Grief, bereavement and loss
Caring for someone with dementia
The grieving process

The death of someone close is often a shock, even if you are expecting it, and it is hard to prepare yourself for how you may feel. For most of us, the death of someone close to us will be the biggest loss we face.

The absence of someone important in our lives challenges us to find new ways of living and coping. This process does not mean you are putting that loss behind you, but you are forced to adjust to a life without your loved one. Your grieving process is to try and make sense of what has happened while learning to live without that person in your life.
Anticipatory grief

When a family member or close friend has dementia, you may experience loss even before they have died. You may find that your relationship starts to change and you find it hard to recognise the person they once were, and you may grieve for how things were before.

Experiencing grief in anticipation of loss is called ‘anticipatory grief’ and can happen throughout the course of someone’s experience of dementia. It can feel as intense as the grief felt after a death. This process is completely normal but is not discussed as much as other types of grief, and it is not a guarantee you will feel more or less grief after your loved one has died.

Acknowledging the feelings of anticipatory grief does not mean that you are giving up on the person or that you love them any less.

What to expect

Grief is an entirely natural response to loss. There are many types of loss, and everyone will react and feel differently. Grief does not happen in a set way and feelings and thoughts may come and go. You may initially feel that you are coping well but could also feel detached from everything around you. Initial numbness can give way to strong feelings as the reality of your loss begins to sink in.
Thoughts

Many people find they think a great deal about the events leading up to the loss and why it happened. It is also common for people to dwell on ‘if onlys’ and imagine how things may have been different.

Although you know the person has died, you may forget it briefly, particularly when you first wake up, or you might imagine you have seen the person who died.

You may struggle with questions you have about what has happened and why. It may bring up questions about the meaning of life and your relationships with others, and make you think about your own mortality.

Feelings

You may experience a huge range of emotions, including:

- sadness
- despair
- guilt
- relief
- emancipation (feeling free)
- denial
- anger
- regret
- fear

These feelings can come and go and do not follow any particular pattern.
Physical symptoms

Grief can affect the entire body. You may experience physical symptoms such as:

- difficulty sleeping
- poor appetite
- tight throat
- tearfulness
- nausea
- breathlessness or tight chest
- fatigue
- low or loss of concentration
- numbness

Social changes

There may be times you want to be alone, or you may actively seek people out to tell ‘the story’ of your loss many times over. People react differently to grief and death; you may be surprised at the people in your life who can be there and support you, and that others might avoid the subject with you or feel uncomfortable talking about it.

If you’ve spent a lot of your time caring for someone and that ends, you may feel a sudden loss of purpose. You may also find that you feel isolated as the previous regular visits from health professionals and others stop.

You may also feel short tempered and stubborn with people who are trying to help.
What can help?

- Being gentle and patient with yourself as you grieve
- Talking to someone you can trust
- Recognising your loss and the extent of the adjustment ahead
- Allowing yourself time to grieve in a way that suits you
- Trying to sleep well, take exercise and eat regular meals
- Trying not to make any big decisions while you are grieving (like moving house or removing items from your home)
- Asking for and accepting help and support from friends and family
- Trying to meet others who are also bereaved at a local group
- Trying to avoid isolation and develop some new routines or activities

How long will my grief last?

There is no right or wrong length of time to adjust to your new situation.

For some people, grieving can be a lifetime adjustment and some feelings can come back many times. Significant events such as birthdays and anniversaries can make managing grief harder during the year.

However, for most people the passing of time helps to make grief less intense and painful. This does not mean you are ‘over’ your grief – it means you are finding ways to adjust to your new situation.
When to seek help

Some people find the experience of grief very difficult and need extra help. If you feel your grief is unrelenting and is affecting your physical or emotional health, speak with your GP for advice.

You may feel extreme depression or feel suicidal. For many people these feelings don’t last, but it’s important that you don’t try to struggle alone. Seek help from a health professional or call The Samaritans helpline free on 116 123.

You can also talk to one of our specialist dementia nurses on our Admiral Nurse Dementia Helpline. Call 0800 888 6678 or email helpline@dementiauk.org
The information in this booklet is written and reviewed by dementia specialist Admiral Nurses. We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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If you’re caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm

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