

Grief Related to Caregiving

Coping Strategies

In the beginning

Feelings of grief can begin as soon as the diagnosis of dementia is received. Depending upon your relationship with the person and your individual circumstances, you may grieve for the loss of:

- the person you once knew
- the future you had planned together
- the relationship you once shared
- their companionship, support or special understanding
- your own freedom to work or to pursue other activities
- finances or a lifestyle that you once took for granted

The caregiving journey

Each individual finds his or her own way to become reconciled to the disease. Don't compare your grief with anyone else's. Not everyone will go through the grieving process in the same way.

Grieving is an up and down process. In the earlier stages of the person's dementia, you may swing between despair and wild optimism that a cure will soon be found. You may even deny anything is wrong with the person and try to suppress your feelings.

Later, if you have accepted the situation, you may find that there are periods when you can cope well and make the best of things. At other times, you may feel overwhelmed by sadness or anger, or you may simply feel numb. People who care for someone with dementia often feel resentful at times for the restrictions placed on their own life, and may feel unhappy that things have not turned out as they would have hoped.

As caregiving needs increase, a deep sense of "psychological" loss may be felt as the person you once

knew is lost even though the person is physically alive. In the final stages of dementia the person may be unable to recognize you or communicate with you. This can be very painful. Although the relationship seems very nearly over, you are unable to mourn fully because the person is still alive.

Feelings like these are normal and a part of grieving. If you experience them, it is important to realize that you may be under a great deal of stress, and you may need to seek emotional support for yourself.

What to try:

- **Feel the pain.** Denying your feelings only intensifies and prolongs the pain.
- **Cry.** Tears can be therapeutic. Let them cleanse and relieve the pain inside.
- **Talk.** Sharing grief will help diminish it. It is important to talk about your feelings even at the most difficult times.
- **Keep a journal.** A journal is a private place where you can explore your frustrations and express your thoughts and ideas without interruption.
- **Consider your own needs.** If you spend a lot of time with the person with dementia, taking regular breaks can keep you in touch with the outside world and raise your morale.
- **Learn to laugh again.** Rediscover your sense of humour. Finding joy in life can be one way of honouring the happy times that used to be shared.

When the person dies

Some caregivers find that they grieve so much during the course of the illness that they have no strong feelings left when the person dies. Others experience a range of overwhelming reactions at different times. These may include: feelings of numbness, shock and pain, relief, anger and resentment, guilt, sadness, feelings of isolation and a feeling of lack of purpose.

It can take a long time to come to terms with the person's death. Those who have been full-time caregivers for a long time will be left with a huge void when this role ends.

What to try:

- **Hold off.** Tread carefully before making decisions. Thoroughly explore all options before making major steps. You may be unable to make important decisions at this time.
- **Be kind to yourself.** Be patient with your feelings. Find a balance between the happy and sad person, the angry and peaceful, and the guilty and glad self. Have patience with yourself.
- **Find comfort.** Everyone has different ways of finding comfort. Many people find comfort in rituals, such as prayer, meditation or other activities.
- **Attend a Grief support group.** Talking with others in similar circumstances can help you know that you are not alone and that you have support.
- **Consider your own health.** Stay in touch with your family physician. You are likely to be more vulnerable to physical illness, as well as to anxiety or depression, following bereavement.

Getting back on your feet

Although you may feel very tired after someone close to you dies, the time will come when you are ready to re-establish your own life and move forward. Remember that it takes time to adjust, and the length of time will vary from person to person.

You may feel very unconfident at first and find it difficult to make decisions, make polite conversation or simply cope during social gatherings. Don't give up - your confidence will gradually return. Take things slowly, and make sure that you have plenty of support from family and friends, professionals and other people in a similar situation to yourself. If people offer to help, try allowing them to do so - don't refuse straight away.

When you feel ready to do so, talk about the person you have lost. Reminisce with friends and family who can also benefit from the opportunity to share feelings and memories.

Further information on this topic

Some of the information contained in this fact sheet was reproduced with kind permission of the Alzheimer's Society, UK www.alzheimers.org.uk.

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