Supporting a person with Dementia following Bereavement during the COVID-19 pandemic

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This booklet was designed to provide information to help support people with dementia who have experienced a bereavement during the COVID-19 pandemic.

We hope it will help to reduce stress and distress for both the person with dementia and those who love and care for them during this very challenging time.

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Supporting a Person with Dementia Following a Bereavement During the COVID-19 Pandemic

Most of us will experience the death of a loved one or someone we know as a result of COVID-19.

When a person with dementia is told that someone they love has died, what they understand and how they respond will depend on the stage of their dementia. Some people will understand and experience grief and others may not fully understand what this means. Some people may understand and become upset but forget after a short time. This means that they may frequently ask about the person who has died and react each time you tell them as if they are hearing the news for the first time. This can be distressing both for the person with dementia but also those around them who may also be grieving.

It is important that we continue to support the person with dementia when they are grieving or when they ask about someone who has died. It can be difficult, however, to know how to respond and what to say. There is not one way to do this, what you say and how you respond will depend on the person and what they understand.

Below are some suggestions that have been used in palliative care that may help. They come from research from across the world and also from our experience of talking to people with dementia about death and dying.
Sharing the news about death

Share the news as soon as possible. If you can, tell the person face to face. If you are too emotional and feel you can’t tell, ask someone else such as a friend or healthcare professional to tell them.

If you need to tell them by phone or video call because of COVID-19, ensure that someone is with them to help them to understand and offer support. Or ask the person who is with them to tell them and you can also be available by phone or video call.

Choose the right time and place

• Think about when the person is more able to concentrate and engage. For some people this is in the morning, or for others it may be the afternoon. This will give them the best chance to understand and retain the information.

• If the person is sleepy, hungry or needs to use the bathroom, they will be unable to fully attend to what you are saying.

• Think about the best place to have the conversation.

• Turn TV or music off and limit the number of people in the room to reduce distraction. This will help the person to focus their attention on what you are saying.

• Ensure there is good light, as many people will rely on your facial expressions to help them to understand and interpret the emotion in what you say.
**What to say**

- Tell the person what happened, where and when.
- Try not to use words such as “passed away” or “in a better place” as these can be misinterpreted. Use factual words such as “died” to ensure clarity.
- Use short sentences with pauses to give the person time to process and understand what you have said. Answer any questions they have.
- Try to match your tone and facial expression with what you say. This will make it easier for the person to make the connection between the information being given and the emotion that comes with it.
- Ask if they have any questions and answer questions as honestly as possible. If you try to protect them from the truth, this can add to their confusion.
- If their response is very emotional, offer comfort and give them time. Let the person be your guide, they may not need all of the information at the one time.
- We are very used to reaching out to touch or hug someone to offer comfort, but during COVID-19 you need to follow local health authority guidelines.
- A soothing tone of voice can offer comfort when touch is not possible.
- Ask them if they need anything. Is there anything that would offer comfort at this time?
After you have told the person about the death

Be prepared to repeat what you have said many times. Be mindful of the person’s distress.

• If possible and appropriate, involve the person in planning the funeral to help them feel connected with the death.

• The person may want to see the body to help them to believe that the person has died, this is a normal reaction. Explain that this is not possible because of the risk of infection during COVID-19. Tell them that you understand that this is very difficult for them.

Ongoing support

When the person remembers about the death.

Some people will remember that the person has died and will grieve. Continue to support them during this very difficult time.

• Talk with them about the person who has died and use expressions of sadness.

• Ensure your facial expression matches your verbal expression of sadness, as the person may use this to interpret feelings.

• Try not to protect them from loss, they need to express and experience loss in the same way all of us do. Grief is how we process and come to terms with things.

• They may experience intense or painful emotions or alternatively become very quiet. You may be afraid of saying the wrong thing but it is important to continue to offer support by talking, listening or just being with them. You may not be able to hold their hand or hug them because of COVID-19 and social distancing. But if possible, let them see your face or hear your voice, either in person or through phone or video call to offer comfort and provide a sense of safety.

For additional support on bereavement during COVID-19 please see, 'Grief and bereavement during the COVID-19 pandemic: supporting yourself and others' (1).
Some people will not remember that the person has died and they may continue to ask where the person is:

• Tell them that the person has died. Use the same information you did when you first told them. It is important to be consistent to reduce confusion.

• Always speak about the person who has died in the past tense. Even if the person with dementia speaks in the here and now, reply in the past tense.

• Accept that you may have to repeat the information frequently.

• Try not to get annoyed or upset by this. It may be hard, especially if you are grieving too, but it will be necessary to help the person with dementia make sense of the death. Tell them, “I know you are feeling sad and you miss [the person’s name].”

• Spend some time celebrating the person’s life and reminiscing about happy memories.

• Ask the person if there is anything they want to do that would help.
If reminding about the death causes ongoing distress

Sometimes reminding the person about the death continues to cause significant distress, or they may respond as if they are hearing the news for first time each time you tell them. If this happens, you will need to decide if it is in their best interests to continue to remind them that the person they love has died.

- When they ask about the person, ask them if they are missing that person. Spend time talking about them and reminiscing. Gently change the topic of conversation and engage the person in an activity.

- Look for patterns in when they ask about the person. Are there particular times of the day when this happens? If so then try to spend time with them or engage them in an activity at this time. If they have something to occupy them or someone to talk to they will be less likely to be thinking about the person who they are missing.

- If their response continues to be very emotional and you are concerned, it may be appropriate to discuss with a healthcare professional for guidance and support.

For further information on supporting a person with dementia during COVID-19, please see, 'Supporting carers and care staff to understand and respond to changes in behaviour in people with dementia during the COVID-19 pandemic.' (2)

General advice

- Ask everyone who comes into contact with the person to follow the same plan. Use the same words, same information and same process of comforts. Mixed messages will add to their confusion and distress.

- Take care of your own needs. If you are feeling overwhelmed by loss and grief, seek someone to talk to for help and support. You will be better able to offer support to the person with dementia if you are well supported yourself.

This advice is not definitive and you may have found something that works better for you and your loved one. We are all individuals and grieve differently.

If however none of this information helps and you would like more advice or support, please don’t hesitate to get in touch with your healthcare professional, whether that be your General Practitioner, Mental Health Support Team or professionals who specialise in bereavement and support such as CRUSE www.cruse.org.uk

You can contact Northern Ireland Hospice at www.nihospice.org.uk or visit the Northern Trust bereavement advice at www.northernntrust.hscni.net/services/bereavement-services/

There are also many organisations that will support you and your loved one through loss, for example the Alzheimer’s Society www.alzheimers.org.uk and TIDE www.tide.uk.net who are a network of past and present carers of people with dementia.
References


(2) Duffy F and Richardson J (2020) Supporting carers and care staff to understand and respond to changes in behaviour in people with dementia during the COVID-19 pandemic. Northern Health and Social Care Trust. Available at: www.northerntrust.hscni.net/CLEAR