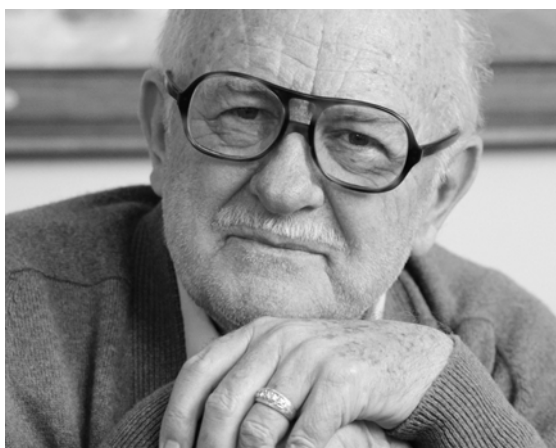


About Grief, Mourning and Guilt

fact sheet - 9

It's normal to feel loss when you care about someone who has Alzheimer's disease. It's also normal to feel guilty, abandoned and angry. Many of the emotions you are feeling may be tied to losses you are experiencing. You're entitled to these emotions and may start to experience them as soon as you learn of the diagnosis.

We usually think of grief and loss at the time of death, but we grieve losses throughout our lives that do not relate to death. With Alzheimer's disease when a patient loses his or her abilities and possibly their personality, there are multiple, on-going losses.



Alzheimer's gradually takes away the person you know and love. As they forget who you are, become incontinent or must get into a facility, you have a right to mourn the losses you feel. As this happens, you'll mourn him or her and experience the phases of: grieving, denial, anger, guilt, sadness and acceptance. The stages of grief don't happen neatly in order. You'll move in and out of different stages as time goes on.

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 hasn't changed.
- Attempting to normalize problematic behaviors.

ANGER

- Being frustrated with the person.
- Resenting the demands of care giving.
- Resenting family members who cannot or will not provide care.
- Feeling abandoned – resenting it.

GUILT

- Wondering if you did something to cause the illness.
- Regretting your actions after the diagnosis.
- Feeling bad because you're still able to enjoy life.
- Feeling that you've failed. For example, when you can't care for your loved one at home.
- Having negative thoughts about the person or wishing that he or she would go away or die.
- Regretting things about our relationship before the diagnosis.
- Having unrealistic expectations of yourself, with thoughts such as: "I should have done...." "I must do everything for him or her." "I must visit him or her every day."

SADNESS

- Feeling despair or depression.
- Withdrawing from social activities.
- Withholding emotions.

ACCEPTANCE

- Finding personal meaning in caring for someone who is terminally ill.
- Seeing how the grieving process affects your life.
- Appreciating the personal growth that comes from surviving loss.

Give yourself time to pass through the stages of grief. If you are mired in any of the stages, seek a counselor. Depression can be especially difficult to recognize and recover from without outside help.

The following are typical responses to the grieving process. The severity depends on the loss and relationship. You may experience only some of these reactions:

PHYSICAL

- Loss of appetite or overeating
- Sleeplessness
- Low energy or exhaustion
- Lack of concentration
- Keeping busy
- Tension

EMOTIONAL

- Guilt
- Anger and impatience
- Crying and depression
- Questioning your faith
- Loneliness and isolation
- Thinking about the person a lot

If you are experiencing any of these, recognize that you may be in a grieving process and therefore, the reactions are appropriate. However, to recover you need to process the grief and give yourself time – both are needed to come to acceptance.

FACE YOUR FEELINGS

- Think about all of your feelings – positive as well negative.
- Let yourself be as sad as you want.
- Accept feelings of guilt – they're perfectly normal.
- Work through your anger and frustration. These are healthy emotions.
- Prepare to experience feelings of loss over and over as the person with dementia changes.
- Take ownership of your feelings, so you can start healing.
- 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 or loss, and on the nature of your relationship with the person who s Alzheimer's.

- Know that it is common to feel conflicting emotions. It's OK to feel love and anger at the same time.
- Consider writing in a journal as a way to help you express your feelings.

ACCEPT YOURSELF

- Think about what you expect from yourself. Is it realistic? Ask yourself: "What do guilty feelings accomplish for me? What do that accomplish for my loved one?"
- Accept things that are beyond your control.
- Make responsible decisions about the things you can control.
- Complete any unfinished emotional business with others.
- Think about the fond memories you share with the person.
- Try to feel that you deserve good things.
- As time permits, get involved in activities that you enjoy.
- Turn to spiritual beliefs, if you choose, for consolation.

Processing grief involves talking about the loss to others, thus getting it outside of yourself. Often people feel they shouldn't burden others with their feelings, however, this thinking keeps us from healing. At a funeral, we talk about the person who died, remember them and share stories. This is a healthy process. It is also necessary whenever we grieve.

TURN TO OTHERS

- Talk with someone you trust about your grief, guilt and anger.
- If you want to meet with a therapist, interview several so you can choose one you're comfortable with.
- Connect with other caregivers, family members and friends impacted by Alzheimer's.
- Combat feelings of isolation and loneliness. Join a support group offered by your local Alzheimer's Association.
- When you talk with other caregivers, share you emotions – cry and laugh together.
- Don't limit conversation to care giving tips.
- Know that some people may not understand your grief. Most people think grief happens when someone dies. They may not know that it's possible to grieve deeply for someone who is fading away.

Talking and time will bring you to the place where you come to acceptance of the situation and can cope with it or move on. The memories will remain, but the painful feelings will lessen in intensity.

TAKE CARE OF YOURSELF

- Remember that switching from concentrating all your efforts on caring for the person to caring for yourself can be difficult. The best thing you can do for the person with Alzheimer's disease is to stay healthy by caring for your physical, mental and emotional well-being.
- Ask others for emotional support and for help with care giving.
- Create balance in your life – do things that bring you joy and comfort.
- Listen to relaxation tapes or soothing music, take a walk, or try deep breathing exercises to help relieve stress.
- Let yourself enjoy humorous moments.
- Dream about the future. As you grieve, new dreams will begin to replace old ones.

SUGGESTED BOOK LIST

Life is Goodbye, Life is Hello
E. Bozarth-Campbell
MN: CompCare Publ. 1982

Living Through Personal Crisis
A. Stearns
NY: Ballantine Books, 1984

Good Grief
G. Westberg
Philadelphia: Fortress Press, 197

The Alzheimer's Association is fighting on your behalf to give everyone a reason to hope. For more information about Alzheimer's research, treatment and care, please contact the Alzheimer's Association.

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