

## Advice for carers and non-medical support for the dying person

*Written by Dr Lindsey Crockett, senior partner at the Peninsula Practice and the Ipswich and East Suffolk Clinical Commissioning Group's end of life care lead.*

**There are many simple practical things that can make a great difference to an unwell person:**

- **Looking after yourself** – Caring for an unwell patient who may die can be exhausting both physically and emotionally. Take time out to eat and rest. Talk to people if you are able to. Try to share the physical care with other people too when possible and remember it's ok to leave a person's side to have a break.
- **Positioning** - Sitting upright or leaning forward can help breathing (if patient is too drowsy sometimes lying on their side in the recovery position can be helpful)
- **Relaxation techniques** - Favourite music, telling stories, singing, prayers for some, recalling memories, showing photos, etc.
- **Cooling** - Keeping the face cool with a facecloth dipped in cold water wiped around the mouth, nose and forehead can soothe
- **Humidify room air**
- **Open windows/doors** – Allow fresh air to circulate
- **Hydration** - Offer drinks / sips of fluids / honey and lemon in warm water / suck cough drops / ice cubes to suck, – yoghurt, ice cream, jelly etc. may be helpful.
- **Food** – As the body shuts down food and water are not necessary to keep it going. When a person is dying, they lose their desire to eat or drink and finally their ability to swallow. This is difficult to accept because we associate food with health and feeding people as an act of

love. Drips and intravenous lines for fluid offers no benefit and can be harmful.

- **Dry lips** - Vaseline/plain lip salve can help keep lips moisturised.
- **Washing** – Sometimes it may be too disruptive for the person to have a full wash. Just washing their hands and feet can feel refreshing.
- **Severe weakness/ unable to get to the toilet:**
  - The Bladder and Bowel UK <https://www.bbuk.org.uk/> has helpful advice. incontinence pads to absorb urine (avoid sanitary towels as they don't absorb as well as incontinence pads) and absorbent sheets to put on the bottom sheet to soak up any leaks.
  - 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 bin bag 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.

## **What to expect as a person becomes more unwell and journeys through what may be the last days of their life:**

- During this time, it is likely that you and others close to you will experience frightening and painful feelings and emotions. Your mind might race with thoughts such as 'what if' thinking, and automatically come up with worst case scenarios. It might feel as if you are on an emotional rollercoaster that won't stop. It will stop.
- Take a deep breath.
- Here we will describe to you what to expect as a person becomes more unwell and journeys through what may be the last days of their life. It is to help reduce the fears and worry that you might have because our minds are very powerful when we feel completely helpless and groundless.

## **Changes to notice as a person becomes more unwell:**

The medicines that might be used to help treat the symptoms (these might include breathlessness, cough, anxiety, restlessness, confusion) will usually make a person more relaxed and more sleepy.

- Sometimes saliva or mucus builds up in the throat or chest and they cannot clear it. It makes a rattling noise which can sound very upsetting but it is important to know that the person is not in pain or distress and is very unlikely to be aware. Because the person is so sleepy and often unconscious, they cannot clear their throat and they do not know it is happening.
- As a person becomes less well, they become progressively more tired and will tend to sleep for longer periods of time. You may also notice that their sleep becomes deeper, and it becomes more difficult to wake them. They will enter periods of deep unconsciousness. Sometimes breathing patterns change and can sound very fast one minute, then

very laboured the next. This is not distressing for the patient but can cause worry to those around them but it is normal as the body slowly closes down,

- Even if a person can't respond they can still hear. You can tell them they are loved, by you and by others. You may cry and feel heartbroken, or withdraw into a numb quietness, there are lots of emotions and feeling these are part of the healing process that we need to happen in time. Don't let your emotions 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 and words. As they become less well and sleepier, they do not feel like eating or drinking so much. This can be difficult for families and carers to watch but it might be helpful to know that the person is not feeling thirsty, hungry or uncomfortable because of it. It is not necessary to encourage food or drink.
- As time goes on more and more time is spent in this deep sleep, or unconscious state. Towards the very end of life, a person will often simply be unconscious all the time. Their breathing pattern will change: sometimes deep and slow, sometimes shallow and faster. Eventually breathing will slow down, and then very gently stop.

### **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.
- Telephone the GP (111 if out of hours), hospice number or the district nurse team in your own time to inform them and arrange verification that death has happened.
- After verification you can contact the funeral director who will arrange a visit to take the person to the mortuary.

**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.