

# Caring for your dying relative at home with COVID-19

This guidance is produced to help support people who are caring for someone who is dying at home from COVID-19 infection

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## Deciding to be at home

This should only be used where it is absolutely clear and recorded in the person's clinical record that he or she does not wish to be transferred to a hospital.

The reasons to decline transfer may be:

1. A clearly expressed wish by the person who has mental capacity that, despite the risk of death, he or she does not give consent to be moved.

If the person lacks the mental capacity to take this decision:

1. There is a previously written Advance Decision to Refuse Treatment in intensive care including ventilation, or
2. The appointed and registered attorney under Lasting Powers of Attorney for Health and Welfare decisions is making a best interests decision on behalf of the person, and that decision is against transfer for treatment (the attorney must be acting under a power which recognises that they have the power to make decisions about life-sustaining treatment).

A best interests decision must be in the *person's* best interests. It must consider their known wishes and feelings. It must be necessary and a proportionate response to the problem being faced. It must not be motivated to bring about the person's death.

In considering what is necessary and proportionate, the clinical pressures on the local hospital and intensive care facilities should be considered, as well as the ability of those in the person's home to take on the emotional and physical responsibility of care.

This is a terribly difficult time. As a relative or friend, particularly if you have already had Covid-19, you may prefer to take on this responsibility rather than be isolated away from the person who is dying. You will need the support of family or friends, either in person (if social distancing allows) or remotely through these difficult final stages. People are often glad to be asked to help.

## Healthcare professionals

You must ensure that the person providing care in the home has immediate access **as a minimum** to:

- 24-hour direct telephone contact with a named healthcare professional experienced in care of dying patients at home
- Emergency medication they may need, including:
  - oral morphine solution 2mg/ml 100-300 mls minimum
  - lorazepam 1mg tablet sublingual x 20
  - haloperidol 5 mg tablet x 10
  - 4 hyoscine patches
- Incontinence pads and sheets if possible
- Ordinary face masks
- Disposable gloves
- Plastic aprons

## Practical tips for home care

### High temperature

- Paracetamol 500mg to 1 gram every 4-6 hours will help lower temperature. You can usually stop all other medications (you may want to check with a phone call to the GP if any should continue).

### Dry mouth and thirst

- Give a few teaspoonfuls at a time in a propped-up position of any drinks that the person can taste. A small amount of a low-alcohol drink is not contraindicated if that is what the person wants. Don't worry about food – yoghurt, ice cream, jelly etc may be helpful.
- Ordinary lip slave or Vaseline helps moisten dry / cracked lips.

### Sickness and agitation

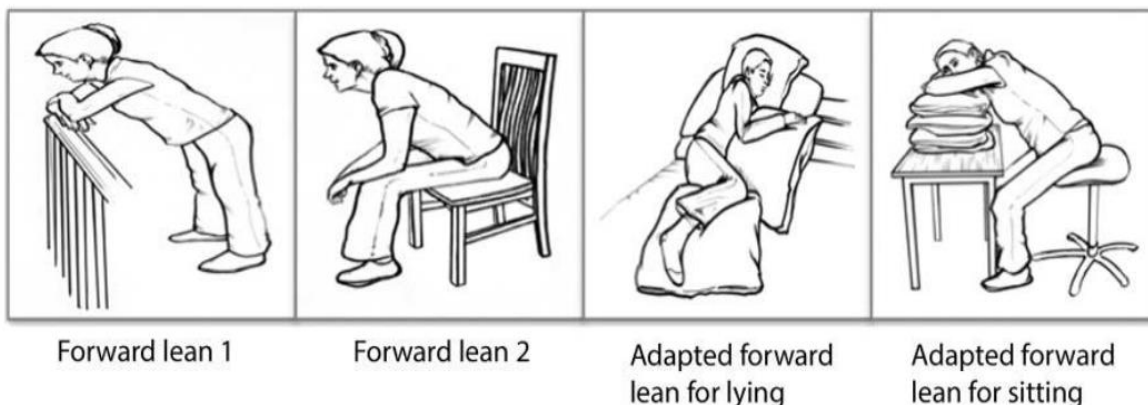
- Give half a haloperidol tablet (it can be crushed in ice cream or similar) for nausea or sickness or agitation. Repeat after 4 hours.

### Severe weakness/ unable to get to the toilet

- The Bladder and Bowel UK <https://www.bbuk.org.uk/> has helpful advice. Ask for (1) incontinence pads to absorb urine (avoid sanitary towels as they don't absorb as well as incontinence pads) and for (2) absorbent sheets to put on the bottom sheet to soak up any leaks. It may be that a catheter will be advised by the district nurse to collect urine.
- If nothing is available, men can pee into a large empty jar such as a coffee jar. Women find it difficult to pee in a bucket, so a large towel folded between her legs that can go straight in the washing machine may be easier.
- For stool (poo), if nothing is available, a few sheets of newspaper can catch stool and be immediately put into a binbag and tied off. If possible, drop the stool off the newspaper into the toilet first, but beware – newspaper may block your drain.
- If you can't get disposable gloves, ordinary household gloves are fine and can be washed in the way you wash your hands under running hot water with liquid soap. Disposable gloves can be recycled by doing this too. Then hang them on the line to dry in the sun – sunlight helps sterilise.
- If you cannot get washable or disposable bed pads you can improvise as follows: Lay any form of plastic sheeting you have available at home, or large opened large plastic bags (e.g. large bin liners) over the mattress, sticking joins with Sellotape or similar. Cover them with large bath-towels in a couple of layers, then put the sheet on top.
- To change the sheet, if the person is too weak to get out of bed, lay the clean sheet longways along the side of the bed and roll it longways. Then roll up the dirty sheet as you unroll the clean one to replace it.

## Difficulty breathing

- Chest tightness and difficulty breathing are a major part of severe Covid-19 infection. Breathlessness is not greatly helped by oxygen.
- Keeping the face cool with a facecloth dipped in cold water wiped around the mouth, nose and forehead can soothe.
- A window open to keep the room air cool can help. Avoid using fans and nebulisers as they blow the virus round the room.
- Sitting propped up makes breathing easier (see illustrations below).<sup>1</sup>



- Simple menthol lozenges may help soothe an irritant cough.
- For severe breathlessness and cough, give a small dose of morphine 1mg (=0.5 ml by mouth) every hour until the breathlessness is less distressing. This may cause drowsiness.
- Breathlessness is frightening. A lorazepam tablet under the tongue and your calm loving voice lessen anxiety.
- Noisy breathing is caused by secretions. Two hyoscine patches stuck on the skin can help. Although the noise is upsetting for you to listen to, it does not cause pain or make the breathlessness worse.

## When the person isn't responding, what should I do?

Even if a person can't respond they can still hear. You can tell them they are loved, by you and by others. Of course, you will cry and be heartbroken, but don't let that stop you saying all you want to say.

Hearing is often the last sense to go. The person dying will gain comfort from your love.

<sup>1</sup> NHS England Clinical guide for the management of palliative care in hospital during the coronavirus pandemic. Publications reference: 001559 27<sup>th</sup> March 2020.

## How do you know the person has died?

- Their pattern of breathing may change shortly before death, when they are already unconscious.
- There may be long gaps between breaths or between a run of breaths.
- Then the breathing stops completely.
- Their colour changes and they look very pale and with a bluish tinge and gradually their skin looks mottled.
- Their heartbeat is no longer felt by a hand on their chest.

## After death

- Write down the time you think they died.
- **There is no rush.**
- **This is a very difficult time** and you may want to take half an hour of peaceful time.
- If you feel you can, put a pillow or rolled up towel under the jaw to support their mouth closed and close their eyes, by gently pressing the eyelids closed for 30 seconds.
- If you can, lie their limbs straight.
- There is nothing more you need to do.
- You don't need to phone 111 or 999.
- Telephone the on-call number you have been given in your own time to be told what to do next.

## Telling other people who are close to the person

- You may find it helps to start with "I'm very sorry – I have very bad news...."
- Don't feel you need to speak on the phone to people if you don't feel up to talking "I'm sorry, I'm exhausted, can I call you later" will help protect you.

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*This document was prepared by Bevan Commissioner, Professor the Baroness Finlay of Llandaff: Honorary Professor of Palliative Medicine, Cardiff University; Past-President of BMA, the RSM and Association for Palliative Medicine*