



Beyond Words
empowering people through pictures



When someone dies from coronavirus: a guide for family and carers

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Support each other

We know that some people are going to die, unexpectedly and before their time. These situations are going to be impossibly difficult and distressing for you as carers and probably quite out of your experience. This is a short guide to help you.

You may have known people for a long time. It is heart-breaking if someone dies and you cannot even be with them. Coping with death and bereavement is extremely tiring, too, so you are likely to feel exhausted. Talk about it with colleagues. Make time for each other to share your emotions and feelings. Respect each other's way of coping with death. Some people cry (that's OK), some people keep themselves frantically busy (that's OK) – there is no right or wrong way.

You may think that you need to be “strong” for the people you support, and of course they need you to be there for them and not fall apart completely. But it doesn't mean that you cannot show your emotions. People with disabilities will feel supported by seeing that you are upset, too. It can make them feel less lonely, and it may even give them the chance to support *you*.

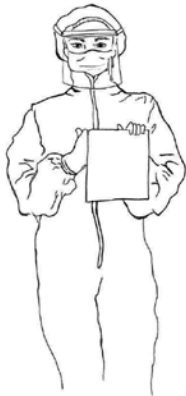
Two stories

Let's talk about a person with a learning disability whose friend Susan (who lives in the same house) dies in her bedroom at home, and whose mother dies in hospital.

- Talk about death openly, honestly and simply. Answer all questions.

- If you know that Susan is going to die, tell everyone about it, so it doesn't come as a surprise: Susan is so ill, she is going to die.
- Acknowledge how awful and difficult it is that we can't be with Mum, or (after death) be close to the body to say goodbye.
- Connect with Susan or Mum via video link. Seeing Susan ill in bed (however difficult) is likely to be less frightening than people's imagination. They can see that she is being cared for. If there is unfamiliar equipment (such as breathing equipment or masks), explain that this is to help.

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- For Mum, this may be more difficult as it depends on the support of busy hospital staff, but it's important to try.
- If friends or relatives are dying at home (but elsewhere), try and maintain virtual contact as much as possible – not just with the ill person, but also with those caring for them.
- When Mum or Susan die, tell people as soon as possible, using the simplest language: "Mum had died." "Susan has died." Repeat this message as often as needed; it may take a long time to sink in or understand.
- Talk about the person with the housemates left at home.

Susan, who dies in the same household

- If restrictions allow it, leave the bedroom door open, so that one housemate at a time can see and talk to Susan from a distance. If not, put a big photograph of Susan on her bedroom door. You can talk about her right there- whilst maintaining social distance.
- Feeling involved, and doing things for Susan, can help. Housemates can help prepare food and drink before it's taken to her. Help them to write, draw pictures, make things (which can be given to Susan, or shown through a window).
- Do not stop people from seeing Susan's body if they want (even if from a distance). Offer this opportunity to everyone. When Susan's body is taken out of the house, mark this as an important event. Encourage people to stand by their own door or window to wave, clap, shout "Goodbye Susan!"
- Follow this immediately by encouraging talking about Susan, saying how much we will miss her, singing her favourite songs, sharing memories, etc.

Mum, who dies in hospital

- Help the person to be in virtual contact with others who are affected by the death, especially their family – both during the illness and after the death.
- Reassure the rest of the family that you are there to support the son or daughter.
- The hospital might not allow items to be sent by post, but you can take a photo of the cards or pictures and send them virtually.

- Explain why we can't see mum, and explain what we can do instead (pray for her, draw a picture, light a candle, show photos of mum to other people in the household).



After the death

- Create a space for remembering.



- Explain that we can't go to the funeral. If possible, follow the burial/cremation via video link. If that is not an option, hold an event in the household that includes "funeral elements" (such as music, readings, eulogies, prayers). Involve people with learning disabilities as much as possible and invite

those who can't be there via video link. Record it, too (it will comfort family and friends afterwards).

- Acknowledge feelings of anger, distress, anxiety. These are all normal. Remember that people might express those feelings in different ways (for example, being withdrawn, hitting others, self-harming, shouting, problems with eating or sleeping). Name the feelings, and say that it's normal to feel like that, because Susan has died.

Some suggested words to explain things

Mum is in hospital. She is very ill. We can't visit her, because of coronavirus. That is really difficult and sad. Shall we call her / write her a card / do a drawing for her?

Mum is going to die soon.

We are not allowed to go into Susan's room.

Only Jean (carer) is allowed to go in and help Susan. Jean is looking after Susan.

We can... (draw a picture for Susan; wave at her through the window; etc)

Susan has died. Shall we go and see Susan? We can see her from the corridor / through the window. She will be very still, because she is dead. We can say goodbye to her. We are all very sad.

We will miss Susan. (Talk about what you will miss.)

People are coming to take Susan away. The people will wear masks and white suits, because of coronavirus. Susan won't notice this, because she is dead. We can watch from the window and wave and say goodbye to Susan.

Mum will be buried in the cemetery / cremated. We can't go to the funeral, because of coronavirus. Only your Dad will be there.

We miss Susan. We remember Susan. What we liked about Susan is... What Susan liked to do is... Susan's favourite food was... etc.

Related titles in the Books Beyond Words series

Am I Going to Die? (2009) by Sheila Hollins and Irene Tuffrey-Wijne, illustrated by Lisa Kopper. This story deals honestly and movingly with the physical and emotional aspects of dying.

When Somebody Dies (2014) by Sheila Hollins, Sandra Dowling and Noëlle Blackman, illustrated by Catherine Brighton. Mary and John are both upset when someone they love dies. They learn to feel less sad by attending regular bereavement counselling sessions and from the comfort and companionship of friends.

When Mum Died and **When Dad Died** (both 2014, 4th edition) by Sheila Hollins and Lester Sireling, illustrated by Beth Webb. Both books take an honest and straightforward approach to death and grief in the family.

Going into Hospital (2015, 2nd edition) by Sheila Hollins, Angie Avis and Samantha Cheverton, with Jim Blair, illustrated by Denise Redmond. This book helps to prepare and support people being admitted to hospital, by explaining what happens, covering planned admission and accident and emergency.

Footnote: *More detailed guidance is being prepared about advance care planning, decision-making (for example about dying at hospital or at home) and how to provide practical palliative care at home without professional support.*