

Caregiver grief, mourning and guilt

It's normal to experience loss when someone you care about has Alzheimer's disease. It's also normal to feel guilty, abandoned and angry. It can help to acknowledge these emotions — they're a natural response to the situation — and seek information and support to deal with them.

Alzheimer's will gradually change the way you relate to the person with the disease. As this happens, it's normal to mourn every loss and experience the stages of grieving: denial, anger, guilt, sadness and acceptance. The stages of grief don't always happen in order. You may move in and out of different stages over time. Common experiences in the grieving process include:

- **Denial.**
 - Hoping that the person is not ill.
 - Expecting the person will get better.
 - Convincing yourself that he or she hasn't changed.
 - Attempting to normalize problematic changes.
- **Anger.**
 - Frustration with the person.
 - Resenting the demands of caregiving.
 - Resenting family members who can't or won't 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're still able to enjoy life.
 - Feeling that you've failed if, for example, you can't care for the person living with dementia at home.
 - Having negative thoughts about the person, wishing that he or she would go away or even wishing he or she would 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.

Face your feelings.

- Think about all of your feelings — positive and negative.
- Let yourself be as sad as you want.
- Accept feelings of guilt — they're perfectly normal.
- Work through your anger and frustration.
- Prepare to experience feelings of loss more than once as the person living with dementia changes.
- Claim the grieving process as your own. No two people experience grief the same way. Some people need more time to grieve than others. Some realize their feelings right away, while others may not grieve until caregiving has ended. 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.
- Know that it's common to feel conflicting emotions, such as 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. Are your expectations realistic?
- Ask yourself whether your feelings of guilt are justified and whether you can do something to change them.
- Accept things that are beyond your control.
- Make responsible decisions about the things you can control.
- Think about the fond memories you have of the person.
- Allow yourself to feel good.
- As time permits, get involved or stay involved in activities that you enjoy.
- Turn to spiritual beliefs, if you choose, for consolation.

Get support.

- Talk with someone you trust – such as a counselor, pastor, family member or friend – about your grief, guilt and anger.
- Connect with other caregivers, family members and friends affected by Alzheimer's.
- When you talk with other caregivers, share your emotions. Cry and laugh together. Don't limit conversations to caregiving 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 still alive but terminally ill.
- Get support from others in similar situations by attending a support group or joining ALZConnected® (alzconnected.org), the Alzheimer's Association online community.

Take care of yourself.

Switching your efforts from caring for the person living with dementia to caring for yourself can be difficult. The best things you can do for the person for whom you provide care are staying healthy and paying attention to your physical, mental and emotional well-being. Here are some ways to do that:

- Ask others for emotional support.
- Ask others for help. Be specific. Ask friends or family to stay with the person while you take a break from caregiving. Or ask others to run errands or do tasks, such as grocery shopping or mowing the lawn.
- Allow yourself to accept the help that is offered.
- Create balance in your life. Do things that bring you peace and comfort.
- Give yourself time to rest. You'll be less vulnerable to illness and better able to provide care.
- Make sure you are getting adequate nutrition and exercise. Keep your medical check-ups.
- Maintain your friendships.
- Listen to relaxing or soothing music, take a walk or try deep breathing exercises to help relieve stress.
- Let yourself enjoy humorous moments.

TS-0041 | April 2017