

Tips for supporting grieving and bereaved people with dementia



Develop skills in recognising loss and grief in people with dementia.

Grief is often disenfranchised for people with dementia. This means that their grief may not be recognised or well-supported. This can occur due to assumptions that a loss of memory or cognitive capacity equals a loss of feeling.

- Don't assume loss of cognition means losing the ability to feel the pain of different losses.
- Recognise that people with dementia may express their feelings in different ways than in the past, before they had dementia (e.g. a person may have seemed 'stoic' in the past, but then become more emotional or teary as the disease progresses, or seem restless or anxious).
- Use good observation skills (e.g. notice how the person is presenting each day – do they seem sad or anxious? Are they sleeping and eating well?).
- Use good communication skills to share information with others involved in the care. This will enable recognition of grief and a consistent approach to support.

Be aware that people with dementia are likely to be dealing with many losses.

- Losses for people with dementia may include loss of memory, loss of independence and personal freedoms, loss of control, loss of roles and the loss of a sense of identity.
- The person may tell their story again and again, which may be worsened by memory loss. Allow time and space for the person to express themselves in their own way.

Be informed and work with others (family, co-workers) when deciding whether to tell a person with dementia the truth relating to their losses (past or present).

It can be challenging to manage concerns about causing distress for someone with dementia alongside their 'right' to hear bad news and to express their grief. Be guided by the individual and others involved in their care. Consider these key questions:

- What does the person know already? Consider that they may think there is another reason the person is no longer present or around.
- How much information can the person with dementia cope with at a time? What is the best way to give information in a way the person will understand?
- What is the best place and time of day to give the person the best chance of understanding?
- Who can best support the person's understanding and ability to communicate, and in what way should they be involved?
- Could receiving this information be harmful for the person? i.e. If a person with dementia is constantly reminded of a death each time they ask about someone who has died, they may experience a strong, distressing response each time as if each time were the first time. If the person has difficulty remembering information, they may be harmed by receiving it.
- Discuss with others involved in care and agree on a consistent, supportive, validating response. For instance, where someone with dementia is not able to process or retain information about a past death, you might instead say something like, 'Tell me about the person,' or reminisce about the person who died.

Regardless of your role, provide grief support that is tailored to the individual person with dementia.

- Know the person well their story, beliefs, values and preferences.
- Validate and acknowledge their emotions. Try to focus on the feelings or intent behind the words, rather than the words themselves. Language like "It sounds like..." or "you seem...", and identifying what the person seems to be feeling (e.g. angry, sad) can help to recognise and normalise emotions.
- Use photos and other items which might be reassuring and help a person with dementia to feel connected with someone who has died.

References

The Irish Hospice Foundation. Loss and Grief in Dementia. The Irish Hospice Foundation, Dublin. 2016. [cited 22 May 2025].