



**DementiaUK**  
Helping families face dementia

## Grief, bereavement and loss



When someone close to you has dementia, moves towards the end of life and eventually dies, it will result in many changes and new phases of life. Each of these can trigger a sense of loss and grief.

Grief does not happen in a set way – it is different for everyone, and feelings and thoughts may come and go. The grieving process is a way to try to make sense of what is happening, cope with the changes, and eventually learn to live without the person in your day-to-day life.

### Anticipatory grief

When someone close to you has dementia, you may experience feelings of loss while they are still alive. Your relationship will change, and it may become hard to recognise the person they once were. You might experience a sense of grief that the person no longer seems physically or mentally present with you.

This is called ‘anticipatory grief’ or ‘living grief’ and it can feel just as intense as the grief felt after a death. People often say that it feels like their loved one is ‘no longer with them’ or ‘already gone’.

It is completely normal to experience anticipatory grief as someone’s dementia progresses. It does not mean that you are giving up on them or love them any less. Neither does it mean that you will feel more or less grief when they die.

Recognising these feelings as grief may help you accept them as natural and normal, and to treat them in the same way as you would after a bereavement – including seeking support from other people. Please see Sources of support on p10 for information on looking after yourself as a carer.

### Grief after a bereavement

For most of us, the death of someone close will be one of the biggest losses we face. Accepting that dementia is a progressive condition and that everyone with the diagnosis will die with or from it may help you prepare for this final loss.

Even if you felt anticipatory grief for the person with dementia while they were alive and were expecting them to die, their death may come as a shock and you may be unprepared for how you feel.

How you respond to your bereavement will depend on many factors, such as your relationship with the person, their age and their state of health when they died. For example, losing a parent in old age may feel very different from losing a middle-aged partner or a child. Be aware, though, that everyone will experience grief differently – there is no right or wrong way to feel.

After the person with dementia dies, you may initially feel that you are coping well or that their death does not feel real. The days and weeks immediately after their death can be very busy, and practical matters such as arranging the funeral may be a distraction from your grief. However, this period can also be physically and emotionally exhausting. It is important to take time for yourself, where possible, to grieve.

Once this busy period has passed, the reality of your loss may begin to sink in. You can read more about the thoughts and feelings you may experience on p4.

If you were unable to be with the person with dementia when they died, or you cannot express

your grief as you need to, you may experience ‘incomplete’ or ‘disenfranchised’ grief, where you feel you cannot move forward.

The absence of a loved one in our lives challenges us to find new ways of living and coping. This does not mean you are forgetting the person or putting your loss behind you, but that you are now adjusting to a life without them.

## Stages of grief

The ‘five stages of grief’ refers to a process many people go through when they are bereaved. These stages are:

- **Denial:** a sense of disbelief that the person has died, often with feelings of numbness. You may find you can carry on as if nothing has happened. You may briefly forget that the person has died, particularly when you wake up, or you might imagine you have seen them or heard their voice
- **Anger:** you may feel angry that the person has died, or – in the case of anticipatory grief – that their condition is deteriorating.

You may feel angry at the person themselves for leaving you. You may think a great deal about the events leading up to the person's death and why it happened.

You may dwell on whether you should have done more, or done something differently

- **Bargaining:** you may spend a lot of time thinking 'What if?' and 'If only'. In anticipatory grief, you might try to make a deal with yourself (or with God or a higher being) that if the person does not die you will do a particular thing or change your life in some way, eg, "If Mum doesn't die, I promise I will keep caring for her at home." You may struggle with questions about the meaning of life and your own mortality
- **Depression:** this is the stage of sadness that many of us recognise as the main element of grieving. It may be constant or come in waves, and may last many months or years. You may feel it is impossible to go on without the person who has died
- **Acceptance:** this is where the pain eases and you are able to accept what has happened and

find ways to live without your loved one. This may include feeling relief that they are no longer living with the challenges of dementia

Although this can be a helpful way to think of grief, it is not a fixed process. You may go through the stages in a different order and move backwards as well as forwards. You may feel as if you have skipped a stage or become stuck in it. This is all completely natural.

### Your feelings

When someone dies, or when you are experiencing anticipatory grief, you may experience a huge range of emotions, including:

- sadness
- despair
- guilt
- relief
- emancipation (feeling free, eg from your caring responsibilities)
- denial
- anger
- regret
- fear



## 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
- poor concentration

## Social changes

People react differently to grief and death. Some people in your life may be very supportive, while others might feel uncomfortable talking about your bereavement

and change the subject, or even find excuses for not contacting or seeing you.

There may be times when you want to be alone, or you may actively seek people out to talk to and tell the story of your loss many times over. You may also feel short-tempered and stubborn with people who are trying to help.

If you have spent a lot of your time caring for someone and that comes to an end, you may feel a sudden loss of purpose. You may feel there is a gap in your life that was previously filled by your caring responsibilities; that you do not know what to do with your extra free time; or that you feel isolated as appointments with and

visits from health and social care professionals stop.

As you resume your normal activities after a bereavement, including returning to work, you may feel guilty for ‘moving on’ and for finding yourself laughing and enjoying time with other people.

### Tips for helping yourself with grief

- Be gentle and patient with yourself. Allow yourself to grieve in a way that suits you – whether that’s crying, reminiscing, spending time on your own or with others, or any other way that feels right
- Talk to someone you can trust about your loss. This could be a family member or friend, your GP, a helpline, a faith leader or a professional such as a bereavement counsellor. To speak to a specialist dementia nurse, please see Sources of support on p10 for contact details
- If you work, it is a good idea to tell your employer and colleagues about your bereavement (or, in the case of anticipatory grief, that someone close to you is living with dementia). This will enable you to access benefits such as compassionate leave or carer’s leave and will allow your employer and colleagues to support you at this time. Please see Sources of support on p10 for our information on employment when you care for someone with dementia
- Talk about and remember the person, eg by reminiscing with family and friends, looking at photos, watching home videos, etc
- Recognise the extent of the adjustment ahead. Accept that life will not return to how it used to be, and that it may take time to find a new normal
- Try to sleep well, take exercise and eat regular meals. Allow other people to help with these – for example, by cooking a meal or going out for a walk with you
- Avoid making any big decisions while you are grieving, like moving house or removing the person’s items from your home – your thought processes may

not be clear at this time and you may regret decisions you made in haste

- Ask for and accept help and support from family and friends
- Connect with others who are also bereaved, for example through face-to-face or online support groups, to share experiences and mutual support
- Take care to avoid isolation or falling into a prolonged state of inactivity. Try resuming your previous routines or activities or starting new ones
- Think about what activities have given you comfort and purpose in the past and consider how you can use those now. Some people find activities such as writing, painting, exercise, mindfulness, yoga and meditation helpful

## Supporting children and teenagers with grief and loss

Young people who are processing the death of someone close to them – or who are coping with changes in a loved one with dementia – will need support with

what is happening and how they are feeling.

For many, losing a grandparent or older relative is their first experience of death. Others are faced with the trauma of losing a parent to young onset dementia (where symptoms develop before the age of 65).

These tips may help you support a child who is grieving:

- Explain what has happened in age-appropriate language. It is best to use the words ‘died’ and ‘death’ – euphemisms like ‘gone to sleep’ or ‘passed away’ can leave children feeling uncertain about what has happened
- Take time to talk about what has happened and encourage the child to share their thoughts, feelings and memories as and when they want to
- Do not worry if the child seems not to be grieving. Young children may not understand that death is permanent or may take time to process what has happened
- Keep to the child’s usual routines as far as possible to provide a sense of security and normality



- Anger is a common emotion in children who are bereaved. You could suggest healthy ways to let this out, such as hitting a cushion, messy painting, or going into the garden to shout
- Some children feel they are to blame when someone close to them dies. If they are at the bargaining stage of grief, they may think, for example, “If I behave better, Dad will come back.” Gently remind them that they cannot bring their loved one back, and that they were not responsible for their death
- Tell the child’s school what has happened so they can look for changes in behaviour and put support in place if necessary
- Like adults, children may experience anticipatory grief. Be honest about what is happening, but take it slowly, giving them time to process the news
- Books and videos can be a good way to help children understand dementia, death and loss
- Look for signs that the child is struggling, eg uncontrollable anger, separation anxiety, reluctance to take part in their



usual activities, insomnia or bedwetting. Speak to your GP for advice, or contact our Helpline or a support organisation that specialises in child bereavement – please see Sources of support on p11 for information

### Continuing bonds after death

Some people find it helps to keep a ‘continuing bond’ with the person who has died. For example, you may find yourself still talking to the person, or keep mementoes to remember them by. You may reminisce about special moments you shared or take up or continue an activity as a legacy to them, such as volunteering. This is all normal and healthy.

Arranging a commemoration of the person’s life may help you celebrate them and share



memories with family and friends. This may be separate from their funeral and could take place several months after their death, or on an anniversary. For example, you may wish to have a religious service of remembrance; scatter the person's ashes in a special location; plant a tree; or buy something to remember them by, like a piece of jewellery or memorial bench.

## How long will my grief last?

There is no right or wrong length of time to grieve, so give yourself as much time as you need. For some people, grieving can be a lifelong process and the feelings can resurface many times – sometimes around significant events such as birthdays and anniversaries, but sometimes for no reason.

If there are specific triggers for your grief, such as anniversaries, music or revisiting special places, you may wish to avoid these at times. But at other times, you may find comfort in allowing yourself to experience these triggers and spend time thinking about them.

As time passes, life will often 'grow around your grief' but this does not diminish it or mean you have got over it. Nor does it mean you have forgotten the person, but that you are now finding ways of coping and adjusting to a life without them.

## When to seek help

Some people find the experience of grief very difficult. This is sometimes known as 'complicated' or 'chronic' (long-lasting) grief. If you feel your grief is unrelenting or extreme and is affecting your physical or emotional health, speak to your GP – they may be able to recommend treatments and support such as counselling, support groups and possibly medication.

If you feel very depressed and/or anxious or feel suicidal, please do not struggle alone. You can seek help from a health professional or call Samaritans free on 116 123. You can also talk to one of our specialist dementia nurses for support on our Helpline or in virtual clinics – please see Sources of support on p10 for details.

## Sources of support

To speak to a specialist dementia nurse about grief, bereavement and loss or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

To book a phone or video call appointment with an Admiral Nurse, please visit [dementiauk.org/book-a-clinic-appointment](https://dementiauk.org/book-a-clinic-appointment)

### **Dementia UK resources**

**Changing relationships and roles**

[dementiauk.org/changing-relationships-and-roles](https://dementiauk.org/changing-relationships-and-roles)

**Caring from a distance**

[dementiauk.org/caring-from-a-distance](https://dementiauk.org/caring-from-a-distance)

**Coping with feelings of guilt**

[dementiauk.org/coping-with-feelings-of-guilt](https://dementiauk.org/coping-with-feelings-of-guilt)

**Dementia and employment**

[dementiauk.org/employment-and-young-onset-dementia](https://dementiauk.org/employment-and-young-onset-dementia)

**Looking after yourself**

**as a carer**

[dementiauk.org/looking-after-yourself-as-a-carer](https://dementiauk.org/looking-after-yourself-as-a-carer)

**Recognising the later stages of dementia and moving towards end-of-life care**

[dementiauk.org/end-of-life-care](https://dementiauk.org/end-of-life-care)

**Resources for parents**

[dementiauk.org/parents](https://dementiauk.org/parents)

**Resources for young people**

[dementiauk.org/young-people](https://dementiauk.org/young-people)

**Understanding dying**

[dementiauk.org/understanding-dying](https://dementiauk.org/understanding-dying)



### Other resources

**Child Bereavement UK**

**Helpline: 0800 02 888 40**  
**[childbereavementuk.org](http://childbereavementuk.org)**

**Cruse Bereavement Support**

**Helpline: 0808 808 1677**  
**[cruse.org.uk](http://cruse.org.uk)**

**Marie Curie bereavement support service**

**Helpline: 0800 090 2309**  
**[mariecurie.org.uk/help/support/bereavement](http://mariecurie.org.uk/help/support/bereavement)**

**Samaritans**

**Helpline: 116 123**  
**[samaritans.org](http://samaritans.org)**

**Widowed and Young – for people who have lost a partner at the age of 50 or below**

**[widowedandyoung.org.uk](http://widowedandyoung.org.uk)**

**Winston's Wish – support for grieving children**

**Helpline: 08088 020 021**  
**[winstonswish.org](http://winstonswish.org)**

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

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or scan the QR code.  
Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.

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

Virtual clinics: [dementiauk.org/book-a-clinic-appointment](https://dementiauk.org/book-a-clinic-appointment)



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