



**DementiaUK**  
Helping families face dementia

**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 one of the biggest losses we face.

The absence of someone important in our lives challenges us to find new ways of living and coping. This does not mean you are forgetting the person or putting that loss behind you; but that you are now adjusting to a life without your loved one. Your grieving process is to try to make sense of what has happened and helping you to live without that person in your day to day 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. You might experience a sense of loss that the person no longer feels physically or mentally present with you.

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 just as intense as the grief felt after a death. This process is completely normal but is not always discussed as much as other types of grief. Experiencing anticipatory grief does not mean you will feel more or less grief after your loved one has died.

Acknowledging your 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.

You may find that the first few days after losing someone can be a very



busy time. Managing practical and legal aspects, such as arranging the funeral and dealing with financial issues, can be physically and emotionally exhausting. It is important to take time for yourself, where possible, to grieve.

## 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
- Talking about and remembering the person
- 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 – perhaps just time together or a chat
- Trying to meet others who are also bereaved
- Trying to avoid isolation or long spells of inactivity. Try restarting or developing new routines or activities. Some people find creative activities such as writing, poetry, painting and drawing helpful, as well as other activities such as mindfulness, yoga and meditation
- Think about what activities have given you comfort and purpose in the past, and consider how you can use those now

## Continuing bonds after death

How we experience loss is very individual. One of the ways that can be helpful for people to adjust and adapt to a death is to keep a ‘continuing bond’ to them. For example, you may find yourself still talking to the person who has died, or keep small keepsakes to remember them by. You may remember special moments together or carry on particular work as a legacy to remember them. This is all normal and healthy.

## How long will my grief last?

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

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 the experience of grief stronger at that time.

However, many people find their own way to live with their loss, over time. This does not mean you

are ‘over’ your grief – it means you have found ways to adapt and 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. It is very important that you don’t try to struggle alone through these feelings. Please 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](mailto:helpline@dementiauk.org) Monday to Friday, 9am–9pm or at weekends, 9am–5pm.





## Sources of support

### **Cruse bereavement care:**

[cruse.org.uk](http://cruse.org.uk)

### **Samaritans:**

[samaritans.org](http://samaritans.org)

## **Our Admiral Nurses can help**

If you have any questions or concerns about dementia, you can call the dementia specialist Admiral Nurses on our Helpline for free.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Opening hours:

Monday-Friday, 9am-9pm

Saturday-Sunday, 9am-5pm

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](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [dementiauk.org/donate](https://dementiauk.org/donate) or call **0300 365 5500**.

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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](mailto:helpline@dementiauk.org)

Open Monday – Friday, 9am – 9pm  
Saturday and Sunday, 9am – 5pm



[dementiauk.org](https://dementiauk.org) • [info@dementiauk.org](mailto:info@dementiauk.org)

Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
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