Coping after the death of someone with dementia

This Help Sheet discusses some of the feelings you may be experiencing when the person you are caring for dies. It suggests some ways to help you deal with these feelings and some practical ways you can deal with the changes in your life.

When a person with dementia dies, their family and carers often experience a range of feelings. You may grieve for the loss of that person, and for the relationship you once had. Even if you did not wish for the person to go on living with dementia you may still feel a sense of loss.

Some people find that they have grieved so much during the course of the illness that they have no strong feelings left when the person dies. However these feelings may surface at a later time, sometimes quite unexpectedly.

Everyone reacts differently

People have different reactions to emotional experiences. Some reactions to the death of a person with dementia 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
• Anger and resentment about what has happened
• Lack of purpose in life now that the caring role has gone

Whether you experience some, or all, of these feelings and how long you feel them for will vary from person to person. The same event, such as the death of a partner, produces different responses in different people. There are no rules for grieving – we all react to the losses in our life in our own way. Whatever your reaction to the death, you will deal with it in your own way and in your own time.

Professional help

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

Call the National Dementia Helpline on 1800 100 500 for further information about counselling. Your doctor may be able to help, or contact Dementia Australia to arrange to speak to a counsellor. Discussions with doctors and counsellors are confidential.

After the death

You may feel shocked and vulnerable in the immediate period after the death.

• Try to avoid making any major decisions
• Accept that, even though you may generally be coping, there may be times when you will feel sad or upset
• 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

Remember

It will take time to adjust to your loss.
Getting back on your feet

Moving on with your life is not always easy. However 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**
  The length of time needed to adjust to life changes varies from individual to individual. Be patient – don’t try to rush the process.

• **Accept assistance**
  Letting other people help you can provide you with extra support and an opportunity to express your feelings, reflect and talk. Over time this will help you understand and adjust to your loss.

• **Share your experience**
  Friends and family also benefit from the opportunity to share their feelings.

• **Write in a journal**
  Recording your thoughts and feelings in a journal or diary can 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 in earlier times 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 to see old friends again or you may need to look around for 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.