

Supporting someone living with dementia who is grieving



Grieving in response to death is unique and personal. People living with dementia respond to the stresses of life events as others do, however changes to thinking, communication and memory may affect their ability to make sense of grief and adapt to bereavement.

How do I tell someone with dementia that their relative or friend has died?

It is generally recommended to tell the person with dementia when someone close to them has died.

Remember to:

- Find a time of day when the person is at their best and rested
- Choose a quiet, calm and comfortable space
- Check what the person already knows
- Keep sentences short and give information gradually
- Allow plenty of time for the person to process the information – don't rush
- Be prepared to repeat the information as needed
- Use body language to express your sadness (e.g. hug them or hold their hand, if it's appropriate)
- Allow the person to talk about how they feel or be with them in their silence

Should someone with dementia attend a funeral?

This decision needs to be carefully thought through.

Consider:

- How did the person deal with grief and loss in the past?
- Prior to having dementia, would they have attended the funeral?

- How close is their relationship with the person who has died?
- How will the person feel if they are excluded from this event, and opportunity to grieve?

If the person with dementia attends the funeral, assign someone to support them on the day. It may help to take them to a quieter place, at times, to reduce agitation and stress.

What do I do if a person with dementia keeps asking for the deceased?

People living with dementia often ask for people who have died (e.g. their parents). This may reflect a need to seek familiarity, security and comfort when their present reality is becoming increasingly unfamiliar and frightening.

For example, imagine a man asking for his deceased wife: "Where's Mary?"

Avoid being blunt – "She died last November" – or evasive – "She's not here now".

Instead try to respond to the emotion behind the words: "You sound as though you're really missing her." "Tell me what you miss about her." "You sound really frightened/lost/angry, let me help you with that." "What would Mary do for you if she was here?" Sharing your own loss can also help: "I miss her, too."

Be aware of any pattern to when someone is asking (e.g. 5pm when the couple always had a cup of tea together) and consider putting in place strategies (e.g. allocating that time to sit together and encourage sharing of happy memories).

How does someone with dementia grieve?

Although people with dementia deal with death much like others do, this is complicated by changes to memory and understanding.

Grief may be expressed as agitation and restlessness. The person may sense something is 'not right', or that someone is 'missing'.

Expression of grief will be affected by many factors, including the extent of the dementia and loss of awareness, how close a relationship the person had with the deceased and how the person has experienced grief or loss in the past.

If the person's behaviour changes it may be a direct reaction to the bereavement, or a sign of distress that they are not being supported to grieve. Generally, a person with early signs of dementia may have greater awareness and insight. They may still be able to understand the news of a death and talk about their grief and loss. It may be appropriate to tell the person and then judge whether or not they understand the news.

As dementia progresses, it is less likely the person will be able to fully understand the news or may no longer even understand the concept of death itself. This may influence the decision as to whether or not it is appropriate for them to be told about a death.

How can I best support someone with dementia who is grieving?

Some suggestions include:

1. Allow quiet time to 'sit with' the person with dementia and give them an opportunity to talk about their grief (if they want to)
2. Notice their emotions (e.g. "it sounds like you're missing your husband a lot")
3. Create a 'Memory or Life Story book' about the person who has died and share time sitting together and talking about memories
4. Consider creative therapies such as art and music. These can help people to express their feelings of grief without the use of words
5. Consider how the person responded to grief in the past, including paying attention to their spiritual needs

Suggestions for carers

Some key ideas for helping a person with dementia cope with a loss include:

1. Be patient and listen, it may take time for them to process information and they may need the information repeated several times
2. Be prepared to accept that the person may never acknowledge the loss
3. Be truthful about what's happened
4. Take time to address and share your own feelings of grief and loss
5. Don't hesitate to ask for help from others
6. Remember you don't need to 'fix' it, just listen
7. Offer safety and empathy, use reassuring touch as appropriate



Contact us

If you are concerned about what is happening to you, or have any further questions in regard to this information, you can contact us during business hours:

Bereavement Counsellor/Coordinator

Northern Sydney

Phone 1800 427 255

- Greenwich Hospital, Greenwich
- Neringah Hospital, Wahroonga
- Northern Beaches Palliative Care Service, Mona Vale

South West Sydney

Phone 02 9756 8878 or 02 9756 8849

- Braeside Hospital, Prairiewood
- SWSLHD Palliative Care Service

For services in other areas of NSW

NSW Bereavement Counselling Service Directory

www.palliativecarebridge.com.au/resources/25-nsw-bereavement-counselling-services-directory-2018

These services are free of charge.

Additional information and resources can be found on our website:

www.hammondcare.com.au/bereavement