



# Caring for someone dying at home

This guidance is produced to help support people who are caring for someone who is dying at home

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## Deciding to be at home

This can be a difficult time. You as a carer will need the support of family or friends, either in person or remotely through these 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.

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 to remain at home

In the first instance you should contact the local GP practice to discuss this; it may be the case that the person has already contacted the GP in relation to their wishes. This decision will be clearly documented and recorded in the person's clinical record that they do not wish to be transferred to a hospital.

## Advance care planning

The person may wish to think about this before contacting the doctor to ensure this is included in their record. The statement can be downloaded from <http://advancecareplan.org.uk/> printed and signed. Although this is not legally binding it gives guidance to health care professionals, family and/or friends and carers about wishes in relation to care at the end of life. It also gives a useful guide to the kinds of things included in advance in a conversation about what the patient wants 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 can 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/> ) or
2. The appointed and registered attorney under Lasting Powers of Attorney for Health and Welfare decisions is making a best interest's 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 interest's 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.

You should have access to:

- 24-hour local telephone number i.e., GP Practice in hours, 111 or community nursing service.
- Emergency medication you may need in discussion with your community nurse or GP

## Practical tips for home care

### Routine medicines normally taken by the person who is ill

- You can usually stop most medications (Although it's worth checking 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 wants (tap water is fine). 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 if they can swallow.

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

- The Bladder and Bowel UK <https://www.bbuk.org.uk/> has helpful advice.
- It may be that the person you are caring for is struggling to get to the toilet. Your community nursing team will advise how best to manage this.
- Men may find it helpful to use a urine bottle to pass urine. Both men and women can use pads if they are unable to get to the toilet or commode. It is best to avoid sanitary towels as they don't absorb as well as incontinence pads. Absorbent sheets can be put on the bottom bed sheet to soak up any leaks.
- Washable or disposable bed pads, urinals and commodes will be available by discussing this with the community nursing team.
- It may be that a catheter will be advised by the community nurse to collect urine. The nurse would insert this and teach you how to manage it if this happens.
- In an emergency, if nothing is available, men can pass urine (pee) into a large empty jar. For women placing a large towel folded between the legs, that can go straight in the washing machine may be easier.
- In an emergency, if nothing is available, for stools (poo) kitchen roll or newspaper can be used. Dispose of the stool (poo) if possible, into the toilet, with the paper into a binbag. 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 do need 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.

## Shortness of breath and secretions

- 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.
- Using pillows to support the patient can improve breathing, for severe breathlessness and cough, the patient may be prescribed medication that could help
- Leaning forward can help with breathlessness as the lungs have more freedom to move
- Noisy breathing is caused by small secretions, often at the back of the throat. 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.

## 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 can 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.

## Remember to look after yourself

- Look after yourself and remember you are doing your best in difficult circumstances. It is better to be calm and reassuring, rather than trying to be the 'perfect nurse' and feeling exhausted. If there is more than one of you caring, take it in turns and try to get some rest and recharge yourself. Please remember that your local community services are there to support you.
- 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 can be a 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 999
- Telephone their GP Practice in hours or 111 out of hours (18:30 – 08:00 weekdays and 24/7 weekends and bank holidays).
- Contact your local community nursing service to inform them of the death

## 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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