

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 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 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 so do take the offers of any support and help that are available to you and that you feel will be what you need. In every local authority area in Wales during the pandemic there is now a structure of volunteers who can collect medicines, shopping or other essential needs. You can find the contact details for your local organisers here: <https://covidmutualaid.org/local-groups/>

There is valuable and useful advice about caring for someone dying at home here. <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/what-to-expect/what-happens-when-someone-is-dying>

The decision

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. In the first instance you should contact your local GP practice to discuss this; it may be the case that they have already contacted you directly in relation to your care wishes.

If you wish to think about this before contacting your doctor to ensure this is included in your record you may want to download the statement from <http://advancecareplan.org.uk/> and print and sign it. Although this is not legally binding it gives guidance to health care professionals, your family and/or friends and carers about your wishes in relation to care at the end of your life. It also gives you a useful guide to the kinds of things you can include in advance in a conversation about what you want for yourself or what you know the person you care for wants.

The reasons to decline transfer to hospital may be:

1. A clearly expressed wish by the person who has mental capacity and is able to understand and communicate 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 (again see information on <http://advancecareplan.org.uk/>) 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 (patient'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.

Healthcare professionals

As understanding of the pandemic and the best way to manage it changes, the guidance for clinicians is being updated. Clinicians should check the guidance on the Association for Palliative medicine website and the Royal College of General Practitioners (links below).

<https://apmonline.org/>

<https://www.rcgp.org.uk/covid-19/latest-covid-19-guidance-in-your-area.aspx>

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

- 24-hour local telephone number dedicated to care of dying patients at home
- Emergency medication they may need, including:
 - oral morphine solution 2mg/ml 100-300 mls minimum
 - anti-anxiety (lorazepam 1mg tablet sublingual x 20 or similar)
 - anti-sickness (haloperidol 1.5 or 5 mg tablet or levomepromazine 25mg x10 or similar)
 - 4 hyoscine patches if locally available
 - Consider a 'just in case box' in advance
- Incontinence pads and sheets if possible
- Ordinary face masks
- Disposable gloves
- Plastic aprons

Practical tips for home care

Routine medicines normally taken by the person who is ill

You can usually stop most medications (you may want to check with a phone call to the GP if any should continue).

High temperature

- Paracetamol 500mg to 1 gram every 4-6 hours to help lower temperature. If the person has difficulty swallowing and the liquid medicine is unavailable, it is acceptable to crush the tablet in a small amount of ice cream or similar food.

Dry mouth and thirst

- Give a few teaspoonfuls at a time in a propped-up position of any drinks that the person wants. A small amount of a low-alcohol drink can be given if that is what the person wants. Don't worry about food – yoghurt, ice cream, jelly etc may be helpful.

Sickness and agitation

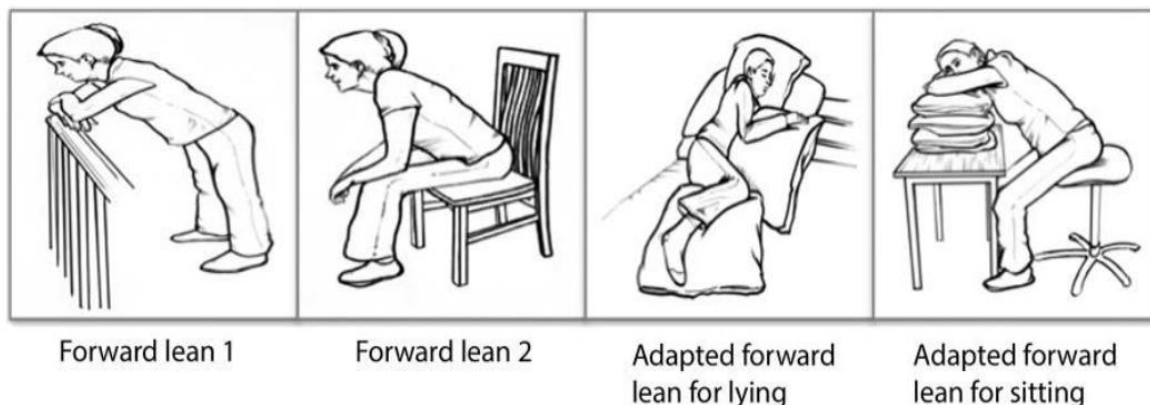
- Give half a haloperidol tablet (it can be crushed in ice cream or similar) for nausea or sickness or agitation. Repeat after 4 hours.

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. The nurse would insert this and teach you how to manage it if this happens.
- 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. Be aware that the local volunteer networks are being very successful at sourcing and delivering surplus unused items such as incontinence pads. The main ways they are offering help are via social media like Facebook but if you contact your local volunteer organiser by telephone they may be able to help with this.
- For stool (poo) if nothing is available, a few sheets of kitchen roll or 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 – kitchen roll and newspaper may block your drain. Baby wipes are an easy way to gently clean the person's body and should immediately be placed in the bin bag you are using for the person, not flushed in the toilet.
- 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, 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 gently rolling the person onto the clean sheet and off the dirty one. Immediately place dirty sheets in washing machine on a hot wash.

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).¹



- Simple menthol lozenges may help soothe an irritant cough.
- For severe breathlessness and cough, a small dose of morphine 1mg (=0.5 ml by mouth) every hour until the breathlessness is less distressing. This may cause drowsiness.
- Noisy breathing is caused by secretions. Two hyoscine patches stuck on the skin can help. Although the noise is upsetting for you, it does not cause pain or make the breathlessness worse. Sometimes fairly simple adjustments of posture make a big difference to noisy breathing so it is worth trying an adjustment of pillows and cushions or whatever you are using to prop the person. Leaning forward can help with breathlessness as the lungs have more freedom to move.

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. Some people may feel the need to 'give the person permission to let go' and reassure them that all will be well. If you feel this is important for you then that is fine. As far as you can, remind yourself that you are doing your best for the person you are caring for. Calm reassurance will help them feel safe if you can manage it, but in any case, being with them on their journey is what you are offering. Some people might like to listen to a favourite piece of music and you might, yourself find this comforting.

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

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

Remember to drink enough yourself and try to eat a meal or snack as regularly as you can. It is important to know that sometimes people decide to let go of life and die when they are alone. This is not a reflection of your care, it just is the case that sometimes people die just as this happens. It is also the case that sometimes people die as they are being moved or washed. This is also 'normal' and no reflection on your care, it just was about to happen anyway.

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.

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 want to "I'm sorry, I'm exhausted, can I call you later" will help protect you. You may find it helpful to ask for help from a close friend or relative to protect you from some calls.

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