

## 5 Steps for Dealing with Anticipatory Grief

It might be the hardest part of caregiving: Watching your loved one slip away step by terrible step, knowing you can't stop the decline and grieving the loss of the person you once knew, long before they're actually gone. Psychologists call this process *anticipatory grief*, and it's very common among caregivers and family members of those living with dementia, cancer, and other terminal illnesses.

### Coping with Anticipatory Grief

“As a disease progresses, there is so much frustration and sadness associated with watching the person you once knew go away,” says Vince Corso, M.Div, LCSW, CT. “It can be overwhelming.”

Corso provided care to his mother, who was diagnosed with Alzheimer's. He found one of the painful milestones of the disease as the point at which she no longer recognized him. “My mom didn't recognize us, and she confused us with other people. As a son and a caregiver, that was really hard. I had to leave the room.” But after a period of time, he says, he became acclimated to his new reality and began to accept it. He found that sharing the sense of loss with family members was very helpful. “It's so crucial that family members talk about the loss.”

If your loved one's condition has advanced, consider asking their physician whether it may be time to transition to hospice care. In addition to providing the right level of care for patients whose illness has progressed, hospice also supports caregivers; [grief counseling](#) begins when their loved one enrolls in hospice.

Here are some other ways caregivers can work through their feelings of anticipatory grief:

#### *Allow feelings of grief to help you prepare*

Take time to examine unresolved issues between you and your loved one. Imagine life without him or her. “Say what needs to be said,” Corso advises. And if your family member is still well enough, settle legal and financial matters and discuss end-of-life wishes.

#### *Educate yourself about what to expect*

Learn about your family member's condition—know the symptoms, the side effects from any treatments, and the prognosis. It may help you to feel in control if you understand what is coming down the pike.

#### *Talk to somebody*

Find a support group of people who are experiencing the same thing, whether it is online, in person, or over the phone. “Someone in a similar situation can provide a lot of insight,” says Corso. “And it's okay to be honest about your feelings. You're not being disrespectful to your family member if you express your frustration.”

### ***Enlist help and continue to live your life***

Reach out to family and friends or hire someone to help with the care of your loved one. Don't put your life on hold. Meet with friends and try to have fun when you can. "In the long run, it will help the patient and yourself," says Corso. "You'll have more energy to care for your loved one and to do what you need to do."

### ***Create moments your family member can enjoy***

Even though your family member is no longer the person she once was, she can still enjoy pleasurable activities with you. Take mom outside for some fresh air, play music for her, do simple puzzles if she is able. In the end, these moments might be what you cherish most.

### **Helping Your Loved One Adjust**

When illness or injury robs your loved one of the ability to remember things about themselves, it can be scary and profoundly difficult. How do you help them cope with the changes in memory and identity?

Look for ways to add new activities to your loved one's life, or think about how you might incorporate elements of a favorite pastime. If your mother was an avid golfer, she may have no interest in taking up knitting if her doctor tells her to stay off the links. Ask her what she misses about golf, though, and you may realize that she misses the camaraderie more than the activity itself. Would she be able to meet her foursome for lunch after they've finished their round?

Remember too that this is a type of loss. Feelings associated with the grieving process, including denial, anger, and depression, are normal. Talking to a social worker, therapist, clergyperson, or even a sympathetic friend may help you or your loved one manage the emotions and come to terms with the loss. If there's a support group in your area, hearing how others have coped with the changes you're experiencing can provide insight and concrete steps, and learning that you aren't alone in your feelings can be reassuring.

Some common experiences in the grieving process include:

#### **Denial**

- Hoping that the person is not ill
- Expecting the person to get better
- Convincing yourself that the person has not changed
- Attempting to normalize problematic behaviors

#### **Anger**

- Being frustrated with the person
- Resenting the demands of caregiving
- Resenting family members who cannot or will not help provide care

- Feeling abandoned

### **Guilt**

- Having unrealistic expectations with thoughts like: “I should have done ...” “I must do everything for him or her” or “I must visit him or her every day”
- Feeling bad because you are still able to enjoy life
- Feeling that you have failed if, for example, you cannot care for the person at home
- Having negative thoughts about the person or wishing that he or she would go away or die
- Regretting things about your relationship before the diagnosis

### **Sadness**

- Feeling overwhelmed by loss
- Crying frequently
- Withdrawing from social activities or needing to connect more frequently with others
- Withholding your emotions or displaying them more openly than usual

### **Acceptance**

- Learning to live in the moment
- Finding personal meaning in caring for someone who is terminally ill
- Understanding how the grieving process affects your life
- Appreciating the personal growth that comes from surviving loss
- Finding your sense of humor
- Asking for and accepting help from others

### **Ways to cope with grief and loss**

- **Face your feelings.**  
Think about all of your feelings — positive and negative. Let yourself be as sad as you want, and accept feelings of guilt because they are normal. Work through your anger and frustration. These are healthy emotions. Know that it is common to feel conflicting emotions. It is okay to feel love and anger at the same time.
- **Prepare to experience feelings of loss more than once.**  
As dementia progresses, it is common to go through feelings of grief and loss again. Accept and acknowledge your feelings. They are a normal part of the grieving process.
- **Claim the grieving process as your own.**  
No two people experience grief the same way. Grief hits different people at different times; some people need more time to grieve than others. Your experience will depend on the severity and duration of the person's illness, on your own history of loss and on the nature of your relationship with the person who has Alzheimer's.

Everyone grieves differently and at their own pace. If your grief is so intense that your well-being is at risk, ask for help from your doctor or a professional counselor.

- **Talk with someone.**  
Talk with someone you trust about your grief, guilt and anger. If you decide to meet with a therapist who specializes in grief counseling, interview several so you can choose one you are comfortable with.
- **Combat feelings of isolation and loneliness.**  
Caregivers often give up enjoyable activities and companionship. Make a lunch or movie date with friends. Taking a break may help you relieve stress and grief, and strengthen your support network. Stay involved in activities that you enjoy.
- **Join a support group.**  
When you talk with other caregivers, share your emotions. Cry and laugh together. Do not limit conversations to caregiving tips. Lewy Body Dementia Association support groups take place all across the country.
- **Know that some people may not understand your grief.**  
Most people think grief happens when someone dies. They may not know that it is possible to grieve deeply for someone who has a progressive cognitive illness.
- **Accept yourself.**  
Think about what you expect from yourself. Is it realistic? Learn to accept the things that are beyond your control. Make responsible decisions about the things you can control.
- **Take care of yourself.**  
The best thing you can do for the person you are caring for is to stay healthy. This includes taking care of your physical, mental and emotional well-being. Create balance in your life. Do things that bring joy and comfort, and give yourself time to rest. Ask for help when you need it, and accept the help that is offered.

Grief is a universal experience and response to significant loss. Psychologically, grief is complex, involving several distinct emotions: denial, anger, sadness and heartbreak, guilt, despair or loss of hope, acceptance, love, and joy. These last emotions may surprise you, but people commonly feel love for the person they have lost and great joy at having had that love during grieving. [Dementia](#) is a unique disease process that creates an unusual situation: the person with dementia gradually recedes from their loved ones while still alive. That is, the family loses the person they loved before physical death and they are lost incrementally over time in concert with a host of other significant losses. The grief that results from the significant losses in dementia is called *dementia grief* and it has unique aspects, properties, and processes.

## **Dying Two Deaths**

The characteristic type of grief occurs from a single or major loss, e.g., physical death of a family member. Usually, the loss is clearly defined, is final, and mourning is understood and supported by the community. Dementia is a unique disease process in that the person with the disease dies what is referred to by Alzheimer's families as "two" deaths: the slow psychological receding of the person they know over years and their eventual physical death. Dementia involves many significant losses with uncommon characteristics that are necessary to understand to manage the losses and recruit your best support. Several essential characteristics of grief associated with Alzheimer's disease, occurring at the same time, set this experience of grief apart from common grief and are discussed in this essay. These elements are: compounded loss; anticipatory grief, disenfranchised grief, and ambiguous loss.

## **Compounded Loss**

The losses that occur in Alzheimer's disease are many, in several areas of life: loss of memories and identifying traits, loss of the ability to drive, to cook, or to make important decisions.

*Compounded losses* typically occur in succession, building up over time and creating a sense of overwhelming anxiety. In this difficult situation, one loss cannot be accepted or resolved before the next occurs. Even relatively small events can trigger intense emotional reactions because of the impact of multiple losses occurring in a short time. Compounded loss is often experienced as a feeling of being weighed down that comes with being unable to process and make sense of what is happening as it occurs. Even families that thoroughly educate themselves about the disease and the many changes that will occur can be overcome by the anguish of trying to handle so many losses over such a short period of time.

## **Anticipatory Grief**

*Anticipatory grief* was first described by Lindeman in 1944, to explain the dread and emotional preparation of family members who tried to accept the high incidence death of loved ones who were soldiers during World War II. The term has been used since to describe feelings of grief that individuals experience prior to the actual loss, by death, of a loved one. Frequently, this concept is applied to the emotions of family members of people dying from cancer or other terminal medical conditions illness. It has been postulated that, by going through the stages of grief while the loved one is still alive, the grief at the actual time of death is less severe.

In Alzheimer's disease, the situation is somewhat different. While the family member may, in fact, feel grief in anticipation of the loved one's eventual death, much of the anguish of the Alzheimer's caregiver is due to losses that have already occurred and anticipation of more significant losses before physical death. Many losses are largely intangible, such as losing the companionship of someone whose personality is now clouded by Alzheimer's, or losing the wit and problem solving abilities that were so strongly valued throughout the relationship, or losing the opportunity for sexual intimacy. From the earliest stages of the disease, caregivers frequently report "*missing the person*"; this is not something they anticipate with dread for the future, but something that is *already very much a reality*. Yet, at the same time there may be elements of true anticipatory grief present as well, as caregivers know that the disease will worsen and that, for example, an afflicted spouse who now recognizes him will at some point in the future no longer be able to do so. And there is, of course, the sad anticipation of death, at some point in the future.

Does the grief felt by the Alzheimer's family member during the disease victim's life ease the grieving that he will experience when the loved one actually dies? Family members report various experiences from within their unique relationships and coping abilities. Many talk about a sense of relief at physical death, but this does not dismiss the very real grief they experience at their loved one's final death.

## **Disenfranchised grief**

*Disenfranchised grief* refers to grief that is not publicly acknowledged and sanctioned. This can occur in a variety of situations in which there is significant loss of some sort but not the opportunity to talk about it openly because of stigma or lack of understanding and sympathy from others. Disenfranchised grief can occur in the parents of adult children with mental illness, criminality, alcoholism, or other substance abuse. Parents commonly talk about experiencing disenfranchised grief following a miscarriage, or a terminated pregnancy. In the early days of AIDS in America, family members who lost a loved one from the disease suffered the stigma of the disease and often grieved privately or alone.

In the case of Alzheimer's disease, the family member grieves for those aspects or qualities of the person that have been lost to the illness, as we discussed above in regard to anticipatory grief. There may not be opportunities to discuss these subtle, ambiguous, and compounded losses with others when the person with dementia is still alive. Often, through well meaning friends who nonetheless do not understand the grief of dementia, family members are encouraged to see the positive side to their situation too quickly; they are reminded that their loved one is still alive and has time left to be with them. The losses of dementia and the grief it creates may not be fully understood by those who have not also experienced losing a loved one gradually to Alzheimer's disease. No matter how close or how caring one's friends and other associates may be, the ability to truly empathize with the anguish of the Alzheimer's caregiver is limited in those who have not dealt personally with the disease.

### **Ambiguous Loss**

*Ambiguous loss* refers to a significant loss that is lacking in clarity, finality, and does not have a normal sense of closure. This is the heart of the experience of dementia grief that will be discussed more thoroughly in future essays on the process of dementia grief, including ways to address and manage the experience.

There are two types of ambiguous loss. In the first, the individual is *physically absent* but remains *psychologically present*. This has been described as "*Leaving without saying goodbye*". Examples include prisoners of war or those missing in action, victims of disasters such as September 11 whose family were unable to recover a body to bury, or even the absence of a parent due to divorce. In the second type of ambiguous loss, the individual remains *physically present*, but is *psychologically absent* – this is described as, "*The goodbye without leaving*". This type of ambiguous loss occurs in a variety of conditions, and prominently in Alzheimer's disease. It is very difficult to grieve someone who may no longer be psychologically present as a spouse, a parent, a companion or other intimate, but who remains very much a physical presence with ever-increasing needs for care that must be met. The very ambiguity of the relationship makes it challenging for the family member to acknowledge the loss, to grieve, and move forward. Since the person with the disease usually changes so gradually, it is not possible for the family member to determine a specific point at which the loved one is really no longer who he once was. *Ambiguous loss* - a loss that resists resolution and complicates the grieving process – is the result.

### **Loss of shared sense of reality**

Alzheimer's is more than a memory disorder, yet the loss of memory creates profound anguish in the sufferer and his family. Memory is the building block of one's personal narrative or autobiography and serves as a vital link in one's connections to others. Couples and families build an ever-growing storehouse of shared experiences and memories over time, and these elements of "shared reality" become some of the most valued treasures in the relationship. A loss of shared sense of reality is nuanced and an example of an ambiguous loss. It can occur during an every day conversation when it becomes suddenly clear that the person with dementia does not remember or understand what's being discussed. A loss of shared reality resonates in moments when family members want to reach out and soothe their loved one, but words are not available that capture the experience and connect them. It is difficult for family members to describe exactly what has been lost, yet they have a sense of deep grief that something essential cannot be retrieved.

### **Loss of the Hope of Reconciliation**

Another special aspect of Alzheimer's grief and ambiguous loss comes from the *loss of the hope of reconciliation* with the patient. Sadly, the disease can progress quite significantly before the angry spouse or child realizes that the opportunity for reconciliation, for "tying up loose ends" or for communicating those long-felt-but-hidden thoughts and feelings has been lost forever: the person with Alzheimer's can no longer remember, reason, reflect, apologize, or forgive. Sometimes, a family member may not even know consciously that they held such a hope that one day issues between them and the person with dementia would be resolved or at least admitted until the moment they realize the opportunity is lost to the disease. Again, this is ambiguous and difficult to name, discuss, or resolve one's self and is difficult for others to understand as well.

### **Some Tips for Coping with the Dementia Grief**

Find a community of other Alzheimer's families, in support groups and/or online. This is the single most important coping action you can take to manage dementia grief. You need to be with people who understand your position from the inside out and do not need you to find words to describe what cannot be articulated.

Find time to mourn and grieve in your own way, whether this is with a support group, being near the ocean, or going to church. Realize that there are different ways people grieve that are valid; do not become caught up in what "grieving" before your family has physically passed looks like. Some people need to cry, some need to revisit happy memories, some need to pray, some express grief creatively, and some need to be active and feel useful. It's possible you may need or want to express your grief in different ways at different times.

Learning and practicing mindfulness skills, or meditation, can be a powerful tool for managing dementia grief. It may sound odd that a powerful tool is to learn to be present, tolerate, and accept the grief. But it's important to understand that dementia grief simply is a part of your life. It may be challenging at times, but in itself, it is not bad; it means you love someone. There is nothing to resolve, nothing to fix, nothing to do with the grief itself, except to recognize the impact on you.

Cherish the one you love, the time you have with them, nurturing and seeding memories that will soothe you for years to come.