

Grief, loss and bereavement

Friends, family and other people close to a person with dementia may experience feelings of grief, and similar emotions related to loss and bereavement. These feelings can occur from the point of diagnosis through to the person's death, and beyond. They may even occur before the diagnosis, as symptoms start to develop.

People with dementia may experience grief at the point of diagnosis, and while living with the condition. They may also experience grief when bereaved by the death of someone close to them.

This factsheet is for carers, friends and relatives of people with dementia. It looks at some of the feelings carers may experience and suggests ways to cope. It also looks at supporting a person with dementia to cope with grief and bereavement.

Grief

Grief is a normal response to a significant loss, but can become a complex psychological and emotional experience. It is common for someone who cares for a person with dementia to experience grief. This can occur while they are caring for the person and after the person has died.

Carers may experience grief as the person's dementia progresses and increasingly affects their relationship with the person. They may grieve for the losses they and the person with dementia experience. Some carers may feel in a continual state of grieving.

The type of grief a carer may experience can depend on a range of factors such as their relation to the person (eg spouse, partner, sibling, child or friend), the type of dementia the person has, and the stage of dementia.

Grief can be difficult to detect as it can be shown in many different ways, including:

- helplessness/despair
- withdrawal
- anger/frustration
- guilt
- denial
- not acknowledging losses
- longing for what has been lost
- sadness
- acceptance.

It is important to acknowledge feelings of grief when they occur. It is a complicated and highly individual experience – there is no right or wrong way to grieve. Carers may find that it changes over time.

People with dementia may also experience grief as their condition progresses. They may grieve for the loss of abilities, skills and independence. They may develop a sense of isolation as their environment becomes more unfamiliar and confusing. They may be frightened about what the future holds.

Anticipatory grief

People with dementia and carers sometimes experience grief in anticipation of the losses the condition may cause. This is known as anticipatory grief. For carers this can happen throughout the course of dementia, and a person in the early or middle stages of the

condition may experience it too. Some evidence suggests that carers who experience anticipatory grief may cope better with the grief they experience after bereavement, though this grief may still be painful. Sometimes experiencing anticipatory grief may also increase the possibility of a carer becoming depressed. It can help for carers to discuss their feelings while they are still caring for the person with dementia.

Loss

People can experience strong feelings associated with loss when a person close to them develops dementia. It can sometimes be more difficult to manage these feelings than it is to cope with practical aspects of caring. Depending on the carer's relationship with the person, and their individual circumstances, they may experience the loss of:

- their relationship
- intimacy
- companionship, support and special understanding from the person
- communication between themselves and the person
- shared activities and hobbies
- freedom to work or pursue other activities
- a particular lifestyle
- a planned future
- previous relationship roles.

Loss and grief can play a part in someone's ability to cope with caring. Some losses, such as the loss of meaningful, interpersonal relationships with the person with dementia, can result in grief that may be more difficult to manage than the person's actual death.

As dementia progresses, a relationship may move from one that was mutually supportive to one where the carer takes on more

responsibility. The person with dementia may become increasingly dependent on their support. This can be very difficult to adjust to.

It's important that carers seek support for emotions associated with loss. Family members, friends or professionals (eg a dementia support worker) could provide this. Attending support groups with other carers, or accessing an online forum (such as Alzheimer's Society's Talking Point) can be good ways to seek support and information.

It can be difficult for a carer to manage these feelings if others don't see the feelings as significant, or don't appreciate or understand them. Those around the carer may be in denial or not fully understand the impact dementia has. This can lead to a lack of support for the carer.

Ambiguous loss

Some carers also struggle with a more psychological sense of loss in the relationship (also known as ambiguous or unclear loss). The personality of the person with dementia is seen as lost or considerably changed, but they are physically still present. Ambiguous loss may result in feelings of unresolved grief, and can also stop people from accessing help and support.

Emotions

It is normal for someone caring for a person with dementia to experience feelings of grief. They may cope well at some times, and at other times feel overwhelmed by sadness or anger, or may simply feel numb. They may feel resentful at how things have turned out and the difficulties they have to face. Some people may be shocked to find that they feel this resentment. It's important to know that caring for a person with dementia can have a huge emotional impact, and feelings like these can be a normal part of grieving. Anyone experiencing such feelings may be under a great deal of stress, and may need to seek some emotional support.

Dealing with emotions: tips for carers

- Try not to bottle up your emotions: talk about your feelings. This may be with a professional (eg a dementia nurse), other carers (eg via a support group), a friend or family member.
- Try to make time for yourself each day. This could be relaxing, walking outside, a hand massage or chatting to friends.
- Consider your own needs. If you feel that you need a break to help you cope, speak to someone about arranging this.
- Try to focus on the positives, for example things that you and the person with dementia can still do together, or other interests you have.
- If you're feeling low or anxious, or are very tired or not sleeping, speak to your GP. It's important to look after your own physical and mental health.

Residential care

When a person with dementia goes into residential care, their carer may experience a range of conflicting emotions, including relief, sadness and guilt. They may be worried about how the person will settle in, and whether the care they receive will be good enough. A move into residential care is a big change in the caring relationship, and the carer may miss the person's presence. They may also feel that they are no longer able to play an active part in the person's care. All of this may contribute to increased feelings of guilt and sadness.

If someone has been a carer for a long time, the move to residential care can have a profound impact on their role. They may feel lost and have a sense of emptiness, and it can be emotionally draining. Other people may expect a carer to be able to re-establish their life quickly after the person goes into care and may not appreciate how emotionally difficult the situation is. Someone who has been caring for a parent may find it easier to re-establish their life than someone who has been caring for a spouse.

There may also be practical and financial issues to consider when the person goes into care (eg living arrangements) which can affect a carer's feelings and ability to cope.

Moving to residential care: tips for carers

- You don't stop being a carer just because you no longer do the practical day-to-day tasks.
- If you still want to be involved in caring for the person, speak to the care home staff and discuss how you can work together.
- You will know the person's likes, dislikes, hobbies, routines, life history and more. All of this can help care home staff to support the person.
- Initially, you may want to take some time away from caring altogether. The care home should support you with this and welcome you back when you're ready.
- Though you may want to visit the person in their new home, try not to build your life around this. You need to take care of yourself and your needs.
- Consider attending a support group: the care home may have a group for relatives and carers. These can help you to talk through your feelings about the changes you're experiencing.
- You will experience your own feelings in your own way. It is important to know that there is no right or wrong way to feel.

Bereavement

Bereavement at the death of a friend or relative with dementia is a unique and complex situation that everyone will cope with in their own way. It is a normal experience and many people won't need professional support. A carer's reaction to the death may depend on many factors, including:

- their relationship with the person
- their personal situation

- the stage of the person's dementia
- responses to losses that have already happened over the course of caring for the person
- the circumstances surrounding the person's death.

It may feel like the final loss of many, and can also represent a turning point in the carer's life.

Carers may experience a range of emotions during bereavement, both positive and negative. Emotional reactions to bereavement may include:

- sadness
- shock and pain (even if the death has been expected for a while)
- anger and resentment about what has happened
- guilt about how the person was cared for
- numbness, as though feelings are frozen
- inability to accept the situation
- feelings of isolation
- a feeling of lack of purpose
- relief, both for the person with dementia and for themselves.

Sometimes when a person dies, the carer may not be in a position to fully experience grief, 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 overwhelming and suppressed at the time
- the carer must sort out the person's affairs and therefore doesn't have time to grieve.

Delayed grief may especially happen if the carer has cared for the person for a long time.

Carers may find they have a sense of emptiness after bereavement. They may struggle to come to terms with the loss of the person, loss of their defined role, excess free time (loss of past interests and hobbies may make this difficult to fill), and not being in touch with previous relationships because of the time spent as a carer. All of this can add to feelings of loneliness. Some people find it hard to adjust to living without the person with dementia. It can help for them to talk through these feelings with someone they trust.

Some carers may find it helpful to meet with professionals who were involved with the care of the person with dementia at least once after bereavement.

It's important for carers to be supported to express and explore their emotions after bereavement.

When the person dies: tips for carers

- Try to avoid making any major decisions in the early months if you're still feeling shocked or vulnerable.
- Take some time to reflect and come to terms with your situation, but try not to isolate yourself.
- 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.
- Keeping hold of items that the person treasured or that remind you of them (such as a watch or a favourite scarf) may help you to keep a sense of connection.
- Even though you may generally be coping, there may be times when you feel particularly sad or upset.
- If you find events such as anniversaries or birthdays upsetting, ask for support from friends or family.

- Stay in touch with your GP. You may be more vulnerable to physical illness, as well as anxiety, stress and depression after bereavement.
- If you feel your grief is becoming overwhelming, seek bereavement support services.

Readjusting after bereavement

Life does not return to being the same after bereavement. However, the time will come when the pain eases and a carer feels ready to cope with life without the person who died. Some carers find getting back on their feet easier than others. It takes time to adjust, and how long it takes will vary from person to person. If someone is struggling and time doesn't seem to be helping, they may want to think about professional support.

Readjusting: tips for carers

- Talk about the person who died, and reminisce about them and the life you shared.
- Try to eat properly and get enough rest (even if you don't manage to sleep).
- Allow yourself space and time to grieve.
- 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.
- Try to get socially involved and re-establish past interests and hobbies, or consider starting new ones.

If you're concerned about forgetting the person, there are some things you can do that may help:

- Talk about the person and your memories of them.
- Create a photo album.
- Keep some of their personal belongings.

- Do something to commemorate them, such as planting a tree or arranging a memorial gathering for those close to the person.

Supporting a person with dementia during bereavement

People with dementia will experience bereavement in a range of ways and their needs will be similar to those of someone who doesn't have dementia. However, the person's cognitive difficulties may create unique challenges.

Telling the person about a death

When someone close to a person with dementia dies, it raises the question of whether or not to tell them. There may also be the question of how much detail to tell them, especially if the circumstances of the death could cause the person distress. These are difficult situations and there is no one solution that will work for everyone. It will depend on the individual, their situation and what is in their best interests. Whatever decision is made, it's very important to acknowledge and support the person's emotional responses.

For more information on how to approach these sorts of decisions see factsheet 484, Making decisions and managing difficult situations.

If the person is not told about the death it may prevent the grieving process and leave them feeling afraid and unsupported when, for example, the person who has died appears to have stopped visiting without explanation. However, telling the person may lead to unnecessary distress and they may be unable to process the information.

Talking over the situation with professionals may help. Whatever is decided, it's important for the person to be supported as much as possible.

Telling the person about a death: tips for carers

- Provide information clearly, simply and without euphemisms (eg 'passed away').
- Use body language and physical contact if appropriate.
- Try not to give too much information at once.
- Allow plenty of time for the conversation and be supportive.
- Be prepared to repeat information.
- If the person becomes very distressed, try a different approach.
- Make sure that you are supported as well.

Like anyone, a person with dementia may respond to bereavement in a range of ways. However, how they understand information and adapt to the bereavement may be complicated by problems with thinking and reasoning. However, just because someone has dementia, it doesn't mean they are unable to feel emotions at the bereavement and experience grief.

The dementia may also interfere with a person's usual means of coping, so it's important for them to feel safe and supported. It can also disturb someone's ability to accept the death, and to vocalise any distress and emotions they're feeling.

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

- They may come up with an alternative reason for why the person is no longer around, for example that they're at work or on holiday. This may be caused by denial, poor memory or confabulation (filling in gaps with things the person believes to be true), or a combination of these things.
- They may mistake others for the person who has died, eg a son for a husband. This can be caused by memory loss and/or problems recognising people.

- Changes in the brain mean they may have difficulty regulating emotional responses and may express their grief in different ways such as through their behaviour. They may become attached to one possession, eg a coat or an ornament, and not want to be parted from it, or they may refuse to take part in an activity they enjoy, eg singing.

Supporting the person to grieve

It may be difficult to know whether a person with dementia is grieving. If they are grieving it's important to support them to do so. Being involved in conversations and arrangements after the death (eg the funeral) may help the person with dementia take in the loss and start the grieving process. However, if the person appears not to be grieving, it may be best to let them be.

If someone starts to behave in challenging ways, it may be a direct reaction to the bereavement, or a sign of distress that they are not being supported to grieve. It can help for carers to observe the person and see if there are things triggering or maintaining a grief response. Identifying these may help a carer to support the person to grieve, or help them find a way to avoid triggers.

Supporting the person to grieve: tips for carers

- Acknowledge feelings and encourage the person to express themselves.
- Reminiscence can be helpful after a bereavement.
- Allow the person with dementia to talk/communicate about the person who has died.
- Giving the person something that reminds them of the person who died may help with feelings of connectedness and can be used to support reminiscence, if appropriate.
- Consider creative outlets such as art and music. These can help support people to express their feelings and grief.

- Consider other ways to meet the person's attachment needs, such as comfort objects, spiritual means and other relationships.
- The person may find comfort in their spiritual beliefs such as prayer, meditation or faith practices.

If the person's main carer dies it can lead to lots of upheaval and change in the person's life. They are likely to need lots of support, guidance and assistance to adjust to these changes.

When a person with dementia experiences a bereavement they sometimes experience and remember a profound shock and sense of bewilderment. At other times they may not recall or understand the loss, but it can still have a strong emotional impact on them, reflected in their behaviour and mood.

Asking for the person who has died

A person with dementia may forget that someone has died. They may ask about them repeatedly, come up with reasons for their absence (such as being away or having left them), or report them as missing. This can be very difficult for family and friends coming to terms with the death, as well as the person with dementia. If they are told again that the person has died, it may be like hearing it for the first time. How a carer should respond will depend on the individual and what is in their best interests.

Reminding a person with dementia of a death: tips for carers

- For some people, a gentle reminder that the person has died may help. For others this will be very upsetting.
- Reminders of the funeral, shown and discussed in a supportive way, may help the person to absorb the news. Personal possessions may also help.
- Recognising and focusing on the person's emotional state can make knowing what to say easier.

- If the person is in the later stages of dementia, trying to remind them that the person has died is unlikely to work and may be very distressing.
- If someone is becoming very upset it may be best not to try and remind them.
- Support the person through changes in emotion and behaviour. Reminiscence and other creative techniques (eg art or music) can be helpful for this.
- Look for patterns to when the person is asking. If there is one (eg at 5pm they always had a cup of tea together) you may be able to put techniques in place to help. For example, at 5pm ask the person about hobbies they used to do together to encourage positive reminiscence.
- Be patient, responsive and aware that adjusting to the loss will take time.

If responding to the emotion or reminiscence doesn't work, you could try distraction. However, while this may alleviate the stress of the moment, it may not help the grief process in the long term.

Past bereavements

A person with dementia may forget about a past bereavement, and hear of it as if for the first time. It can feel as though it's just happened, and they may experience the emotions all over again. They may struggle to process the information that the death happened a long time ago, and be left with the feeling of a recent bereavement. They may also confuse a present loss with a previous one (eg husband with father).

Supporting a person with dementia who is bereaved can present many challenges. However, there are things carers, family and friends can do to help the person feel safe and supported. It is also important for carers, family and friends to address their own needs and feelings of grief during loss and bereavement.

Other useful organisations

Carers Trust

32–36 Loman Street
London SE1 0EH

T 0844 800 4361
E info@carers.org
W www.carers.org

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

Carers UK

20 Great Dover Street
London SE1 4LX

T 0808 808 7777 (free carers' advice line, Monday – Friday
10am–4pm)

E advice@carersuk.org

W www.carersuk.org

www.carersuk.org/forum (online discussion forum)

Provides information and advice about caring, alongside practical and emotional support for carers.

Cruse Bereavement Care

PO Box 800
Richmond
Surrey TW9 1RG

T 0844 477 9400 (national helpline)
E helpline@cruse.org.uk
W www.cruse.org.uk

Aims to promote the wellbeing of bereaved people, and to enable anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support. It also offers information, advice, education and training services.

Help the Hospices

Hospice House
34–44 Britannia Street
London WC1X 9JG

T 020 7520 8200
E info@helpthehospices.org.uk
W www.helpthehospices.org.uk

Provides hospices with information and support to improve end-of-life care. They have details of hospices across the UK, some of which may be able to provide bereavement services.

Samaritans

T 0845 790 9090 (24 hours, seven days a week)
E jo@samaritans.org
W www.samaritans.org

Samaritans provide confidential non-judgemental emotional support, 24 hours a day, for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

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This factsheet has also been reviewed
by people affected by dementia.

A list of sources is available on
request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–5pm Monday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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