

GRIEF AND LOSS

Grieving is a normal and natural part of life which is commonly experienced during any significant loss. The process of grieving takes place so that you can adjust to your losses. Grief is individual and each person's experience of grief will vary according to their their personal experiences.

Grief is a constant companion to Alzheimer's disease and other types of dementia. People with dementia, their carers and family members are likely to experience feelings of loss and grief as they come to terms with the changes that are occurring in their lives and the lives of their relative.

The Sense of Loss

The onset of dementia and its subsequent diagnosis leads to a progression of changes that are unique to each person and unpredictable in their course.

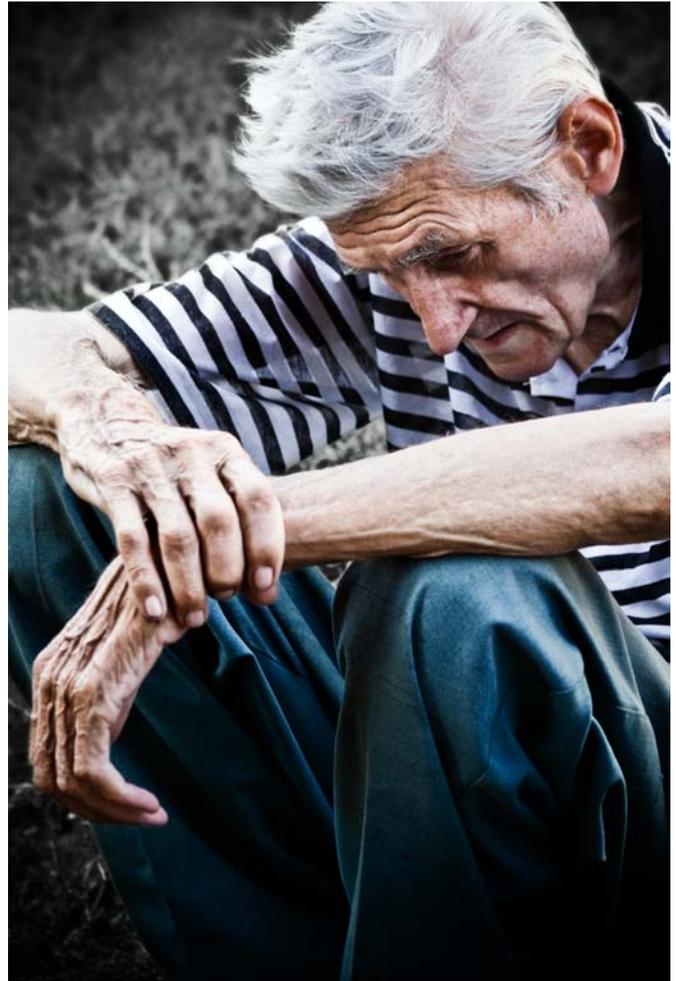
As the illness progresses losses occur for people with dementia and their family which may include:

- Loss of independence and freedom
- Loss of past memories
- Changes in relationships
- Loss of status and role
- Loss of employment
- Loss of the ability to drive
- Loss of financial control or finances
- Loss of future plans
- Change of lifestyle

The ups and downs

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

Later, when 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.



In the early stages, people with dementia may experience grief when they encounter symptoms and consider what lies ahead.

Carers can experience a range of emotions because of the changing nature of their relationship as the dementia progresses. Different losses become apparent over time, such as loss of companionship, intimacy and mutual support.

However willingly a person assumes the role of caregiver, there is bound to be sadness associated with restrictions to work or social life and the fact that life has taken an unexpected turn. You may feel sad, angry, anxious, resentful, exhausted, guilty or numb. These feelings are a normal part of grief.

Tips for coping

- Don't bottle up your feelings. Talk with a trusted friend, family member, minister, or an understanding professional. Alzheimers Societies throughout New Zealand have qualified staff that can provide support and information about help available to you.
- Support groups for carers are held and, in some areas, are provided for people with early-stage dementia where meeting and sharing with people in similar circumstances can be helpful.
- Relieve tension by talking, crying, shouting or punching a pillow.
- Talk to your GP if you are feeling anxious, low or are very tired and having trouble sleeping. It is important to prevent normal feelings of sadness slipping into depression which may be harder to deal with.
- Consider your own needs as a carer, taking regular breaks and maintaining social contacts.
- Attendance at a day programme for the person with dementia has the two-way benefit of providing a break from day-to-day caring whilst also providing social contact and stimulation.
- Respite care may be available to enable longer periods of relief.

Residential care

If the person with dementia goes into long-term residential care you may grieve at facing yet another change in your relationship. Relief felt initially may be replaced by feelings of emptiness, loss and sadness, and mixed with guilt.

When their journey alongside dementia finally ends, carers often feel they have completed their grieving and can be taken aback at the intensity and feelings associated with this final loss.

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers, families and whānau. Alzheimers member organisations located throughout New Zealand provide a variety of services and support to all people affected by dementia. Contact your local organisation on freephone 0800 004 001.

This information sheet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person with dementia or their carer or family/whānau should seek professional advice about any individual case. Alzheimers New Zealand is not be liable for any error or omission in this publication, as a result of negligence or otherwise. This information sheet was produced in March 2010.

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