing with the ambiguity and uncertainty of caring for people you love who are physically with you, but seem psychologically absent.

To talk to a Caregiver Specialist at PCOA, call the Help Line at 790-7262

or call 609-1271 to register for a Caregiver Support Group.

You can be both an excellent caregiver and a person caring for your own needs!