

Grief and bereavement

When a person develops [dementia](#), the people closest to them are likely to experience feelings of grief and bereavement not only in the period after the person's death, but also before they die, as the illness progresses. [A carer](#) may adapt and come to terms with one stage of the person's illness only to find that their behaviour alters or their abilities decline further and the grieving starts all over again. This factsheet is for carers, friends and relatives of people with dementia. It looks at some of the feelings that people close to someone with dementia might experience and suggests some ways to cope with them.

Loss

A sense of loss is one of the most powerful feelings that people experience when someone close to them develops dementia. Depending on 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 ups and downs

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 that 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. Some people are shocked to find that they sometimes wish that the person they

are caring for were dead.

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

Tips:

- Talk about your feelings to an understanding professional, to other people coping with a similar situation, to a trusted friend or to supportive members of your family. Don't bottle up your feelings.
- Relieve tension through crying, shouting or punching a cushion. However, make sure that the person you are caring for is safe and out of earshot first, or you may distress them.
- Invite friends to drop in for a chat or to phone you regularly.
- Make sure that you see your [GP](#) if you are feeling low or anxious, or if you are very tired and unable to sleep. It is important to try to prevent normal feelings of sadness from slipping into depression, which is much harder to deal with.
- 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.
- Make time for yourself each day. Just relaxing with a cup of tea or having a good chat on the phone will help you recharge your batteries and cope with your emotions.

Long-term care

If the person goes into [long-term care](#) you may grieve at another change in your relationship. The relief which you might feel initially may be replaced by feelings of loss and grief, mixed up with guilt, which can last for a surprisingly long time. You may miss the person's presence. You may experience feelings of emptiness. You may feel very tired, both physically and emotionally.

Tips:

- Try to take it easy until you feel your energy levels rise again.
- If your daily routine previously revolved around caring for the person, giving a structure to your day may help you get through the difficult early months.
- If you still want to be involved in caring for your relative while they are in care, speak to the staff and explain exactly what you would like to continue to do for them.
- Don't fall into the trap of building your life around visiting the person in their new home. You need to build a new life for yourself that includes these visits.
- Remember that there is no 'right' or 'wrong' way to feel. You experience your own feelings in your own way, and no one has the right to tell you how you should feel.

Final stages of dementia

In the final stages of dementia the person may be unable to recognise 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.

Tips:

- Holding the person's hand or sitting with your arm around them may be comforting for both of you.
- There is no right or wrong way through the caring role, take comfort from the knowledge that you have done the best that you could.

(See also [Factsheet 417, Later stages of dementia](#).)

When the person dies

Some people who have loved ones with [dementia](#) 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:

- numbness, as though their feelings are frozen
- inability to accept the situation
- shock and pain, even if the death has been expected for a long time
- relief, both for the person with dementia and themselves
- anger and resentment about what has happened
- guilt over an incident that happened in the past
- sadness
- feelings of isolation
- 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 [carers](#) for a long time will be left with a huge void when this role ends.

Tips:

- Try to avoid making any major decisions in the early months if you are still feeling shocked or vulnerable.
- Accept that, even though you may generally be coping, there may be times when you feel particularly sad or upset.
- If you find events such as anniversaries or birthdays distressing, ask friends and family for support.
- Stay in touch with your [GP](#). 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 or goes into long-term care, 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 take decisions, make polite conversation or cope with 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.

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo
For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

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