



## Ask an Expert

### Question

My husband has Alzheimer's disease and recently began receiving hospice care at home. Although he has been declining for years, and I have missed what we once had together, I feel especially especially sad now. Is it possible that I am grieving even though my loved one is still alive?

### Answer

Yes, it is not only possible but common. Grief is often thought of as something that happens after a loss, but especially for families facing dementia, grief can begin long before the final farewell. As a loved one's memory, personality, and independence gradually fade, family members may experience what's known as anticipatory grief; the heartache that comes from losing someone little by little, while they are still physically present.

Anticipatory grief is a very natural response to an unfolding loss. It can show up as sadness, anger, frustration, confusion, or even relief when a loved one has a good day. It may surface when

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## Understanding anticipatory grief

by Patti Anewalt

Caring for a loved one with a serious and life-limiting illness often means that losses keep coming. Some may be significant and sudden, such as hearing the physician's prognosis or experiencing a loss of income when work is no longer an option. Some losses are anticipated and anxiety provoking. Examples might be the fear of losing the companionship a spouse, parent, child, or sibling has always provided. Others may be subtle, such as mourning the absence of alone time as your caregiving responsibilities increase.

These are anticipatory grief reactions, which are similar to the grief reactions commonly experience after death. Anticipatory grief may affect you behaviorally, physically, cognitively, emotionally, or spiritually. It may impair your previous level of functioning. Your sleep may be disrupted. You may be exhausted, lose your appetite, overeat, or experience headaches. You may withdraw or find yourself needing to stay constantly busy. You may cry or wish you could. You may question your faith or be drawn closer to it. You may feel sadness, guilt, anxiety, anger, or helplessness. And like many going through this experience, you may have difficulty concentrating, worry about the "what if's," crave predictability,

or feel like you need more information about how the illness will progress.

These are all natural and common anticipatory grief reactions. Life has changed; it's not like it was. You may also sense more changes are coming. Mourning involves recognizing how grief responses affect you individually and then acting on them. Your environment and your culture will influence how you address your anticipatory grief and the ways you mourn these mounting losses that precede death.

The experience of anticipatory grief may extend to other family members, friends, and the patient as well, so open communication is critical. Each person is unique about what they feel they need to do about

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*"Grief is forever. It doesn't go away; it becomes part of you, step for step, breath for breath."*

— Jandy Nelson