

Caring for the Carer

Grief & bereavement

If someone close to you develops dementia, you are likely to experience feelings of grief and bereavement as the illness progresses, not just in the period after their death. It may help to know that such feelings are normal and that other people in similar situations experience similar reactions.

It is often difficult to deal with feelings of grief when you are caring for someone with dementia because of the many changes which occur. You may adapt and come to terms with one particular stage only to find that their behaviour has altered or that their abilities have further declined and your grieving may start all over again.

Sense of loss

A sense of loss is one of the most powerful feelings that carers experience. Depending on your relationship with the person and your individual circumstances, you may grieve for the:

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

Restrictions

However much you wish to care, you are bound to feel resentful at times at the restrictions placed on your own life and distressed that things have not turned out as you would have hoped.

- It is important to consider your own needs. Having regular breaks away from caring can keep you in touch with the outside world and raise your morale.
- Make time for yourself in the day. Just relaxing with a cup of tea will help you recharge your batteries and cope with your emotions.

Up-and-down process

Grieving is an up-and-down process. In the earlier stages, you may swing between despair or wild optimism that a cure will soon be found. Some people even deny that anything is wrong and try to suppress their 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, however, you may feel overwhelmed by sadness or anger or you may simply feel numb. Many caring relatives are often shocked to find that they sometimes wish that the person were dead.

Such feelings are a normal part of grieving. But it is important to realise that you are under a great deal of stress and to seek emotional support for yourself.

What can help

- Talk about your feelings to an understanding professional, to other carers, to a trusted friend or to supportive members of your family. Don't bottle them up.



- Relieve tension through crying or, perhaps, by punching a cushion. However, make sure you do it well away from the person with dementia or you may distress them.
- Persuade friends to drop in for a chat or to phone you regularly.
- Make sure you see your GP if you are feeling very low or anxious or if you are very tired and unable to sleep. It is important to try to prevent your normal feelings of sadness slipping into depression, which is much harder to deal with.

Long-term care

If the person goes into long-term care, you may grieve at another change in your relationship. You may miss their presence and experience feelings of emptiness. You will also probably feel quite exhausted.

- Try to take it easy until you feel your energy return.
- A structure to your day may help you get through the difficult early months.

Towards the end

In the final stages of dementia, the person may be unable to recognise you or communicate and this can be a very painful experience. It may seem as if the relationship is almost over, but you are unable to mourn fully because they are still alive.

Holding the person's hand or sitting with an arm round them may give them some comfort. You may also find it helps you to feel that you did all that you could.

When the person dies

Some people find that they have gone through so much grieving as the dementia progressed that they have no very strong feelings left once the person dies. Others experience a range of quite overwhelming reactions at different times. These may include:

- Shock and pain, even if the death has been long-expected

- Relief both for the person with dementia and themselves
- Numbness, as though their feelings are frozen
- Inability to accept the situation
- Anger or resentment about what has happened
- Guilt over some small incident in the past
- Sadness
- Feeling isolated and alone.

Carers need to be prepared for the fact that it may take them a long time to come to terms with the person's death.

- Try to avoid making any major decisions in the early months if you are still feeling shocked or vulnerable.
- Accept that there may be times when you feel very sad or upset, although you generally seem to be coping.
- Events such as anniversaries or birthdays are often very distressing. If so, ask friends and family for support.
- Stay in close touch with your GP. You are likely to be more vulnerable to physical illness as well as to anxiety or depression following a bereavement.

Getting back on your feet

Although you may feel physically and emotionally exhausted after someone dies or goes into long-term care there will come a time when you will be ready to try and re-establish your own life.

You may not feel very confident at first and may experience difficulties in making decisions, making polite conversation or managing journeys, but don't give up. Your confidence will gradually return. Take things slowly and make sure you have plenty of support from other former carers, professionals, family or friends.