



Understanding Grief and Loss, for Caregivers

- Grief is a deep sadness caused by loss or death. It's a normal and natural response to loss.
- Grief is not an event, it's a process. It's not linear and doesn't necessarily happen in stages.
- Grief doesn't start strong and then taper off. It's like a storm that grows smaller or larger in the same day, and often within hours.
- Grief is work that must be done, now or later.
- Grief requires care.
- Grief creates a wide variety of responses, influenced by culture, family, circumstance of loss, coping skills, expressiveness, beliefs, health, and support system.



Emotional Responses to Grief	Physical Responses to Grief	Social Responses to Grief
Anger	Fatigue	Desire to isolate yourself from others
Sadness	Stomach ache	Feeling pressured to be social
Guilt	Headache	Feeling detached from others
Relief	Difficulty sleeping	Angry that others' lives are going on as usual
Feeling alone	Difficulty eating	Not wanting to be alone, feeling needy and clingy
Anxiety	Difficulty concentrating	Inauthenticity, pretending to feel OK when you're not
Helplessness	Tears	
Blame		
Numbness		
Confusion, short attention span		
Difficulty concentrating		

Feelings of Loss When Someone is Ill

When someone has a chronic illness, they change. A person living with Parkinson's disease may no longer be able to button a shirt, or someone with Alzheimer's disease may not remember who you are. Caregivers have to adjust to the needs of the care receiver.

In doing so, caregivers 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
- loss of someone to talk things over with - a partner, a parent.

**The process of accepting
the unacceptable
is what grieving is all about.**

Someone with a chronic illness has to adjust to many of the same losses, but also

- loss of dignity
- loss of mobility
- loss of a carefully planned future or retirement.
- loss of roles or responsibilities
- loss of a sense of worth

Sometimes we try to ignore these losses and just keep doing the things that need to be done.

*The only cure for
grief is to grieve.*

It's important to identify our losses, feel 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.

Instead, they can more easily be expressed as a shared loss of something treasured, and family and friends close to the situation can likely empathize with this, leading to deeper communication and stronger relationships with those going through the loss with you.

Ambiguous Loss

Ambiguous loss is what we experience when someone is still "here" but also not "here."

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 or she is clear and makes sense for a short period of time. It's hard not to think that if they can do this every once in awhile, they ought to be able to do it all the time. When they return to their confused state, we often experience anger, frustration, and disappointment—renewed grief.

Anticipatory Grief

This is grief that comes from feelings of loss while someone is still living, often experienced when caring for someone with a chronic illness. Caregivers can experience grief and loss right now, even as they provide care for someone living.

*It's natural to grieve
the death of a loved one
before, during, and after
the actual time of their passing.*

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, and the relationship we had.

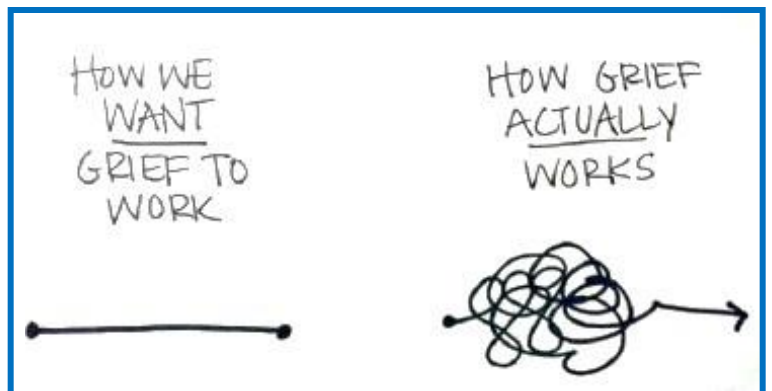
Experiencing loss every day, as well as anticipating the loss at the end of life, knowing what is coming, can be just as painful as the loss associated with a death.

Caregivers may experience guilt or shame for "wishing it were over" or thinking of their loved one as already gone.

It is important to recognize these feelings as normal.

Anticipatory grief is a way of allowing us to prepare emotionally for what's to come. Preparing for the death of a loved one can allow us to think about and clear unresolved issues, make end of life plans, and experience 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.



How to Take Care of Yourself While Grieving

(<https://griefwatch.com/self-care>)

Listen to your body: If you need to cry, then cry. If you need to sleep, sleep. If you need to talk to someone, seek out someone who will listen. If you need to reminisce, then take the time. It is important for the grieving process that you go with the flow.

Lower expectations for yourself: You can't expect yourself to run at full capacity. Give yourself a break and don't expect yourself to perform as well as you did prior to your loss. Educate others that it will take some time before your capacity is back to normal.

Let others know what you need from them: Don't expect others to know what you need. Communicate to family and friends how they can support you.

If you need counseling, get it: Get all the support you need. There are many bereavement support groups as well as counselors or who specialize in grief counseling. Don't hesitate to contact someone if you have feelings of hopelessness or suicidal thoughts.

Take the time to do the things you need to do for yourself: When you feel up to it, engage in activities to which you feel drawn. It could be visiting a place you haven't been to in a while, walks in nature, reading, etc.

Pamper yourself: Treat yourself well. Without breaking your budget, do things for yourself that are helpful like walks, being with people who are nurturing to you, and inexpensive activities.

Keep a journal: Writing down your thoughts and feelings can help you to validate and work through your grief.

Get physical exercise: If you exercised prior to your loss, try to maintain the same routine. If you didn't, try to get out for some walks. Physical exercise can improve the way you feel.

Eat and sleep as well as you can: Eating well and getting a good sleep is essential for the grieving process.

Be aware of others' reactions: Many people do not know how to react appropriately to your grief. Some are more comfortable than others in responding to your situation. Be aware that people have different ideas not only about death, but also about how bereaved individuals should react. Be true to yourself and let others know if they say something inappropriate.

Grief is like the ocean,
it comes in waves,
ebbing and flowing.
Sometimes the water is
calm, and sometimes it
is overwhelming. All we
can do is learn to swim.

Vicki Harrison

Support that Feels Supportive:

Things that are helpful...	Things that are not...
<ul style="list-style-type: none"> • Someone who doesn't say anything, who can be present as a witness to your pain. • Someone who can listen without problem-solving or giving advice. • People who offer specific assistance (housework, meals, childcare). "I'd like to bring you dinner on Wednesday, would that be ok?" • Someone who can acknowledge your loss: "I heard what you've been going through, and I'm so sorry." • "I don't really know what to say, but I just want you know I'm here, and I care." • "I can't imagine what you're going through, and I'm here for you." • "Do you want to talk about it?" • Someone who can normalize your intense emotions: "It's natural to feel that way." "Anyone would feel that way in your situation." • Someone who can give you a chance to talk, and the freedom not to. • Someone willing to share memories and stories: "Remember that time..." • Anyone who can see and hear you, who listens and is patient. • Someone who can accept how you've changed. • Someone who can offer ongoing support, beyond the rush of sympathy. • Someone who can give you a hug, if you'd like that. Someone who acknowledges birthdays, anniversaries, and holidays, and offers extra support at these times. 	<ul style="list-style-type: none"> • Someone who doesn't see you accurately: "I know how you feel." • Anyone who tries to minimize or judge the intensity of your grief: "But you weren't really that close." • "At least..." • "You knew it was coming." • "You must be relieved on some level, he was suffering so much." • "It was for the best." • Anyone who tries to gloss it over or make it ok before you're ready: "You just need some time." • "Everything will be ok." • "Things will look better tomorrow." • "Everything happens for a reason." • People who offer vague support that you have to follow up on: "Let me know if there's anything I can do." • Narcissistic mirroring: "I lost someone, too, let me tell you all about my experience." • Anyone who puts a timeline on your grief or gives you advice to distract yourself: "Time to put it behind you." • "You need to keep busy." • People who avoid you or are uncomfortable with your feelings; people who are afraid of your pain. • People who can't handle it when you express bitterness, despair or anger, which are normal and natural. • Anyone who tries to protect you from the grieving process – it is normal and necessary.

