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National Center on Caregiving



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## Grief and Loss

### Introduction

We generally think of grief as a reaction to a death. But there is another grief that comes from loss while someone is still living. This grief is often experienced when caring for someone with a chronic illness. Chronic illness, and particularly any illness that impairs a person's cognitive ability, causes caregivers and loved ones to experience grief and loss right now. In this fact sheet, we will discuss the grief related to death and dying, and grief associated with chronic illness. It is natural to grieve the death of a loved one before, during, and after the actual time of their passing. The process of accepting the unacceptable is what grieving is all about.

### Chronic Illness and Loss

Over time, with most chronic illnesses, there are changes in a person's abilities. Whether it is someone living with Parkinson's disease who can no longer button a shirt, or someone coping with diabetes who has to follow a special diet, or someone with Alzheimer's disease who can't remember who you are, caregivers have to adjust to the needs of the care receiver. Caregivers may experience many kinds of losses: loss of independence; loss of control; loss of the future as it had been imagined; loss of financial security; loss of the relationship as it once was; loss of freedom, sleep, and family harmony; loss of someone to share chores and other tasks with; or simply the loss of someone to talk things over with. Persons with chronic illnesses also have to adjust to many of the same losses, but also—loss of dignity, mobility, a carefully planned future or retirement, a loss of roles that were played, or the loss of a sense of worth (all depending on what disability is associated with the illness).

It is easy to ignore these losses and just keep doing the things that need to be done. However, these losses lead to grief, and grief can lead to sadness, depression, anger, guilt, sleeplessness, and other physical and emotional problems. It is important to identify our losses, identify our

feelings, and let ourselves grieve the changes that have happened in our lives. When we can do this, our feelings will less often erupt as angry outbursts weighed down by guilt, or creep over us as depression and hopelessness; they instead can more easily be expressed as a shared loss of something treasured—which family and friends close to the situation can likely empathize with, leading to deeper communication and stronger relationships with those going through the loss with you.

Writing in a journal can help you to name and express your feelings about these losses. You can combine it with a gratitude journal—things that you are thankful for. Prayer, meditation, relaxation exercises, attending a support group (or simply talking with a friend or counselor), or creating a ritual can help you to let go of the intensity of the feelings so that you can grieve but also heal.

## **Ambiguous Loss**

Ambiguous loss is what we experience when someone is still “there” but also not “there.” This is mainly experienced when someone has a cognitive impairment from dementia, a traumatic brain injury, or a stroke. We also experience ambiguous loss when someone with dementia has “moments of lucidity,” when he/she is clear and makes sense for a short period of time. It is hard not to think that if they can do this every once in awhile, they ought to be able to do it all of the time. When they return to their confused state, we often experience anger, frustration, and disappointment—renewed grief. (See the FCA fact sheet [\*Caregiving and Ambiguous Loss\*](#) for more information on this topic.)

## **Anticipatory Grief**

When caring for someone over time, we may start to grieve that person long before they die, we grieve the loss of the person’s “former self.” Experiencing loss on a daily basis, as well as anticipating the loss at the end of life, knowing what is coming, can be just as painful as the loss associated with a death. Caregivers may experience guilt or shame for “wishing it were over” or thinking of their loved one as already “gone” (particularly when someone has a cognitive impairment). It is important to recognize these feelings as normal. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues, make end of life plans for funeral and burial, and experience their pain in stages. Sometimes, when someone has grieved a death over a long period, there is less grief when the person dies; sometimes there is more pain when a person dies.

## **Grief at Death**

Grief is a natural emotion, a universal experience that makes us human. Because it is intense and uncomfortable to feel, we often try to find ways to avoid experiencing the immensity of the emotion—through distraction and busyness. We grieve because we are deprived of a loved one; the sense of loss is profound, the change in roles is confounding, and we may become uncertain

of our identity. Often caregivers are in the situation of having to make changes in their circumstances—where to live, financial concerns, relationships—along with fear of not knowing what lies ahead.

Grief lasts a long time. Recent research has shown that intense grieving lasts from three months to a year and many people continue experiencing profound grief for two years or more. Our society expects us to be “doing fine” in about two weeks. It is common to think there is something wrong with us if our grief “lasts too long.” The grieving process depends on our belief system, religion, life experiences, and the type of loss suffered. Many faiths and cultures have rituals for recognizing grief and loss during at least the first year after a death. We also expect other family members to show their grief in the same way we do, even when we can say that everyone grieves differently. There is no right or wrong way to grieve; grief is an individual process. Many people find solace in sharing their grief with family and friends; others find solace by attending grief support groups offered in every community through their local hospice (even if you did not have hospice services). If you are feeling overwhelmed and concerned about your own grief process over time, seek professional help.

When someone dies suddenly, our first response is often denial, then shock, confusion, and pain. Fatal heart attacks and strokes, car accidents, and suicide can leave family members troubled and searching for answers. In these cases, family members may be left with unresolved issues, such as guilt, anger, anxiety, despair, and feelings of emptiness. Sometimes we have to learn to forgive ourselves and our loved one who died. It can take longer to heal from this loss and it is important to give yourself time to grieve before pushing yourself to “move on.” Getting support from family, clergy, friends, and grief groups can help.

## Symptoms of Grief

Grief affects our whole being—physically, socially, emotionally, and spiritually. Each of us will have different symptoms. If you have had a previous loss, you may experience grief this time in a similar or different way, depending on the situation, your relationship with the deceased, and other significant emotional factors in your life at the time. Culture, religion, and social norms influence what we are comfortable showing to others and even what we are comfortable admitting to ourselves.

### Physical

- Crying
- Sighing
- Low energy/exhaustion/weakness/fatigue
- Headaches
- Stomach aches, loss of appetite
- Eating too much, particularly comfort foods
- Sleep disturbance—too much or too little, disturbed dreams
- Feelings of heaviness, aches, pains
- Being super busy, pushing yourself to do too much
- Reckless, self-destructive activities such as drinking too much

## **Social**

- Feeling alone
- Wanting to isolate yourself from socializing, finding it hard to pretend to feel OK, being pushed to be social by others
- Feeling detached from others
- Angry that others' lives are going on as usual and yours isn't
- Not wanting to be alone, feeling needy and clingy

## **Emotional**

- Sadness, crying spells
- Anger/frustration/rage
- Confusion/overwhelmed
- Guilt
- Worry/anxiety/panic
- Yearning
- Edginess/irritability
- Memory problems, feeling distracted, preoccupied
- Depression
- Euphoria
- Passive resignation
- Fluctuating emotions
- Sense of lack of control
- Others might see you as “unreasonable” or “overreacting”

## **Spiritual**

- Questioning your faith/meaning of life/suffering
- Questioning reason for the death/disease
- Anger at God
- Coming closer to faith/God for solace

## **Stages of Grief**

There is no road map for dealing with grief. There are stages that most people go through, but they are not a linear progression from stage 1 to stage 2, etc. We “visit” these stages at different times during the grieving process, depending on what is happening in our lives, for instance, special occasions, like anniversaries and birthdays. And we might go back to a stage years later, such as loneliness and isolation or depression. Although Elizabeth Kübler-Ross defined the five stages below, many clinicians think there are more or different stages.

### **• Shock/denial**

- Trouble accepting the fact of death, diagnosis or new reality, numbness
- Inability to do usual activities

- **Anger**

- Anger at yourself, others, professionals (particularly doctors), God, life
- Feeling helpless and powerless, abandoned

- **Bargaining**

- Making “deals” with God or friends hoping to change the situation
- Thinking about “what could have been” or “should have done differently”

- **Depression**

- Feeling overwhelmed with loss and change, sadness, regret, fear, anxiety
- Lonely, isolated, self-pity, empty, lost

- **Acceptance**

- Adjusting to the new reality, starting to move on
- Sense of hope, healing, and integration

## Helping Those Who Are Grieving

We often feel uncomfortable when approaching someone we know who is grieving. It is hard to know what to say or do. Here are some tips:

- Be available. Offer support in an unobtrusive but persistent manner.
- Listen without giving advice.
- Do not offer stories of your own experiences with grief. This can have the effect of dismissing the grieving person's pain.
- Allow the grieving person to use expressions of anger or bitterness, including such expressions against God. This may be normal behavior in an attempt to find meaning in what has happened.
- Realize that no one can replace or undo the loss. To heal, the individual must endure the grief process. Allow him/her to feel the pain.
- Be patient, kind, and understanding without being patronizing. Don't claim to "know" what the other person is feeling.
- Don't force the individual to share feelings if he/she doesn't want to.
- Physical and emotional touch can bring great comfort to the bereaved. Don't hesitate to share a hug or handclasp when appropriate.
- Be there later, when friends and family have all gone back to their routines.
- Remember holidays, birthdays, and anniversaries that have important meaning for the bereaved. Offer support during this time.
- Don't be afraid of reminding the person of the loss; he/she is already thinking about it. Share stories and memories of the deceased.
- Send cards, flowers, deliver a meal, offer to do chores, donate to a cause that is important to the person who died or who is grieving.

# Taking Care of YOU

Taking care of yourself in difficult times is hard. Trusting your own process will help you to do what you need to do in order to best take care of yourself. Acknowledging your feelings—good and bad—will help you to cope better with whatever is happening. Read, journal, get support, cocoon, or do whatever is nurturing for you.

## Resources

### **Family Caregiver Alliance**

#### ***National Center on Caregiving***

(415) 434-3388 | (800) 445-8106

Website: [www.caregiver.org](http://www.caregiver.org)

Email: [info@caregiver.org](mailto:info@caregiver.org)

FCA CareJourney: [www.caregiver.org/carejourney](http://www.caregiver.org/carejourney)

Family Care Navigator: [www.caregiver.org/family-care-navigator](http://www.caregiver.org/family-care-navigator)

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's, and other debilitating disorders that strike adults.

## Other Organizations and Links

### **Center for Loss and Life Transition**

[www.centerforloss.com](http://www.centerforloss.com)

### **National Hospice and Palliative Care Organization**

[www.nhpco.org](http://www.nhpco.org)

### **Hospice Foundation of America**

[www.hospicefoundation.org](http://www.hospicefoundation.org)

### **The Fisher Center for Alzheimer's Research Foundation**

[www.alzinfo.org](http://www.alzinfo.org)

## Recommended Readings

*Beyond Sympathy, What to Say and Do for Someone Suffering an Injury, Illness or Loss*, Janice

Harris Lord, Pathfinder Publishing, 1992.

*Don't Take My Grief Away*, Doug Manning, BookBaby, 2013.

*A Journey Through Grief: Gentle, Specific Help to Get You Through the Most Difficult Stages of Grieving*, Alla Renee Bozarth, Hazeldon Publishing, 2010.

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*This fact sheet was prepared by Family Caregiver Alliance, revised and updated in 2013, and reviewed by Rabbi Jon Sommer, Professional Grief Caregivers' Network, October 2013. Copyright © 1996, 2013 Family Caregiver Alliance. All rights reserved.*

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