Grief and bereavement after the death of someone with dementia

This help sheet discusses grief and bereavement when the person you care for dies. It suggests some ways to help you deal with these feelings and practical ways to adjust to change.

When someone with dementia dies, their family and carers often experience a range of feelings. Everyone reacts differently.

You may grieve for the loss of that person and your relationship. You may feel shocked and vulnerable. Some people find they grieved so much during the person’s illness that when the person dies, they have no strong feelings left. However, these feelings may surface later, sometimes quite unexpectedly.

If you would like support coming to terms with your grief or to talk about your feelings, you may find it useful to talk with a professional.

Everyone reacts differently

People have different reactions to emotional experiences. Some reactions to the death of a loved one may include:

• sadness for what could have been or for what has been lost
• shock and pain
• disbelief and an inability to accept the situation
• guilt about something in the past
• relief, both for the person with dementia and for themselves
• guilt associated with a sense of relief
• anger and resentment
• lack of purpose in life now that the caring role has gone
• inability to recommence living and focus on themselves.
Whether you experience any of these feelings, and how long you have them for, varies from person to person.

There are no rules for grieving. We all react individually to loss. Whatever your reaction to the death, you will deal with it in your own way and in your own time.

**After the death**

You may feel shocked and vulnerable in the immediate period after the death, with grief potentially influencing thinking, reasoning, planning, physical behaviour and emotions.

At this time:

- Try to avoid making any major decisions.
- Accept that there may be times when you feel sad or upset.
- Acknowledge that events such as birthdays or anniversaries may be difficult.
- Talk to your doctor. You are more likely to become physically ill or depressed following a bereavement. It will take time.
- Talk with a family member or friend. Often the person you talk to will feel the same emotions. Supporting each other may help.

**Getting back on your feet**

Moving on may not be easy. But the time will come when you are ready to re-establish your own life and move forward.

Consider these ideas for getting back on your feet:

- **Take time.** How long it takes to adjust varies for each person. Be patient and don’t try to rush the process.
- **Accept assistance.** Other people can support you and provide an opportunity to express your feelings, reflect and talk. In time, this will help you understand and adjust to your loss.
- **Share your experience.** Talk with friends and family. They will also benefit from the opportunity to share their feelings.
- **Write in a journal.** Record your thoughts and feelings in a journal or diary to help you come to terms with your grief and loss.
• **Remember the person.** Many people like to talk about the person they have lost, especially before dementia affected them. Reminiscing about happy times can help. Celebrate the person with family and friends. Many people find this helpful on birthdays or anniversaries.

• **Re-establish your social networks.** Start seeing old friends again or develop interests to form new friends.

• **Keep trying.** You may not feel confident at first. You may find it difficult to make decisions, chat about ordinary things or cope with social gatherings. But don’t give up. Your confidence will gradually return.

**Professional help**

If you would like support coming to terms with your grief, talking with a professional may be useful.

For information about counselling, call the **National Dementia Helpline** on **1800 100 500** or talk with your doctor. Discussions with doctors and counsellors are confidential.

**Additional reading and resources**

- **Dementia Australia library service**
  Visit: [dementia.org.au/library](dementia.org.au/library)

- **Dementia Australia support**
  Visit: [dementia.org.au/support](dementia.org.au/support)

- **Dementia Australia counselling**
  Visit: [dementia.org.au/support/counselling](dementia.org.au/support/counselling)

**Further information**

Dementia Australia offers support, information, education and counselling.

**National Dementia Helpline:** 1800 100 500

**For language assistance:** 131 450

Visit our website: [dementia.org.au](dementia.org.au)