

Bereavement, loss and dementia

Supporting
people with
dementia
and those
close to them
through the
grieving
process



 Cruse
Bereavement
Care

Somewhere to turn when someone dies

Bereaved by dementia project

in partnership with
Alzheimer's Society Cymru

What is the aim of this booklet?

1. To provide information about bereavement for people with dementia
2. To provide information for those supporting people with dementia who are bereft

Why this booklet?

- This booklet has been written with the needs of people with dementia in mind
- People with dementia may require additional support which takes into account cognitive and communication factors that may impact on how they experience grief and loss
- It is estimated there are 850,000 people living with dementia in the UK

Who is this booklet for?

This booklet is designed to be used by wide range of people including:

- People with dementia (to be used independently or with support)
- Health and Social Care professionals
- Family members and carers

This booklet has been produced by the Bereaved by Dementia project, a partnership between Cruse Bereavement Care Cymru and Alzheimer's Society Cymru in collaboration with people with dementia and their carers.

This pioneering three year project, funded by the Welsh Assembly Government is working to raise awareness of bereavement and improve access to support for people affected by dementia and those close to them.



Contents

Part 1:

Bereavement and dementia

4

Part 2:

- a) The affects of bereavement
- b) Supporting someone following a bereavement

8

12

Part 3:

Good practice for communicating with someone with dementia experiencing loss and bereavement

16

Part 4:

The journey through loss and bereavement (a pictorial guide)

20

Part 5:

Bereavement and Dementia - communication tips for family and carers

34



Part 6:

Useful contacts & references

38

The following information is intended as useful background reading on bereavement for those working with a bereaved person. While the information is generic to anyone who has been bereaved, it is of course equally relevant to those who have dementia. All of the information is reflected in the accessible information in Part 4.

1.

Bereavement and dementia

Bereavement

Losing someone you love through bereavement may be one of the hardest things you will ever face. Bereavement affects people differently and can be devastating; there is no 'normal' or 'right' way to grieve.

How a person reacts will be influenced by many things, including:

- Age
- Personality
- Cultural background
- Religious beliefs
- Individual circumstances
- Previous experiences of bereavement
- Coping mechanisms
- Support from others

How bereavement and loss are experienced by people with dementia

- People with dementia, and those close to them, can experience bereavement and loss at different stages from diagnosis through to a person's death, and beyond
- For some people, they may even experience feelings of loss and grief: before diagnosis, as symptoms start to appear
- Cognitive difficulties can also create unique challenges for people with dementia when a loved one dies, such as, forgetting that the person has died

Key terms

- **Bereavement:** the death of someone close to you
- **Loss:** the feeling of grief after losing someone or something you care about
- **Grief:** the feeling of intense sorrow, especially following a bereavement or loss
- **Grieving:** the period of time spent adjusting to a loss or bereavement

What does grief feel like?

For family and carers:

The grief friends, family and carers may experience can depend on a range of factors including: their relation to the person (e.g. spouse, partner, sibling, child or friend), the type of dementia the person has, and the stage of dementia.

Grief can be expressed in many different ways including:

- Helplessness/despair
- Withdrawal
- Anger/frustration
- Guilt
- Denial
- Not acknowledging losses
- Longing for what has been lost
- Sadness
- Acceptance

For people with dementia:

In addition to the above, people with dementia may experience

- Grief for the loss of abilities, skills and independence as their condition progresses
- Develop a sense of isolation as their environment becomes more unfamiliar and confusing
- Fear about what the future holds

For people with dementia and those close to them

Both may experience grief in anticipation of the losses the condition may cause - this is known as anticipatory grief.

- For the person with dementia this tends to occur in the early stages of the condition
- For family and carers this can happen throughout the course of dementia

This can include feeling loss of:

- Their relationship
- Intimacy
- A particular lifestyle
- Shared activities and hobbies
- Companionship, support and special understanding from the person. A particular life style and sense of identity
- Communication between themselves and the person
- Previous relationship roles - e.g. the person who usually deals with the family finances
- Freedom to work or pursue other activities
- A planned future

It is important to acknowledge feelings of grief and loss when they occur

It is a complicated and highly individual experience - there is no right or wrong

Key points

- Experiences of bereavement and loss are individual; there is no right or wrong
- People with dementia and their carers experience grief in different ways at different times
- Loss can be felt prior to a bereavement due to the loss of an imagined future

2a.

The affects of bereavement

Bereavement can affect different people in different ways.

It can affect:

1. Feelings
2. Thoughts
3. Behaviours
4. Physical reactions
5. Relationships

Feelings

Feelings following bereavement can be very strong and can include:

- **Fear** - of being left alone; of the same thing happening again
- **Confusion** - taking in what has happened, that the person has gone
- **Sadness** - about the death and about other deaths the person has experienced
- **Longing** - for things that are gone or can't happen now
- **Guilt** - for being alive when the other person is dead; for things they may have said or done or not said and done in relation to the dead person
- **Shame** - for being seen to be helpless, emotional and needing others
- **Anger** - about what has happened; about having to deal with the aftermath
- **Numbness** - the death may seem unreal, like a dream
- **Emptiness and hopelessness about the future** - feeling that life is not worth living. Some people may even feel they want to end their own lives
- **Relief** - sometimes a death can feel like a relief for the bereaved person - this may be because their relationship with the deceased person was difficult or because the deceased person suffered a lot before their death
- **Mood swings** - a bereaved person can feel that they're on an emotional rollercoaster

Thoughts

Bereavement can also affect a person's thinking processes.

- **Inability to concentrate** - feeling jumpy, restless and anxious
- **Difficulty making decisions** - often about simple things, because of anxiety
- **Pre-occupation with the events or circumstances of the death** - constantly going over the events leading to or circumstances of the death

Additionally the bereaved person may also have thoughts such as:

- 'I will never get over this.'
- 'Will I always feel this way?'
- 'It can't be true'
- 'Why me?'
- 'I feel scared and lonely'

Behaviours

Grief can also change a person's behaviour and may include:

- **Crying** - more frequently than before or crying in situations that wouldn't normally be seen as an occasion for tears
- **Withdrawal** - from friends, relatives and situations that are a reminder of the person who has died
- **Physical and verbal aggression**
- **Sleep disturbance** - caused by dreams, flashbacks and restlessness
- **Change in appetite** - eating less or more than usual
- **Humour/laughter** - which can seem inappropriate and upsetting to family members and carers
- **Mood altering substances** - drinking alcohol excessively or taking drugs to dull the pain



Physical reactions

Grief and loss can be associated with changes in body functions, including:

- Increased heart rate
- Shortness of breath
- Dizziness
- Shaking
- Tingling sensation
- Stomach upsets
- Exhaustion

In addition, people who have experienced bereavement are often more vulnerable to physical illness.

Relationships

Relationships with others - e.g. family and friends may be affected. Some people may be able to support one another, but others may struggle.

A bereavement can bring people together but it can also create tensions and strains. A bereaved person can feel isolated, despite the presence of family and friends and this can be particularly the case when a person has dementia.

Key points

- Bereavement can affect you: thoughts, feelings, behaviours, physical reactions and relationships
- The experience is different for each person and can change over time



2b.

Supporting someone following a bereavement

Encouraging Self-care

It is important for the bereaved person to:

- Have time to grieve and understand that crying is a normal way to release feelings. It is important that people do not keep their emotions bottled up
- Be able to talk or communicate to other people about the person who has died and not to isolate themselves
- Eat properly and try to get enough rest (even if they can't sleep). Turning to drugs and alcohol will only offer temporary relief
- Try to set routines - this might be to re-establish old routines or set new ones
- Have space to grieve and a comfortable place to relax
- Be able to seek help and support if they need it and not feel guilty or weak when they are struggling

Suggested activities that can help

- Spending time with people who understand
- Visiting places that hold meaning - for example the grave of the deceased person
- Creating a memory book or box of photos, cards or letters
- Keeping a journal, which can help to process painful feelings that a bereaved person may find hard to share
- Putting together a calendar that helps the person plan and look forward to upcoming events



Significant times and triggers

There are some occasions and triggers which are unique to each bereaved individual. When supporting them it is helpful to be sensitive to these.

Such occasions and triggers may be:

- Birthdays and anniversaries
- Seasons of the year
- Weddings and funerals
- Music
- Pictures
- Photos
- Films
- Other people's stories
- And even global events

Some people find it helpful to plan in advance what they are going to do on those days.

All of these ideas can be used to help a bereaved person get used to the reality of the death and get through times of anguish. As a person does this, they may slowly begin to find a way of living without the person, while still having their thoughts and memories.

What is useful and what is not, when supporting a bereaved person

It is important when communicating with a bereaved person to have empathy; to be able to accept and respect a bereaved person irrespective of their reactions; and to be genuine.

- Avoid using clichés such as :
'I understand how you feel'; 'You'll get over it'; 'Time heals';
or 'It is part of God's plan'
- Try not to use statements that begin with 'You should' or 'You will.'
These can be seen as instructions. It's better to begin your comments with:
'Have you thought about. . .' or 'You might'
- Avoid suggesting that: 'This is behind you now; it's time to get on with your life.'
Sometimes bereaved people feel this means forgetting the person who has died
- How long a person needs to grieve is entirely individual
- Remember you do not have to have the right answers and get it right all the time

Key points

- There are many ways to express your grief
- Certain days or times of year can be more difficult when grieving, it can be helpful to make a plan in advance for these days
- When working with someone who is bereaved it's important to: show empathy, be non judgemental and genuine, irrespective of the person's reactions

3.

Good practice for communicating with someone with dementia experiencing loss and bereavement

This section is intended to provide guidance to support individuals with dementia, who are bereaved.

Good communication guidelines:

When supporting a bereaved individual with dementia effective communication can be supported by an awareness of:

- Adapting the environment,
- Good communication practices
Also see parts 4 and 5.

Adapting the environment

Ensure that the environment is suited to the individual's needs in terms of: location, furnishing and background sounds.

Prepare the environment for the interaction so that there are no time pressures or interruptions.

Consider the time of day that the interaction takes place:

Some people with dementia find that their concentration and memory is better in the morning and this enables them to communicate better at that time,

While others find they can communicate better in the later part of the day.



Good communicating practices for communicating effectively with a person with dementia:

- Keep sentences short and simple
- Face the person at eye level
- Be calm, talk in a gentle, matter-of-fact way
- Leave plenty of time for the person to understand what you say and to answer you
- Don't interrupt when the person is speaking
- Give the person time to come up with a word or thought
- Avoid competing noises; turn off the TV or radio or turn down the volume
- Don't order the person around or argue
- Ask people to join in rather than telling them to do things
- Use orienting names when you can, such as 'Your son John'
- Stay still when talking to the person so they can see you
- Respect the person's rights and wishes
- People with dementia can still speak for themselves
- Think about the person's literacy level when giving them written information
- Think about using an interpreter, if this might be helpful
- If the person has not understood what has been said, try repeating it using different words
- Don't take the person's response or behaviour personally
- Make time to talk the person through issues that arise

Key elements for effective communication:

- Environment
- How you communicate

Notes



4.

The journey through loss and bereavement

(a pictorial guide) experiencing loss and bereavement

What is grief?



Grief is what we feel when someone dies or we lose someone

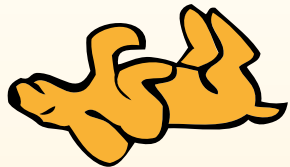
Grief could be caused by:



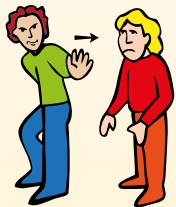
Someone dying



A medical diagnosis



A pet dying



A relationship ending

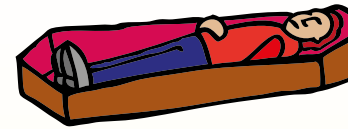


Not being able to reach a goal you wanted

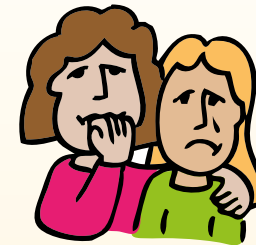


Not being able to do the things you used to

A Funeral



A funeral is a gathering when someone dies



People come together to remember and talk about the person who has died



They may sing songs and say prayers

It can help to go to the funeral,
but it is OK if you do not want to go.



Bereavement can affect different people in different ways.

It can affect:

- Feelings
- Thoughts
- Behaviours
- Physical reactions
- Relationships

Feelings

You may feel:



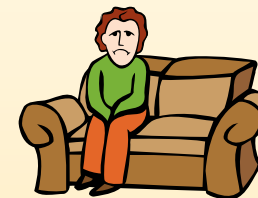
Sad / upset



Angry / frustrated



Confused



Lonely

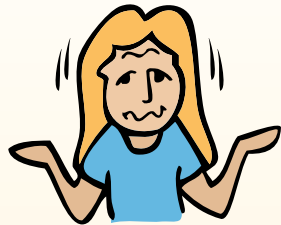
It's okay to have lots of different feelings

Thoughts

You may:



Have difficulty concentrating



Feel confused



Have difficulty making decisions



Have a loss of confidence in your abilities

You may have thoughts such as:



"Why me?"



"I feel lonely and scared"



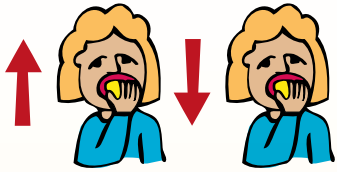
"It can't be true"



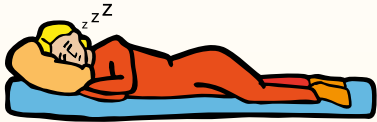
"Will I always feel this way?"

Behaviours

You may find you:



Eat more / less



Sleep more / less



Cry



Want to talk



Not want to talk

Physical reactions

You may:



Get headaches



Feel sick



Feel pain



Get short of breath



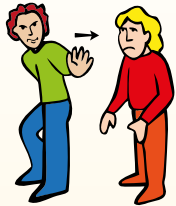
Feel exhaustion

Relationships

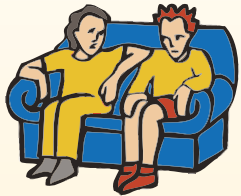
Relationships may change - a death can:



Bring family and friends together

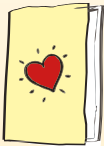


Push family and friends apart



Make you feel alone even when you're with people

You may feel sad on special days:



Anniversaries

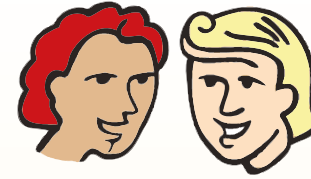


Holidays and festivals

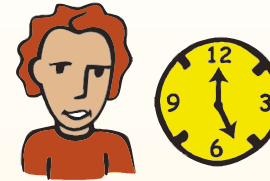


Birthdays

What helps:



Sharing your feelings with someone you are comfortable with



Give yourself time



Remember it's ok to go through a hard time

Other things that might help:



Eat properly



Try to get enough rest



Do the things you normally do

Do things that may give you comfort, such as:



Visiting the grave/a place that holds special memories



Making a book of sympathy cards



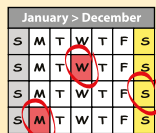
Making a memory book/box about the person



Finding a poem, saying or song that helps



Planting something in memory of the person



Putting together a calendar to help you plan and look forward to coming events

Remember:



What you decided to do is up to you



Acceptance takes time

“Grief doesn’t always disappear with time, this doesn’t mean you will always feel as bad as you do right now because life will grow around the grief”

“It’s okay for grief to be part of your life”
(Lois Tonkin)



Ask for help:
Cruse Bereavement Care
and Alzheimer’s Society



5.

Bereavement and Dementia - communication tips for family and carers

Telling the person about a death:

- Provide information clearly, simply and without euphemisms (e.g. '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

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:

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. Showing personal possessions may 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 (e.g. art or music) can be helpful. Look for patterns of when the person is asking. If there is one (e.g. 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

Emotions:

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.

Some other ways of supporting the person to grieve:

- 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

6.

Useful contacts & references

Support

Cruse Bereavement Care
National Helpline 0808 808 1677
www.cruse.org.uk

Alzheimer's Society National Dementia Helpline
0300 222 11 22
www.alzheimers.org.uk

Helpful information

www.hospice-foundation.ie

www.alzheimers.org.uk

www.opentohope.com/10-artistic-activities-to-help-with-grief/

Acknowledgements

Lois Tonkin - Growing around grief.
www.loistonkin.com

We would like to thank the Service User Review Panel members from the Alzheimer's Society for their contribution to the development of this booklet.

Illustrations

Gulbenkoglul, H. (2013).
Grief and Loss: Supporting people with a disability coping with grief and loss.
An easy-to-read booklet. Melbourne: Scope (Vic).



Somewhere to turn when someone dies

Cruse Bereavement Care is the leading national charity for bereaved people in England, Wales and Northern Ireland.

Our mission is to offer support, advice and information to children, young people and adults when someone dies and work to enhance society's care of bereaved people.

Cruse offers face-to-face, group, telephone, email and website support. We have a Freephone National Helpline and local services throughout England, Wales and Northern Ireland, and a website specifically for children and young people.

Our services are provided by trained volunteers and are confidential and free. Cruse provides training and consultancy for external organisations and for those who may come into contact with bereaved people in the course of their work.

For more information, please email:
training@cruse.org.uk

For more information:

www.cruse.org.uk

Freephone National Helpline number: **0808 808 1677**

www.hopeagain.org.uk



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