



Caregiver Grief Triggers Mixed Emotions

From the initial diagnosis to a loved one's death and beyond, caregivers are faced with a barrage of conflicting feelings. Here's how to cope with them.

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The nation's grief surfaced on Saturday, when former President Ronald Reagan finally succumbed to Alzheimer's disease after a 10-year battle. But in millions of individual American homes dealing with a similar fate, it often starts long before a death.

It may come with the initial diagnosis -- of multiple sclerosis, ALS, cancer, Parkinson's, Alzheimer's, or other chronic, debilitating conditions. Or when a once-vibrant loved one can't recall a treasured memory, move without difficulty, or even go to the bathroom. As their withering continues, over days or decades, this grief often intensifies.

"As a family caregiver, you are grieving throughout the entire process, not only with the death of your loved one," says Suzanne Mintz, president and co-founder of the National Family Caregivers Association, who cares for her MS-afflicted husband and whose father also died from Alzheimer's five years ago. "You grieve with each loss -- each time they go down a notch, with each reminder of what was and what it has become."

During the course of a chronic illness, caregivers typically experience a range of emotions: Hopelessness. Stress. Guilt. Sadness. Anger. Depression.

A Range of Feelings

"Grief is a reaction to a loss, but it can be -- and with caregivers grief often is -- a multifaceted reaction," says Kenneth Doka, PhD, MDiv, professor of gerontology at the Graduate School of the College of New Rochelle and the author of 17 books on grief, including the new *Living with Grief: Alzheimer's Disease*.

"We tend to associate grief with strictly negative emotions, but it's much wider than that," he tells WebMD. "We know that with the death, there's often relief that the suffering has ended. But there can also be strong feelings of fulfillment. Right now, Nancy Reagan may be saying, 'I got through this. I was by his side, even when he didn't know I was by his side.'"

These conflicting emotions can play havoc with an already stressed and vulnerable psyche, which may explain why nearly one in three caregivers meets the medical diagnosis for depression, according to a study last year in the *American Journal of Geriatric Psychiatry*. "Caregivers' depression often improves following the loss, but not always," says study researcher and psychologist Holly G. Prigerson, PhD, a grief and bereavement expert at Yale University School of Medicine.

"The emphasis is often on the great relief that occurs following the death, once the caregiving and agonizing is over," she tells WebMD. "They think it should be downhill after that, but it's not as easy as that. These people typically have been caregivers for about 10 years -- that has been their identity and mission -- and it can be very difficult for them to regain their life.

"I just read a book about a woman whose husband had ALS. After he died, she became suicidal because her main reason for living was to care for him. When he died, she had a gaping hole she had to fill. Just because someone feels relief doesn't mean they also don't feel huge amounts of grief, loneliness, and abandonment."

How to Cope

So how can caregivers better work through the barrage of emotions that occur during and after a loved one's illness?

- **Be more than a caregiver.** "For many people, the role of caregiver is all-consuming," says Doka. "So when it ends, life can feel as though it's lost its meaning and purpose."

That's why it's important for caregivers to set up regular "me" time, says Prigerson. "You need to make sure you're not socially isolated, and your days prior to the death consist of just more than just caregiving. We found that one of the great aspects of caregiving burden that leads to depression isn't from the hours spent giving care, but that the caregiver feels deprived of their own time. You really need to take time for yourself, whether it's going for a walk or enjoying a nice dinner out sometime."

- **Nurture a network ...** Many caregivers feel it's their responsibility to offer care and hesitate to seek help elsewhere. Bad move. "What I do on a clinical basis is have caregivers write down the names of all the people that could be in their network," says Doka. "Not just family members, but also friends, neighbors, or if they're involved in a faith community, consider members of their church, who can be a strong part of your network."
- **... And assign tasks.** Understand that different people can perform different roles, he adds. "Some people are more prone to be good listeners, others are doers, while others are good for helping you with rest and relaxation. Even when caregivers have a big network of support, a common problem is that they don't use it well. I suggest on your list you assign tasks to different people: Some are Ls (listeners), Ds (doers) or Rs (relaxers)."
- **Get help with housework.** "You would think that emotional dependency is the biggest predictor of a caregiver's complicated grief," says Prigerson, "but studies indicate that when a caregiver has been dependent on their ailing spouse for household chores, that can have an even bigger impact." In other words, try to get help with routine chores such as laundry, cleaning, and shopping.
- **Mind your own health.** Since they are preoccupied with a loved one's illness, caregivers often turn a blind eye to their own health. "The risk of hospitalization of a caregiver is greatest in the months following the death," she says. So when the patient is falling, and especially afterward, be especially mindful of your eating, sleeping, and exercise habits. "This is where 'me' time becomes especially important."
- **Consider respite care.** The Alzheimer's Association and similar advocacy groups often offer respite care -- in essence, adult day care for afflicted patients that allow caregivers time for themselves. "One of the best things you can do is contact your local chapter or a VA hospital to see what's available in your area," says Mintz. "There is help out there."