

Caring for your dying relative at home with COVID-19

This guide can be given to any person providing care for someone who is dying at home from Covid-19 infection

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Looking after someone with severe Covid-19 at home

This guide is to be used when it has been decided, and all agree, that the person will remain at home, even though there is a very high chance of dying at home. If the person is very ill but the thought of dying at home has not been discussed, then this guidance is not relevant.

It is important that both you and the person who is ill with Covid-19 know when and who to call for more help, without having to go through a long telephone call process.

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.

Ask your GP or health and social care professionals for:

- The number of a 24-hour advice line number, dedicated to the care of dying patients at home.
- Any emergency medications that may be needed – be sure to ask for instructions how to appropriately use them. If you don't understand something, please ask.
- Advice which regular medication can be stopped. An up to date copy of the person's advance care plan. This will help all professionals to respect and support the person's decision to die at home. If one has not been done, ask your GP or health and social care professional for information how to arrange this.
- Incontinence pads and sheets if possible.
- Ordinary face masks.
- Disposable gloves.
- Plastic aprons.

Practical tips for home care

High temperature

- Fever causes shivering, shaking, feeling chilly, and aching all over.
- It can make people sweat profusely.
- It can help to open a window to cool the room and change wet nightwear.
- Give paracetamol 500mg to 1 gram every 4-6 hours to help lower temperature, but not more than 4 grams in 24 hours.

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 or jelly may be helpful.
- Ordinary lip salve or Vaseline helps moisten dry / cracked lips.

Sickness, vomiting and diarrhoea

- When people are very ill or on certain medications to help relieve symptoms from Covid-19 infection, they often lose any appetite and can't taste food properly. You should have been supplied with some medication to give to help relieve nausea and sickness.
- If a person finds tablets difficult to take, they can usually be crushed and put in liquid, ice-cream, jam or something similar.

Severe weakness/ unable to get to the toilet

- Bladder and Bowel UK <https://www.bbuk.org.uk/> has helpful advice. Ask for incontinence pads to absorb urine (avoid sanitary towels as they don't absorb as well as incontinence pads) and for 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 urinate into a large empty jar such as a coffee jar. A woman might find it difficult to urinate in a bucket, so a large towel folded between her legs that can go straight in the washing machine may be easier.
- Diarrhoea and bowels not opening can be a normal variation for someone in the last days. Ask your GP for advice if medication may be helpful.
- For stool - 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.
- 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-out 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, lay it 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.

Cough

Some simple measures reduce the risk to a caregiver catching the virus:

- Ask the person (if possible) to cover the nose and mouth with a disposable tissue when sneezing, coughing, wiping and blowing the nose.
- Dispose of used tissues promptly into a closed waste bin.
- Clean their and your hands with soap and water, alcohol hand rub or hand wipes after coughing, sneezing and using tissues.



Cough can be helped by:

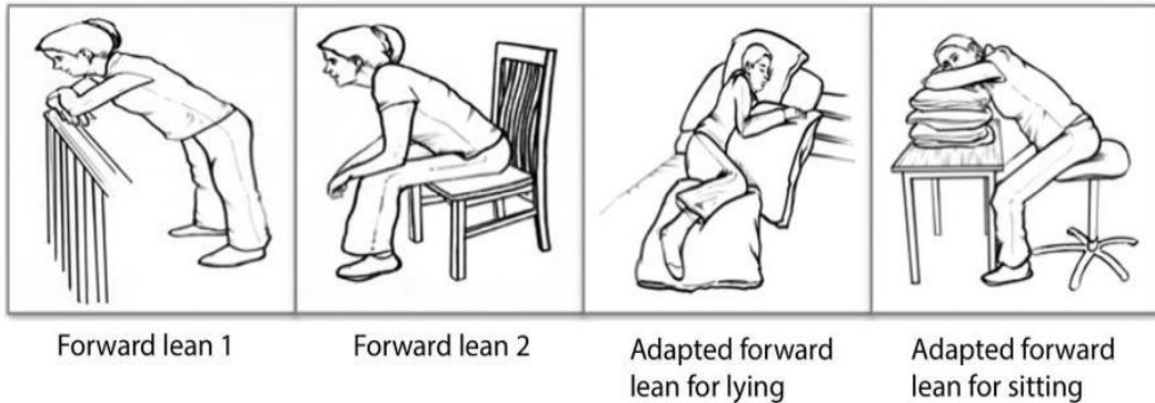
- Sips of fluid (cold drinks, clear soup or honey & lemon in warm water).
- Sucking cough sweets.
- Sleeping propped up by pillows.

Where the cough is troublesome, ask your doctor or pharmacy for simple linctus or codeine linctus, which may help.

Difficulty breathing and restless agitation

- Breathlessness is a frightening feeling: 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) ¹
- For severe breathlessness and cough, a small dose or regular doses of morphine can help to make the breathlessness less distressing. This may cause drowsiness. Constipation can occur with morphine which a laxative may prevent. Make sure you have one available. Sickness is also a possible side effect; so, make sure you have anti-sickness medication prescribed in case it is needed.

¹ NHS England Clinical guide for the management of palliative care in hospital during the coronavirus pandemic
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- Noisy breathing is caused by secretions. Some medications will have been prescribed to help in case this happens. Although the noise is upsetting for you, it does not cause pain or make the breathlessness worse.

Confusion and agitation

People with Covid-19 infection may become confused. You can help a person if they get confused by:

- Reassuring the patient gently and slowly. It can help to explain where the person is, remind them who you are.
- Ensure there is adequate lighting and the room is quiet, to help it feel calm and safe.

If distress is severe, use the medication your doctor has prescribed in case this happens.

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.

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.
- Remove all valuables from the person's body as it will not be possible to retrieve them once the body had been taken away and put them in a sealed plastic bag or box and don't open for 7 days.
- If they had a pacemaker or indwelling defibrillator implant, it may keep firing after death, but there is nothing for you to do. Please tell the undertaker.

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 you don't want to: "I'm sorry, I'm exhausted, can I call you later" will help protect you.

Death certificates and paperwork

When someone dies, some legal paperwork needs to be done by the doctor involved in the person's care, usually a GP. For someone who has died with Covid-19 infection (either confirmed or suspected) the process for doing this paperwork may be different. Your GP or funeral director can guide you through the next steps and will advise you which paperwork needs to be done.

Pastoral, spiritual and religious support – before and after death

If the person and/or you have a faith or would like spiritual or pastoral support whilst a person is unwell, connect with your local faith leader. They will be able to put you in touch to talk with someone and help arrange any relevant ceremonies. Your GP surgery and community support groups may also be able point you in the right direction.

Bereavement support

You will feel a strange range of emotions after someone you love dies, such as shock or anger. You might feel very upset and cry. You may feel numb for a few days. Your feelings can change daily and other people around you may experience different feelings to you at different times. There is no set pattern.

Although it does not bring your loved one back, talking with other people who also cared about the person can be helpful. We are all different. Some people find it helpful to share with other people that the person has died and talk about your feelings with them.

If you find it difficult to reach out to others, you could ask them to keep contact with you. People want to help. They are glad to be asked to help with shopping or preparing a meal for you or other tasks.

Bereavement support groups in your community are working differently now, but are still available.

Your GP surgery can advise you on local support and psychological support if you need it. Don't be afraid to ask; there is help out there. Some national examples include:

- National example of GP Surgery Bereavement leaflet - <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/03/NHS-Bereavement-Leaflet.pdf>
- COVID CRUSE - Grief and Trauma - <https://www.cruse.org.uk/coronavirus/trauma>
- A collaborative guide to COVID-19 care - <https://covid-at-home.info/>
- Marie Curie Information and Support service 0800 090 2309 <https://www.mariecurie.org.uk/help/support/marie-curie-support-line>

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