When you are close to a person with dementia you may go through feelings of grief and loss. You can have these feelings at any time, from the time the person is diagnosed (or before), as their dementia progresses, or during or after the person’s death.

People with dementia may of course also experience grief that can start when they are diagnosed, or at any point while they’re living with the condition. Like anyone, people with dementia may grieve when someone close to them has died.

This factsheet is for those who are close to a person with dementia, especially if you care for or support 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

- What are grief, loss and bereavement?
- Feelings after a diagnosis of dementia
- Feelings as dementia progresses
- Feelings after the person has died
- Supporting a person with dementia during bereavement
- Other useful organisations.
What are grief, loss and bereavement?

There will be times when dementia is hard to deal with. Both the person living with the condition and those around them can feel strong emotions at any stage. When this involves grief or loss, giving yourself time and finding support will help you to cope.

Grief

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

- shock
- helplessness or despair
- withdrawal
- anger or frustration
- guilt
- denial or not accepting the loss
- longing for what has been lost
- sadness
- acceptance.

Some people find they even feel positive emotions, such as relief. You may feel different at different times. You might find yourself more able to deal with feelings from one day or week to the next.

For some people grief comes in stages: shock, longing for the person, anger, guilt and finally acceptance. You might find you go through these stages, or go back and forth between some or all of them.

Grief is a normal response, but for some people it can lead to more difficult feelings, and they find they need help from a professional such as a GP or bereavement counsellor. This is known as complicated grief.
You are not alone – many people who care for someone with dementia experience grief. This can be while they’re caring for the person, after the person has died, or both.

**Loss**

Some people have strong feelings of losing what is important to them when a person close to them develops dementia. You may find managing these feelings harder to cope with than practical aspects of caring. Depending on your relationship with the person and your individual circumstances, you might feel that you’ve lost:

- your relationship
- 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**

Bereavement is the death of someone important to you. It is likely to bring about strong feelings of grief and sadness. See ‘Feelings after the person has died’.
Feelings after a diagnosis of dementia

When someone has been diagnosed with dementia, they and the people close to them may have feelings of grief and loss, such as anger, denial or helplessness. It can help to talk about these feelings when you feel ready. You could talk to a friend, family member, or a professional such as a counsellor or psychotherapist.

Anticipatory grief

People with dementia and their carers sometimes go through feelings of grief when they think about how dementia might develop and imagine the changes and losses it may cause. These changes may affect the person’s physical and mental abilities, relationships and future plans.

This type of grief – thinking ahead to things that may happen – is known as ‘anticipatory’. A person in the early or middle stages of the condition may experience this. As a carer you may grieve at any time as the person’s dementia progresses.

Some evidence suggests that carers who experience anticipatory grief may cope better with grief after the person dies, though this may still be painful. For some people, anticipatory grief may also increase the possibility of becoming depressed. It can help to talk about these feelings while you are still caring for the person with dementia.

Of course it is not possible to know exactly how dementia is going to affect someone. Although it can be helpful to think ahead, try to also reflect on the time that you have with the person in the here and now.

Feelings as dementia progresses

You may feel grief as the person’s dementia progresses and your relationship with them changes. You may grieve for the losses that you both go through. For some people this happens over a short period, but for others grief is ongoing.
How you experience grief can be affected by many things, such as:

- your personality
- your relationship to the person
- how dementia affects them
- the stage of the person’s dementia.

As dementia progresses, your relationship might shift from both supporting each other, to one where you take on more responsibility caring for the person. They may become more dependent on support – including from you – which might be very difficult for you both to adjust to.

Feelings of loss and grief can play a part in someone’s ability to cope with caring. Some of the changes you both go through can lead to feelings of grief that may be more difficult to manage than the person’s actual death.

It is important to acknowledge any feelings of grief you may have. This is unique to you – there is no right or wrong way to grieve. You may find that your feelings change over time.

**Ambiguous loss**

Some people also feel a sense of loss in their relationship, even though the person with dementia is still there (known as ‘ambiguous’ or ‘unclear’ loss). You may feel that the person’s personality has changed or gone. Ambiguous loss may lead to feelings of grief that haven’t been resolved.

**Managing your feelings**

As someone supporting a person with dementia, you may cope well at times, and at other times feel overwhelmed by sadness or anger, or simply feel numb. Some people find they 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 way. Caring for a person with dementia can have a huge emotional impact, and feelings like these can be very difficult but they are a normal part of grieving.
Ask for support if you want to. It can really help you to manage your feelings. This can be difficult if there are people around you (such as friends or family members) who don’t understand your feelings or see them as significant. They may not fully see or accept the impact the person’s dementia is having on you.

It may help to talk about this with other friends or family members, or a professional. You may also find it helpful to attend a support group with other people caring for someone with dementia, or join an online community (such as Alzheimer’s Society’s Talking Point) where you can discuss your feelings honestly with people in similar situations. Go to alzheimers.org.uk/talkingpoint.

It is important to acknowledge any feelings of grief you may have. This is unique to you – there is no right or wrong way to grieve. You may find that your feelings change over time.

Tips for managing your feelings

- If you wish to, talk about your feelings with a professional (such as a dementia support worker, dementia specialist nurse or counsellor), other carers (perhaps by attending a support group), or a friend or family member. To find professionals or support groups, speak to your GP or local Alzheimer’s Society, or visit our online directory alzheimers.org.uk/dementiaconnect.

- You may want to find other ways of expressing your feelings. For many people, crying helps them to express their grief. Some people find it helpful to write a journal or use art or music, for example.

- Try to make time to do something for yourself each day. For example, going for a walk, a hand massage, chatting to friends or simply relaxing.

- Look after your own physical and mental health – try to eat well, get plenty of rest and some exercise such as walking or swimming. Looking after your spiritual needs will help (for example, with prayer or singing). If you’re feeling low or anxious, or are very tired or not sleeping, speak to your GP. For more information see factsheet 523, Carers: Looking after yourself.
Consider your own needs. If you feel that you need a break to help you cope, speak to someone (such as a social worker or dementia support worker) about arranging this.

Try to focus on the positives, such as the things that you and the person with dementia can still do together, or other interests you have.

Supporting a person with dementia during grief

People with dementia may also develop feelings of grief as their condition progresses. They may grieve for the loss of their abilities, skills and independence. They may feel more isolated as their environment becomes unfamiliar and more confusing. They may be frightened about what’s going to happen in the future.

Tips for supporting the person during grief

- Support them to express how they’re feeling (if they want to). They may not be able to communicate this verbally but look for other ways to support them such as music or creative activities.
- Give them time to express how they’re feeling and reassure them when they’re feeling distressed.
- Support them to keep doing the things they want to and enjoy. For example, you could use assistive technology or adapt activities to meet the person’s needs. For more information see factsheet 437, Assistive technology – devices to help with everyday living.
- Help them find new things they enjoy doing – for example, they could try a new hobby or get involved in their local community.
- Think about any spiritual needs they may have (such as meditation, prayer or attending a service) and how these can help the person to cope with their feelings.
- They may find it helpful to talk to a professional (such as a dementia support worker or counsellor) about how they are feeling.

Residential care

If the person with dementia goes into residential care, you may experience a range of feelings including relief, sadness and guilt. These feelings are normal and may change over time. You 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 a relationship, and you may miss having the person around. You may also feel that you are no longer able to play an active part in their care. All of this may contribute to feelings of guilt and sadness.

If you’ve been a carer for a long time, the move to residential care can have a big impact on you. Some carers find they feel lost and have a sense of emptiness. Other people may expect a carer to be able to get on with their life quickly after the person goes into care and may not appreciate how they might be feeling.

There may also be practical and financial issues to think about when the person goes into care (such as living arrangements) which can affect your feelings and ability to cope.

**Tips for when the person moves into residential care**

- You don’t stop being a carer just because someone has moved into a care home. If you still want to be involved in caring for the person, such as helping with mealtimes, 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 is important for helping care home staff to support the person. If the person has communication difficulties, you may also wish to use our support tool **This is me** (1553). This is an easy-to-fill-in form to record these details and help staff understand the person better – see [alzheimers.org.uk/thisisme](alzheimers.org.uk/thisisme)

- At first, 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.

- However much you are involved with the person in their new home, make time to take care of yourself and your needs.

- Consider attending a support group. The care home may have a group for family members and carers. These can help you to talk about your feelings and the changes you’re going through.

- Accept your own feelings in your own way – there is no right or wrong way to feel.
If the person with dementia goes into residential care, you may experience a range of feelings including relief, sadness and guilt. These feelings are normal and may change over time.

Feelings after the person has died

Everyone reacts and copes with bereavement in their own personal way. Many people will go through this without needing professional bereavement support.

How you feel after the person has died may be affected by different things, including:

- your relationship with the person
- your situation and personality
- how you’ve responded to changes while you’ve been caring for the person
- how much you’ve already grieved while the person was living with dementia
- the situation – whether you said or did the things you wanted to
- the circumstances surrounding the person’s death.

When the person dies, this may feel like the final loss of many, and can also represent 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
- anger and resentment about what has happened
- guilt about how the person was cared for
- emptiness or numbness, as though feelings are frozen
- being unable to accept the situation
- isolation
lack of purpose

relief, both for the person with dementia and for yourself.

Sometimes when a person dies, their carer 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 overwhelming and you aren’t able to deal with 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.

Some carers may feel a sense of emptiness after bereavement. This can be for different reasons, including struggling to come to terms with the loss of the person, missing their defined role as a carer, feeling like they have too much free time (especially if they’ve lost past interests and hobbies), and not having been in touch with other people while caring. All of this can add to feelings of loneliness and isolation.

Some people find it hard to adjust to living without the person. It can help to talk through these feelings with someone you trust.

Even though you may generally be coping, there may still be times when you feel especially sad or upset. Try to find ways to express and explore your emotions after bereavement. Some carers find it helpful to meet with professionals who were involved with the person’s care at least once after bereavement.

Tips for when the person dies

- Try to avoid making any big decisions in the early months, such as moving house or taking on extra responsibilities, if you’re still feeling shocked or vulnerable.
Take some time to reflect and come to terms with your situation, but try not to become isolated.

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 to them.

If you find events such as anniversaries or birthdays upsetting, ask for help from supportive friends or family members.

Look after your spiritual needs. Many people find practising their spiritual beliefs (for example through meditation, prayer or singing) helpful after a bereavement.

Stay in touch with your GP. After bereavement you may be more vulnerable to physical and psychological illness such as viruses, anxiety, stress and depression.

If you feel your grief is becoming overwhelming, look for bereavement support services.

Readjusting after bereavement
Life does not just go back to being the same after bereavement. However, the time will usually come when 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. If you’re struggling and time doesn’t seem to be helping, you may want to think about professional support.

Tips for readjusting

- 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 do things with other people – you could start doing past interests and hobbies again, 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 to friends or family.
- Create a photo album.
- Keep some of the person’s personal belongings.
- Do something to commemorate the person, such as planting a tree or arranging a memorial gathering for those close to them. Or you could take part in an event such as our Memory Walk (for more information go to memorywalk.org.uk).

Supporting a person with dementia during bereavement

Like anyone, a person with dementia may respond to bereavement in a range of ways. However, their problems with thinking and reasoning may affect how they understand and adapt to the bereavement. This doesn’t mean they are unable to feel emotions after bereavement and experience grief.

Telling the person about a death

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

If the person is in the early stages of dementia, it is usually best to tell them about the death and see how they react to the news. 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. When making the decision, think about what is in their best interests. You may find it helpful to discuss what to do with a professional such as a dementia specialist nurse, dementia support worker or doctor.
If the person is not told about the death it may prevent them from grieving. It may also leave them feeling afraid and unsupported if, for example, the person who has died appears to have stopped visiting without them knowing why. However, telling the person may lead to unnecessary distress and they may be unable to process the information.

Whether to tell the person will depend on a range of things – who the person is, what situation they are in and what is in their best interests. Whatever you decide to do, it is important to acknowledge and support the person with their feelings.

There is no right or wrong answer that works for every person and situation. Always do what you think is best for the person.

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

Tips for telling the person about a death
- Explain what has happened clearly and simply. Don’t use euphemisms like ‘losing’ someone or saying they have ‘gone to sleep’, as they can be misunderstood.
- 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. Try to be patient.
- If the person becomes very distressed, offer them reassurance (for example by holding their hand). It may help to try a different approach later on when the person is no longer distressed.
- Make sure that you are supported as well.

The person’s dementia may also mean they struggle to do the things they’d normally do to cope, such as speaking to friends about how they feel or using hobbies to keep themself busy and doing things. Try to help them feel safe and supported. It can also affect their ability to accept the death, and to talk about 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 think there’s another reason 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). It may be a combination of these things.

- They may 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.

- Changes in the brain mean they may have difficulty expressing how they’re feeling and may express their grief in different ways, such as through their behaviour. They may become attached to one possession, for example 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, such as singing.

**Supporting the person to grieve**

It may be difficult to know whether a person with dementia is grieving. If they are, it’s important to support them. It may help the person to be involved in conversations and arrangements after the death (such as the funeral). This can help them take in the loss and start the grieving process.

If someone starts to behave differently and this is challenging (for example if they ae becoming agitated, aggressive or trailing – where they follow their carer round), it could be a direct reaction to the bereavement. It may also be a sign of distress because they are not being supported to grieve. 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 may help you support the person to grieve, or help them find a way to avoid these triggers.

**Tips for supporting the person to grieve**

- Acknowledge the person’s feelings and encourage them to express themselves.
Reminiscence work can be helpful after a bereavement. You can speak to a professional such as a dementia support worker or dementia specialist nurse for more information on using reminiscence. If the person lives in a care home you can speak to staff about this.

Allow them to talk or communicate in other ways about the person who has died. For example, they might want to listen to music they used to enjoy with that person or look through photos.

Giving the person something that reminds them of the person who died may help them to feel more connected. This is another way of supporting them using reminiscence.

Art or music can support people to express their feelings and grief.

They may find comfort in their spiritual beliefs or faith practices such as prayer or meditation. Support them to find the right time and way to express these beliefs if they wish to.

If the person’s main carer dies, as well as feelings of grief and loss for the person, it can also lead to lots of change in the person’s life. They are likely to need lots of support, guidance and assistance to adjust to these changes.

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 talk about it. Instead it may show in their mood or behaviour (for example, they may be crying a lot more or be more agitated). This may explain changes in their mood or behaviour that don’t otherwise seem to have an obvious cause.

**Asking for the person who has died**

A person with dementia may forget that someone has died. They may ask about them often, 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 the person with dementia as well as any family and friends coming to terms with the death. If they are told again that the person has died, it may be like hearing it for the first time. How you handle this situation will depend on the circumstances, but most importantly on the person and what is in their best interests.
Tips for reminding a person with dementia of a death

- For some people, a gentle reminder that the person has died may help. For others this will be very upsetting.

- Reminding them about the funeral in a sensitive and supportive way, such as looking through the order of service with them, may help them to understand. Personal possessions may also help.

- Recognising and focusing on how the person is feeling at the time 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 their feelings and behaviour. Reminiscence and other creative techniques (such as art or music) can be helpful for this.

- Look for aspects of the person’s behaviour that give clues to how they are feeling. For example, at 5pm they always had a cup of tea together and this is when they seem to ask about the person who has died. If there is a pattern you may be able to use techniques to help. For example, at that time you could ask the person about hobbies they used to do together to encourage positive reminiscence (try to remind them of these hobbies if you need to).

- Be patient and aware that adjusting to the loss will take time. Respond to whatever the person is communicating.

If responding to the emotion or reminiscence doesn’t work, you could try distracting the person. However, while this may help them to be less distressed in the moment, it may not help the grief process in the long term.

It may be difficult to know whether a person with dementia is grieving. If they are, it’s important to support them. It may help the person to be involved in conversations and arrangements after the death (such as the funeral). This can help them take in the loss and start the grieving process.
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 feel the emotions all over again. They may struggle to process the information that the person died a long time ago, and be left with the feeling of a recent bereavement. They may also confuse a recent bereavement with a previous one (for example, confusing losing their husband with losing their father).

Supporting a person with dementia who is bereaved can bring many challenges. However, there are things you can do to help the person feel safe and supported, such as talking to them about the person who has died and letting them know you are there for them. Also remember to acknowledge and take care of your own needs and feelings of grief during loss and bereavement.

Other useful organisations

Age UK
Tavis House
1–6 Tavistock Square
London WC1H 9NA

0800 678 1174 (information and advice, 8am–7pm every day)
0800 169 8787 (enquiries)
contact@ageuk.org.uk
www.ageuk.org.uk

Wales – Age Cymru
Ty John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ

029 2043 1555 (general enquiries)
08000 22 3444 (advice line, 8am–7pm every day)
enquiries@agecymru.org.uk
Northern Ireland – Age NI
3 Lower Crescent
Belfast
Northern Ireland BT7 1NR
028 9024 5729 (general enquiries)
0808 808 7575 (advice line, 8am–7pm every day)
Provides information and advice for older people in the UK.

Carers Trust
32–36 Loman Street
London SE1 0EH
0844 800 4361
info@carers.org
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
0808 808 7777 (carers’ advice line, Monday – Wednesday 10am–4pm)
advice@carersuk.org
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
0808 808 1677 (national helpline, Monday and Friday 9.30am–5pm; Tuesday, Wednesday and Thursday 9.30am–8pm)
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. They provide counselling and support, information, advice, education and training services.

**Dementia UK**
Second Floor
356 Holloway Road
London N7 6PA

020 7697 4160
info@dementiauk.org
www.dementiauk.org

Charity providing specialist dementia support for families through its Admiral Nurse service.

**Hospice UK**
Hospice House
34–44 Britannia Street
London WC1X 9JG

020 7520 8200
info@hospiceuk.org
www.hospiceuk.org

National charity for hospice care. They have details of hospices across the UK, some of which may be able to provide bereavement services.

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

Samaritans offers a safe, confidential phone line providing non-judgemental emotional support, 24 hours a day. This is for people with feelings of distress or despair, including those that could lead to suicide.
Factsheet 507LP

Last reviewed August 2017 by Alzheimer’s Society
Last reviewed July 2014 by Dr Sylvia Dillon, Chartered Psychologist and Danuta Lipinska, British Association for Counselling and Psychotherapy, accredited independent trainer, counsellor and supervisor

Next review due: August 2020

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

To give feedback on this factsheet, or for a list of sources, email publications@alzheimers.org.uk

Alzheimer’s Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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