Grief, loss and bereavement

Alzheimer's Society

Together we are help & hope
for everyone living with dementia

This factsheet is for anyone who is close to a person with dementia, and might be especially helpful if you are providing care and support for them. It suggests ways of coping with some of the difficult feelings you may have. It also offers advice on supporting a person with dementia to cope with their own grief and loss, and any bereavements they experience.

Contents

1 What are grief, loss and bereavement?

Most people who are close to someone with dementia will experience grief, loss or bereavement. This is because dementia is progressive (which means it will get worse over time) and life-shortening. There will be lots of changes to adjust to and this can be extremely difficult.

These feelings can be very strong, and can be even harder to cope with than the practical aspects of caring. Try to remember that you are not alone. It's very important to ask for help if you need it. Support is available from many services – for more information see 'Other useful organisations' on page 15.

For information about supporting a person with dementia at the end of life see factsheet 531, **End of life care**.

Grief

Grief is the process of reacting to loss. It often involves strong feelings of sadness or distress, especially when the loss is significant. It is very personal and can affect people in many different ways, including:

- shock
- helplessness or despair
- social withdrawal (avoiding contact with others)
- anger or frustration
- guilt
- denial or not accepting the loss
- longing for what has been lost
- sadness.

Some people even feel positive emotions at the same time, such as relief. How you feel may change, and you might find yourself more able to deal with feelings from one hour, day or week to the next.

For many people grief comes in stages: shock, longing for what has been lost, anger, guilt, and acceptance or finding ways to live with the loss. You might find you go back and forth between some or all of these stages. This is very common and there is no 'normal' length of time that grief will last.

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Grief is a natural response to loss. However, for some people it can lead to more difficult feelings or unhealthy behaviours that they are unable to move on from. This is known as 'complicated grief'. People who experience this often need help from a professional such as a GP, bereavement counsellor or psychologist.

Loss

When a person close to you develops dementia, you may both have strong feelings of loss. These feelings may develop or change as the person's dementia progresses. Depending on your relationship with the person and your individual circumstances, you might feel that you are losing or have lost:

- the person
- your relationship with the person
- intimacy with the person
- companionship, support and special understanding
- communication between you
- shared activities and hobbies
- freedom to work or take part in other activities
- a particular lifestyle
- future plans.

Bereavement

When a person dies, this is likely to bring about strong feelings of loss and grief which can vary in intensity and duration. This period of time is called bereavement.

2 Feelings after a diagnosis of dementia

A dementia diagnosis can be difficult to cope with and accept, for both the person with dementia and those close to them. Feelings of loss and grief, including anger or helplessness, are common. Some may be in denial about the diagnosis – for more information see factsheet 533, **Understanding denial and lack of insight**.

But you're not alone – help is available, every step of the way. Alzheimer's Society can put you in touch with the right support for you, from professional dementia workers to support groups. Visit our website at **alzheimers.org.uk** or call **0333 150 3456**.

Talking about your feelings can also help, whether that's with a counsellor or psychotherapist, or informally with friends and family.

Anticipatory grief and dementia grief

You or the person with dementia may feel grief when thinking about how their dementia might develop. You may imagine the changes and losses it may cause, and how the person's physical and mental abilities, relationships and future plans may be affected. This type of grief – thinking ahead to things that may happen in the future – is known as 'anticipatory grief'.

'Dementia grief' is similar to anticipatory grief but is specific to dementia. You may experience this if the person's dementia is causing them problems with communicating, reasoning, and understanding and being able to discuss what may happen in the future.

For some carers, anticipatory grief can be even harder to deal with than the grief they feel after the person has died. For some people, anticipatory grief may lead to depression. It can help to talk about these feelings while you are still caring for the person with dementia.

It isn't possible to know exactly how dementia is going to affect someone. Looking into what may happen in the future is not always useful and can cause unnecessary distress. While it can be helpful to think ahead and make plans, try to also focus on the time that you have with the person here and now.

If the person is feeling a sense of loss about what they may not be able to do in the future, **My life, my goals** can help. This is an electronic resource to support people living with dementia to set meaningful goals based on what matters to them. It can be downloaded at **alzheimers.org.uk/mylifemygoals**

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3 Feelings as dementia progresses

You and the person with dementia may both feel a sense of loss as their condition progresses and your relationship changes. You may grieve for a short time as you experience these changes, or grief can be ongoing. Your feelings of grief may also change or go back and forth over time.

How you and the person experience grief can be affected by many things, such as:

- your personalities
- your relationship
- how dementia affects the person
- the stage of the person's dementia.

As dementia progresses, your relationship might shift from both of you supporting each other, to one where you take on much more caring responsibility. The person may become more dependent on support from you and others, which might be very difficult for you both to adjust to.

Feelings of loss and grief might make it harder for you to cope with caring. Some of the changes you both go through can be harder to process than the person's death. It's important to acknowledge any feelings you have and try not to feel guilty about them. There is no right or wrong way to grieve.

Ambiguous loss

Some people feel a sense of loss in their relationship, even though the person with dementia is still alive. You may feel that the person's personality has changed so much that they do not seem to be the same person, leading to a sense of grief that is difficult to process. This is known as 'ambiguous loss' or 'living grief'.

> **"I hate that turn of phrase, 'other half', but it does feel like I've lost my other half, even though she's still physically there."**
>
> Partner of a person with dementia

Managing your feelings

When you're supporting a person with dementia, you may sometimes feel you're coping well, and at other times feel overwhelmed by grief, or as though you have no feelings left. Some people find they feel angry or resentful at how things have turned out, things they have lost, and the difficulties they have to face. Some feel a sense of loss about their own life. You may feel guilty or shocked if you are experiencing these emotions yourself. Try to remember that these feelings are a natural and valid response to a difficult situation.

Caring for a person with dementia can have a huge emotional impact, and feelings like these can be very difficult to cope with. It can be even harder if there are people around you who don't fully understand or accept the impact the person's dementia is having on you.

Support is available, and it's important to ask for this if you need to. It can help to talk about your feelings with a trusted friend or family member, a professional such as a dementia support worker, dementia specialist nurse or counsellor, or other carers (perhaps by attending a support group). To find professionals or support groups, speak to your GP or local Alzheimer's Society, or visit our online directory **alzheimers.org.uk/dementiadirectory**

You can also join an online community such as Alzheimer's Society's Dementia Support Forum to discuss your feelings openly with people in similar situations. Go to **forum.alzheimers.org.uk**

For more information on managing your feelings and looking after your wellbeing see factsheet 523, **Carers – Looking after yourself**.

Tips for managing your feelings

- **Find ways to express your feelings** – For example, many people find that allowing themselves to cry helps them to express their grief. Some people find it helpful to write a journal or to do creative activities such as art, music or drama.
- **Consider your own needs** – Try to make time to do something for yourself each day, such as going for a walk, having a massage, or meeting or calling friends. Taking some time to relax even for a short time is very important.
- **Look after your physical and mental health** – Try to eat well, get plenty of rest and do some exercise. If you're feeling low or anxious, or are very tired or not sleeping, speak to your GP.

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- **Look after any spiritual needs you have** – For example, if you regularly go to religious services, try to continue doing so. If you're not able to go to a place of worship, watching online services, praying or singing at home can be helpful.
- **Take a break** – If you feel that you need a break to help you cope, you can speak to a social worker or dementia support worker about arranging this. Friends or family may also be able to step in to help. For more information see factsheet 462, **Respite care in England**, W462, **Respite care in Wales** or NI462, **Respite care in Northern Ireland**.
- **Focus on the things that you and the person can still do together** – There will be lots of changes to adjust to as the person's dementia progresses. But try to also look for new opportunities to spend time with the person, as well as other interests you have that you enjoy.

Supporting the person with dementia to manage their feelings

The person with dementia may also develop feelings of loss and grief as their condition progresses. These feelings might vary as their awareness of their condition comes and goes. They may grieve for the loss of their abilities, skills and independence and worry about what's going to happen in the future. As their environment becomes unfamiliar and more confusing, they can feel more isolated. This can be difficult for the person to cope with, but there are things you can do to support them.

Tips for supporting the person to manage their feelings

- **Give the person time to express how they're feeling (if they want to)** – Reassure them when they're feeling distressed. If they're not able to communicate as they normally would, look for other ways they can express themselves such as through music, art or other creative activities.
- **Support them to keep doing the things they want to do and enjoy** – Some activities may need to be adapted as the person's condition progresses. Or you could help them find new things they enjoy doing – for example, they could try a new hobby or get involved in their local community. For more information see booklet 77AC, **The activities handbook**.
- **Consider using assistive technology** – This can help make it easier for the person to meet their needs. For more information see factsheet 437, **Using technology to help with everyday life**.

- **Think about any spiritual needs the person has** – For example, support them to continue with any religious or spiritual practices such as praying, singing, meditating or attending services (in person or online). These may be a source of comfort for the person.
- **It may be helpful for them to talk to a professional** – For example, they could talk to a dementia support worker, counsellor or psychologist about how they are feeling. Support groups – either face-to-face or online – can also be helpful. For more information see factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy**.

It's important to stay connected with the person. If you're unable to meet in person, keep in touch via telephone or video calls. There might be practical help you can give them too. For example, you could help with their shopping, household or gardening chores or cooking.

Residential care

If the person with dementia goes into residential care, it's a big change for you both. It can bring a range of feelings, including a strong sense of loss. You may miss the person, especially if they are your partner or they have been living with you. It can also feel like you are no longer able to play an active part in their care.

These feelings are normal and it can take time to adjust. There will be ways that you can stay involved, which might help you to accept the changes. For more information see booklet 689 **Care homes and other options: Making the decision**.

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4 Supporting a person with dementia during a bereavement

Like anyone, a person with dementia may respond to bereavement in a range of ways. However, difficulties with thinking and reasoning may affect how they understand and adapt to the bereavement. This doesn't mean they are unable to experience loss and grief.

If the person who has died was the main carer of the person with dementia, it can also lead to lots of change in the person's life. They may need professional carers for the first time, or have new people around them providing care. In some cases the person may need to move into residential care. They are likely to need lots of support, guidance and assistance to adjust to these changes.

There are other things to think about when a person close to someone with dementia dies. This includes whether to tell the person, or whether they attend the funeral.

Telling the person about a death

When someone close to a person with dementia dies, you may wonder whether to tell them. It can also be hard to know how much detail to give, especially if finding out how the person died could be distressing.

There are a few things to consider, such as the person's situation and their relationship to the person who died. If they are not told about the death it may mean they don't have a chance to grieve. It may also leave them feeling confused and unsupported. For example, they may be aware that the person who has died has stopped visiting them, without knowing why. However, telling the person the truth may lead to avoidable distress and they could be unable to understand or remember the information.

If the person is in the early stages of dementia, it is usually a good idea to tell them about the death initially and see how they react to the news. This will give you an idea about what to do and whether to tell them again if they keep forgetting (see 'The person's past bereavements' on page 11). If they are in the later stages, they are less likely to be able to understand so it may not be appropriate to tell them at all.

Whatever you decide to do, it is important to acknowledge and support the person with their feelings. Think about how to tell the person and what language to use.

There is no approach that works for every person and situation. Always do what you think is best for the person. It can be helpful to discuss what to do with a professional involved in the person's care such as a dementia specialist nurse, dementia support worker or a doctor.

Tips for telling the person about a death

- Give yourself plenty of time before the conversation to prepare and make sure you have support in place for yourself.
- Explain what has happened clearly and simply. Phrases such as 'gone to sleep' or 'no longer with us' might be confusing if these are not how the person would usually describe a death.
- Try not to give too much information at once.
- Allow plenty of time for the conversation and be supportive.
- Be prepared to repeat information. Try to be patient.
- Use body language and physical contact if appropriate.
- If the person becomes very distressed, offer them reassurance (for example by holding their hand). It may help to give the person time to process the news and try again later on.

Supporting the person to grieve

If the person with dementia is going through a bereavement, it's important to support them. Dementia may mean they struggle to do things they'd normally do to cope with a death, such as speaking to their friends or family about how they feel or keeping busy with hobbies or tasks. Their dementia may also affect their ability to accept the death. Try to gently encourage them to communicate how they are feeling and try to help them keep active and busy. You might need to keep reminding them that help and support is available.

There are many ways that a person with dementia may respond to the death of someone close to them:

- **They may think there's another reason why the person is no longer around** – for example, that they're at work or on holiday. This can be caused by denial, memory problems or 'confabulation' (where a person fills in memory gaps with things they believe are true). It may also be a combination of these things.
- **They may be more confused than normal** and mistake others for the person who has died – for example, thinking their son is their husband. This can be caused by memory loss or problems recognising people. For more information see factsheet 527, **Changes in perception**.

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"She has had a huge shock. Sometimes she seems to understand her husband has died, but then she asks where he is."

Family member of a person with dementia

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- **Sometimes it might be difficult to know whether a person with dementia is grieving**. Changes in the brain mean they have difficulty communicating their feelings in the way they usually would. Instead they may express their grief in different ways, such as through their behaviour. For example, they may become attached to one possession such as a coat or an ornament, or refuse to take part in an activity they usually enjoy.

If the person becomes withdrawn or behaves in ways that challenge, this may be a sign of distress at not being able to grieve as they need to. It can help to try and see if there are things that trigger their grief, such as a photo or an activity that they associate with the person who died. Identifying these triggers may help you find a way to avoid them. For more information see factsheet 525, **Changes in behaviour**.

You and the person with dementia may be grieving about the same person. This can make it harder for you to feel you can offer the person support. Remember to be kind to yourself and take your own feelings into account too. For more information see 'Readjusting after bereavement' on page 13.

Tips for supporting the person to grieve

Some of the tips on pages 6–7 may help when supporting a person with dementia during bereavement. The following tips can also be useful:

- **Keep the person involved** – Being involved in conversations and arrangements after the death might help the person accept what has happened and start the grieving process.
- **Respond to whatever they are communicating** – Recognising and focusing on how the person is feeling can make it easier to know what to say or do.
- **Look for ways to help them feel connected to the person who has died** – This may help encourage them to talk about the person and how they are feeling. For example, they might want to listen to music that they used to enjoy with that person, or look through photos. Or they might like to keep an object that reminds them of the person.
- **Reminiscence work can be helpful after a bereavement** – Speak to a professional such as a dementia support worker or dementia specialist nurse for more information. If the person lives in a care home you can speak to staff about this.

If other approaches aren't working, you could try gently distracting the person's attention onto something else. However, while this may help them to be less distressed in the moment, it may not help the grief process in the long term.

Be patient and remember that adjusting to the loss will take time.

Attending the funeral

You may wonder whether it's best for the person with dementia to go to the funeral. What is right for one family may not be right for another, and any decision should be made in the best interests of the person with dementia.

Thinking about the following questions can help:

- Will the person be able to cope physically and emotionally with attending the funeral?
- Will the person need any special support to attend? How might you manage things if the funeral becomes too difficult for them?
- Will the person know where they are and understand what is happening?
- If they did not have dementia, would they want to go to the funeral?
- If the person's dementia is causing changes in their behaviour, how might this affect others at the funeral?
- How might the person's family and friends feel if the person isn't told about the funeral and so does not attend?

The person's past bereavements

A person with dementia may forget about a past bereavement. This can be due to memory loss, confusion or time-shifting, which is when a person believes that they are living in an earlier time in their life. They may think that people who have died are still alive and ask you where they are. Telling the person may shock and upset them, as for some people it will feel like the first time they have heard the news. As they are likely to have short-term memory problems, they could experience the shock of grief repeatedly if they continue to be told every time they ask. Explaining that the death happened a long time ago may add to their confusion.

Think about whether it is in the person's best interests to continue to be told this news. If you do choose to tell the person more than once, try to give them the news in a sensitive and compassionate way, offering warmth and support. It is important to gauge how they respond and make a decision about what is in their best interests. For more information on supporting the person see factsheet 527, **Changes in perception**.

If the person is in the later stages of dementia and remembers a bereavement they've had in the past, they may not be able to communicate this. Instead it may show in their mood or behaviour – for example, they may be crying a lot more or be more agitated. This can explain changes in their mood or behaviour that don't otherwise seem to have an obvious cause.

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5 Your feelings after the person with dementia has died

Everyone copes with bereavement in their own personal way, and there is no right or wrong way to react. How you feel after the person has died will be affected by different things, including:

- your relationship with the person
- your life circumstances and personality
- how much you've already grieved while the person was living with dementia and how you responded to changes while caring for them
- the circumstances around the person's death – how and where they died, as well as whether you were able to say or do the things you wanted to.

When the person dies, it can feel like a turning point in your life, especially if you have been the person's main carer. You may feel a range of emotions after bereavement, some of which may even be positive. Feelings can include:

- shock and pain (even if the death has been expected for a while)
- sadness
- numbness, as though you can't feel anything at all
- being unable to accept the situation
- anger and resentment
- guilt
- lack of purpose
- relief, both for the person with dementia and for yourself.

Bereavement can leave you with a sense of emptiness. This can be for different reasons, such as struggling to come to terms with the loss of the person or missing your role as a carer. You might feel like you have too much free time (especially if you've lost past interests and hobbies), or you might have lost touch with other people while caring. All of this can add to feelings of loneliness and isolation.

It's not unusual to think you have heard the person's voice or seen the person after they have died and while you're grieving. You might also dream about them and find yourself thinking about the past or events just before and after their death.

Delayed grief

Sometimes when a person dies, those close to them may not fully grieve at first, and it can take a long time for feelings to come out. This is called 'delayed grief'. It may happen because:

- it takes a while to accept the person has died
- the feelings are so overwhelming that it's not possible to process them at the time
- there are so many practical things to do and arrange that there isn't time to grieve.

Delayed grief may especially happen if you have cared for the person for a long time.

Readjusting after bereavement

Grief can be complex and difficult, and it can be hard to adjust to living without the person. Take some time to reflect and come to terms with your situation, but try not to become isolated. It can help to talk through your feelings with someone you trust.

Some people find speaking to professionals can be a very helpful way of processing their feelings and finding a way forward. There are many organisations that offer grief and bereavement support, including Cruse Bereavement Support, Dying Matters and Sue Ryder. For more information see 'Other useful organisations' on page 15.

Try to stay in contact with your GP and tell them how you are feeling physically and emotionally. After a bereavement you may be more vulnerable to physical and psychological illness such as viruses, anxiety, stress and depression. Your GP can look at ways to help, including medication or referring you for talking therapies. The coronavirus pandemic has caused longer waiting times at some surgeries so bear this in mind when trying to book an appointment.

It's also important to look after your spiritual and religious needs. Many people find these practices helpful and a source of comfort after a bereavement.

Life does not just go back to being the same after bereavement. In time, you may find that the pain eases and you feel ready to cope with life without the person who died. Some carers find readjusting easier than others. How long it takes will vary from person to person, and there is no 'right' length of time.

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"**I have had bereavement counselling and with their help I now have a beautiful homemade memory book.**

I also have a positive diary in which I write at least one positive thing each day and then on a low moments I can look back at all the positives.

Partner of a person with dementia"

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Tips for readjusting

- **Be kind to yourself**. Allow yourself space and time to grieve.
- **Try to eat properly and get enough rest** (even if you don't always manage to sleep).
- **Take things slowly** and ask for help and support if you need it. Tell people what you need – if you don't, they may not know how to help or they may not feel comfortable offering.
- **Try to do things with other people**. You could start doing past interests and hobbies again, or consider starting new ones.
- **If you're struggling** and time doesn't seem to be helping, you may want to think about asking for professional support.

If you're worried that you will forget the person over time, there are things you can do that may help:

- When you feel ready, talk to friends and family about the person who died, and reminisce about the life you shared.
- Create a photo album or a file of digital videos of the person.
- Keep some of the person's belongings.
- Do something in memory of the person. This could include:
  - arranging a memorial gathering for those close to them
  - organising a tribute to them on social media
  - planting a tree in their name
  - taking part in an event such as a Memory Walk – for more information go to **memorywalk.org.uk**

Other useful organisations

At a Loss
www.ataloss.org

Support for people who have been bereaved including a free, online counselling service called GriefChat.

Bereavement Advice Centre
0800 634 9494 (helpline, 9am–5pm Monday–Friday)
www.bereavementadvice.org

Free helpline and online information service. Practical information and advice on the issues and procedures after a person dies.

Carers Trust
0300 772 9600 (9am–5pm Monday–Friday)
info@carers.org
www.carers.org

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend.

Cruse Bereavement Support
0808 808 1677 (helpline, 9.30am–3pm Monday–Friday)
www.cruse.org.uk

Counselling and support, information, advice, education and training services.

Dementia UK
0800 888 6678 (helpline, 9am–9pm Monday–Friday, 9am–5pm Saturday and Sunday)
helpline@dementiauk.org
www.dementiauk.org

Specialist dementia support for families through the Admiral Nurse service.

Dying Matters (Hospice UK)
www.hospiceuk.org/our-campaigns/dying-matters

National Campaign that aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement.

The Good Grief Trust
www.thegoodgrieftrust.org

Bereavement support website that signposts to a wide range of immediate, tailored local and national support.

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Hospice UK
020 7520 8200
www.hospiceuk.org

National charity with details of hospices, some of which may provide bereavement services.

Independent Age
0800 319 6789 (helpline, 8.30am–5.30pm Monday–Friday)
advice@independentage.org
www.independentage.org

Information and advice for older people, their families and carers. They have an online service called GriefChat with a specially trained bereavement counsellor.

Samaritans
116 123 (24 hours, seven days a week)
jo@samaritans.org
www.samaritans.org

Safe, confidential phone line providing emotional support. This is for people with feelings of distress or despair, including those that could lead to suicide.

Sue Ryder
0808 164 4572
www.sueryder.org

Support for people living with a terminal illness or a neurological condition, or who are bereaved. They have local services and also offer online bereavement support.

Winston's Wish
0808 8020 021 (helpline, 9am–8pm Monday–Friday)
ask@winstonswish.org
www.winstonswish.org

Support for bereaved children, young people, their families and the professionals who support them.

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We are reviewing this publication. If you would like to give us any feedback, you can email us at publications@alzheimers.org.uk or call us at 020 7423 7455

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Living with dementia**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**

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Together we are help & hope for everyone living with dementia

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