



Loss & bereavement in people with dementia

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Introduction

This information sheet looks at how loss and bereavement affects people with dementia and how best we can help them through this difficult process. It focuses on the best possible techniques available, including: -

- Person centred care – seeing the person first
- Validation therapy – responding to the underlying emotion
- Reminiscence work – sharing the past experiences of the person through pictures and music.

Each person's experience of bereavement will be unique to them and will depend on their individual relationship and how much contact the deceased person may have had with the person with dementia.

It is hoped that the information provided in this information sheet will provide support at some level, regardless of the relationship or context of the bereavement

What is grief?

Grief has been described as 'the constant yet hidden companion of dementia' both for

people with dementia and their families.

There is information and research about grief and bereavement available for family carers of someone who has dementia but there is very little information on how to support a person with dementia come to terms with the loss he/she may face on the death of someone close to them.

We all have losses in our lives but, for people with dementia, these losses are more profound - loss of a life, a relationship, a sense of self and memories. As memory fades, other losses follow – work, driving, hobbies, skills, abilities and finally independence. The way people deal with these losses or little deaths will affect the way they deal with the ultimate one of their own death or the death of someone close to them.

Grief is a normal response to loss but, depending on the relationship and past experiences, it may be expressed differently. Mourning is the outward expression of grief and it manifests itself in many ways - physical, mental, emotional and spiritual - and is usually associated with unhappiness, anger, guilt, pain and longing for the lost person or thing.

The purpose of the grieving process is to adapt over time to the loss of someone important to you. The aim is to accept the reality of the loss, work through the pain and adjust to life without the deceased. As Christina Rossetti wrote in her poem Remember "Better by far you should forget and smile than that you should remember and be sad". This may be extremely difficult for people with dementia.

The mourning process may be experienced by people with advanced dementia but they may not have the cognitive skills to resolve or make sense of their grief.

It is widely believed that protecting a person with dementia from the truth can cause confusion because the story will not match the reality. For example, telling someone who is agitated and asking where her late husband is to "Go on up to bed because Bob will be up later" might solve the immediate problem (getting the person to go to bed) but she might still be waiting for Bob to arrive and get anxious and upset when he doesn't. Loss of cognition should not be confused with the absence of emotion. We know that, however severe the dementia is, the person is still able to feel emotions.

Grief may be expressed by a person with dementia as agitation and restlessness. They may have a sense that something is not right, or a generalised feeling of 'wrong being' or perhaps that someone who is close to them is missing. The person may confuse the present loss with an earlier one. It is also possible that the person may not be able to retain the information that the person has died.

Expression of grief will be affected by a variety of factors: the extent of the dementia and loss of awareness, how close a relationship the person had with the deceased and how well the person can express their loss.

Breaking the news

If at all possible, tell the person that someone close to them has died. This is especially important if the person with dementia has regular contact with the person who has died either as a carer, friend, spouse or sibling. This may not be easy, especially if you are also upset, but it is much better to tell the person than try to pretend everything is all right as they may pick up on your sadness and not understand why. If you can't bring yourself to break the news, try to identify

someone else who is not so emotionally involved, such as another member of the family or a care worker, nurse or doctor.

Find a time of day when the person is at their best and rested. It is best if one person is delegated to break the news as a family group might be overwhelming. Find a quiet comfortable space and stay calm. Use body language to express your sadness, cuddle them or hold their hand. Keep the sentences short and do not give too much information at once. Avoid using euphemisms such as 'passed away' or 'at peace now.' Allow plenty of time, and be prepared to frequently repeat the information. If this becomes too difficult, invite other members of the family or carers to share the load.

Case study

Mary and Bob have just heard the news that their 45 year old son Keith has died whilst playing a game of squash. Mary has to tell Bob but knows he will not really understand as he has advanced dementia. They have always shared everything and she feels very much alone. She sits quietly next to Bob and shares the news with him. Bob senses her distress and they spend a long time holding each other and then they look at photos. Mary knows Bob will not remember and she will have to have this conversation with him many times over the weeks to come, but the sense of love and comfort they gave each other remains with Mary and strengthens her.

Planning the funeral – rituals

Where possible, involve the person with dementia as much as possible in discussions about the funeral and in making the practical arrangements. This will be dependant on the religion and wishes of the deceased person and on how close the person with dementia was to the deceased person. If appropriate, involving the person with dementia in the funeral planning can help to embed awareness of the death and create more references for gentle 'reminders' such as sharing messages,

letters and cards of sympathy. Avoiding such information and involvement tends to cause more problems in the long run and denies the person the opportunity to grieve.

The funeral - a rite of passage

Support the person with dementia to attend the funeral, especially if it is a close family member or friend who has died. If you are concerned you will be unable to cope because of dealing with your own grief, try to identify someone else to take care of the person with dementia. People tend to behave appropriately at such events as often they recall the rituals and conduct required of such an occasion and can take many cues from the setting and from others.

An 'order of service' with the person's photo on the front is a good visual reminder. Family members shouldn't hide their own grief for the person's sake as this can be more confusing.

Case study

Ada and Jim had been married for 65 years. Ada had vascular dementia and Jim had lovingly cared for her for many years. For the last two years they had lived together in a care home. Sadly, Jim died and their daughters thought it would be too upsetting for Ada to attend the funeral and did not involve her in the planning of it. The care staff encouraged the daughters to reconsider and allow them to take Ada to the funeral and sit at the back. Reluctantly, the daughters agreed.

When Ada entered the church, she had no intention of sitting at the back and took her seat with the family. Her behaviour was appropriate throughout the service and she was able to join in with the hymn singing, although she did not approve of the choice of hymns! It was felt that this helped Ada to come to terms with her loss of Jim. Her daughters were pleased she was there and able to take part.

After the funeral

This may be a sad and difficult time for you if you now have to sort out the deceased person's clothes and possessions but do consider involving the person with dementia in some small way. You may want to give them some item of clothing which had a particular smell or feel, or perhaps a familiar object. This can help embed the information that the person has died and gives many opportunities for reminiscing.

Reminiscing is something that gives us all comfort after bereavement. Try using photos and telling shared stories about the person. Taking the person with dementia to visit the grave or memorial site can also help and keeping up faith rituals can give solace. It is also important to allow the person with dementia to talk about how they feel.

Handling awkward questions

If you haven't been able to do any of the above, or even if you have, there is a strong possibility that the person with dementia will continue to ask for the person who has died wanting to know where they are and when they will be back.

A gentle reminder may work for some people; for others being reminded that the person has died is greatly upsetting. It can be as if they are hearing the news for the first time, with each reminder having the same upsetting effect. This is also very hard to cope with, especially if you have to contend with your own grief and you may feel frustrated, angry and lonely. If this is the case, try to give yourself some space, then try a different approach.

Imagine a man asking for his deceased wife, Mary. The response to his question "Where's Mary?" could be the blunt truth ("She died last November, Dad") or avoidance ("She's not here just now").

Instead, try tuning into the emotion the person is expressing beneath the words and respond to that emotion. If you are giving the

message that you understand how they feel, this can override the need to have the question answered. The emotion(s) may be: -

- genuine longing for the person
- bewilderment as to why the person isn't nearby
- fear
- distress
- suspicion
- anger
- concern.

If you can latch on to the emotion, then knowing what to say comes easier. For example:

"You sound as though you are really missing her. Tell me what she was like/what you miss about her."

OR

"You sound really frightened/lost/angry, let me help you with that."

There may also be something practical you could do. If the person is saying, "Mary would help me!" then ask "What would Mary do for you if she was here?" This could involve, for example, giving the person a hug or finding something they are looking for. This may meet their immediate need and reduce the distress.

Sharing your own loss can also help. ("I miss her too.")

Use the past tense when speaking as this will help orientate the person. ("We used to love Mum's chocolate cake, didn't we Dad? Do you think we could make one as good?")

Be responsive to the moment, paying attention to the mood of the person and responding appropriately. If the person seems unaware of change and is not distressed, don't try to force reality on him/her. If the person seems sad or angry or there is any other

unexplained change in behaviour, provide support for these emotions. Be prepared to revisit the experience or to never again address it, depending on the response of the person with dementia.

Accept that the person may want to talk about the deceased person frequently or infrequently and that they may have far more understanding of the situation than you think.

Consider using reminiscence, talking about the deceased person. Having a favourite piece of music or photographs can help the person work through their grief.

If regularly responding to the emotion and reminiscence really isn't working then, as a last resort, try distraction, bearing in mind that this will not help the grief process but may alleviate the stress of the moment.

Look for any patterns as to when the person is asking about the person who has died. Is it always early evening or always in the morning? Is it related to a particular routine that he and Mary always had? If you can spot a pattern then having the distraction in place or fulfilling a routine before the questions start may help.

Be consistent

A consistent approach is essential when supporting someone with dementia so there must be good communication between all family members and professionals about what techniques are being used to manage the bereavement and awkward questions. Everyone involved must use the same techniques to avoid further confusion and upset to the person. This should be clearly written in support plans.

Finally.....

The key to helping a person with dementia cope with the loss is to be patient and responsive and that it will take time. Remaining present in the situation will help responses to be authentic and supportive.

Take time to address your own feelings. Be honest with yourself and with the person with dementia. Do not hesitate to ask for help from others in dealing with either your own grief or the person with dementia's grief.

Useful links

www.alzheimers.org.uk

www.scie.org.uk/publications/elearning/dementia/dementia06/resource/flash/index.html

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