

Family and Caregiver Education

BEREAVEMENT

Living When a Loved One Dies With Dementia

The grief a person experiences when a loved one dies with dementia can be profound and lasting. This type of grief is unique because your journey began a long time ago, usually before a loved one was officially diagnosed. Initially, your loved one may not have looked impaired, yet emotionally and mentally, you noticed changes. They may have said things they never would have said or behaved in ways you never saw before. As their dementia progressed, they were not the same person you once knew, and you learned to adapt to their changes and what those changes meant for you, especially if you were the primary caregiver.

Some losses unique to dementia you may have experienced are:

Lack of meaningful communication. Your special person may have become forgetful, repetitive, confused or silent.

Their ability or willingness to do familiar tasks became challenging. Things like dressing, bathing, cooking or problem-solving declined as their dementia progressed.

Changes in their personality or behaviors. That start to mirror those of early childhood. They may have seemed more combative, aggressive or argumentative as the disease progressed.

Altered roles and responsibilities. You may have felt more like a parent and less like a partner or their adult child as you provided supervision, transportation or assistance with daily living tasks.

Lack of social connections. Family events and holidays may have been overstimulating to them, prompting inappropriate responses or anxiety. Friends and family members may have distanced themselves. You may have hoped that these changes were temporary and that things would go back to the way they were. It is hard to reconcile the person your loved one became with who they used to be. When your loved one was physically present, but emotionally and mentally absent, it often meant you lacked emotional or physical support when it was most needed. Many times, you continue to miss that support even after their death, making the grieving process more difficult. This experience is known as ambiguous loss. It can lead to feelings of distress and isolation by making you reluctant to talk openly about your loss with others.

Bereavement Services

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Grief is the natural, normal yet very personal response to loss. It affects us in many ways: physically, emotionally, mentally, spiritually and socially. With a dementia diagnosis, you may experience the following grief symptoms before, during and after their death:

Physically: Fatigue, stomach upset, sleep disturbances, appetite changes, chest tightness.

Emotionally: Sadness, loneliness, anger, depression, guilt, regret, impatience, irritability.

Mentally: Forgetful, overwhelmed, hypervigilant, disorganized.

Spiritually: Anger at God, questioning individual beliefs.

Socially: Social withdrawal, isolation, apathy.

Your grief journey will include adjusting to a different life with new daily routines and activities. You may also reflect on the long caregiving journey and wonder, “Who am I now?” and “What is my purpose?” As you cope with the ups and downs of grief emotions, you may acknowledge that you have neglected your own needs and decide to focus on self-care. This is a smart decision and allows you to tend to health concerns that may have been neglected while you were caring for your loved one. Supporting your emotional health by finding a grief group or counselor who understands your unique grief and can companion you through this journey can help you process some of the more complicated emotions you may be experiencing.

After your loved one’s death, you may initially find some solace and relief. You also may think that you completed your grieving prior to the death. Sometime later, you begin remembering the person you loved before the dementia changed them. You may wonder, “Why am I so sad and lonely?” — and discover that you are experiencing a new range of grief symptoms, especially around holidays or special occasions. The symptoms may include going over and over your loved one’s illness and what you feel you “should” have done.

You may feel what seems like guilt, remembering times when you lost your patience, expressed frustration or had been irritable while caring for your special person. Many people identify this feeling as guilt when, for most people, it is regret. Guilt is warranted when a person does something to injure another deliberately and may feel shame. Regret is wishing the situation or your behavior could have been different. No matter how loving you are, there are moments when the challenges of caring for someone with dementia can feel like too much. Ask yourself: “Were my outbursts or behaviors intentional or were they a normal response to lack of sleep, worry, overwhelming responsibility and little time for self-care?” Many times, you might have been alone or one of a handful of people caring for your special person. Be gentle with your heart and emotions — you did the best you could with the information available to you at the time.

Caring for a loved one with dementia is life-changing, so be kind to yourself. With patience and determination, you will rediscover your own joy and find renewed meaning in your life.

Visit [hov.org/grief-support](https://www.hov.org/grief-support) for more information.