

End of Life Care Information for Nursing Homes (This is for a Registered Nurse):

What to expect in the last few days of life.

This guidance relates to patients who have been identified as dying by a GP or registered Health Care Professional and all treatment is aimed at comfort. If a patient is deteriorating and there is no plan in place for their treatment contact your GP or 111.

This information describes some of the things that are likely to happen when someone is dying or close to death. Everyone is an individual and can experience things differently; hence the dying process is unique to every single person. Care should be individualised for that person. You should ensure that the patient's GP is consulted and updated about the person's condition; in particular if a GP has not reviewed the patient recently. The GP will decide about which medications are to be prescribed. **NB: This guidance does not provide information about specific medication. This can be found on separate BNSSG guidance.**

Please do remember that you can phone the advice line of your local Hospice on the numbers below if you would like advice:

St Peter's Hospice - 0117 9159430

Weston Hospice - 01934 423900

Discussion about Care Plans:

Conversations about preferences and priorities, including Advance Decisions to refuse treatment, are part of advance care planning for anybody who has a progressive life-limiting illness. Advance care planning is a voluntary process, no one should be forced to discuss this, good practice is to provide the opportunity for someone to express and document their preferences about how they wish to be cared for as their illness progresses. Advance care planning usually includes preferred place of care, goals of care and treatment escalation planning - so that a personalised care plan can be documented and revised as the situation changes. Families and carers should be involved in these discussions as far as possible and in line with the person's wishes.

Deterioration maybe anticipated, or happen very quickly, families may find news of change difficult however being kept informed helps to reduce anxiety, even in highly uncertain situations and even if the conversations need to be conducted behind PPE or, by telephone or video consult.

In Bristol, North Somerset and South Gloucestershire these plans are usually documented on a ResPECT form (Recommended Summary Plan for Emergency Care and Treatment). Ideally a GP will complete a form electronically and print off a paper ReSPECT form for the Nursing Home. The GP can then share the plan through our Electronic Palliative Care Coordination system and it can be viewed in a system called Connecting Care by out of hours doctors, hospitals, hospices and ambulance services. For further information regarding ReSPECT form: <https://remedy.bnssgccg.nhs.uk/adults/end-of-life-care-and-hospice/respect/>

(Adapted from: COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care. Role of the specialty and guidance to aid care. NHS Northern Care Alliance NHS Group. Association of Palliative Medicine of Great Britain & Ireland. V3. 6/4/20).

Coping with Dying

Each person is unique but in most cases we notice some characteristic changes that help us to know that a person is dying. These fall into four main categories:

- 1) Less need for food and drink
- 2) Withdrawal from the world
- 3) Changes in breathing
- 4) Changes that happen just before death

1. Less need for food and drink

When someone is dying, their body no longer has the same need for food and drink as before. Their body slows down and cannot digest food so well or take up its goodness. The patient may want to eat or drink but try not to worry if they do not want very much.

Some people may not want to eat or drink at all in the last days of life and swallowing may become difficult as they become more unwell. Although their mouth may look dry, this is not necessarily a sign that they are dehydrated. Gently moistening their mouth with a damp sponge and applying lip salve can give comfort.

2. Withdrawal from the world

For most, this usually happens gradually. The person spends more and more time asleep. When they are awake they are often drowsy and less able to show interest in what is going on around them. This is a natural change, not usually caused by medication. This period often lasts several days but for some it can be longer or shorter. We are aware that people who are dying from COVID-19 might die fairly quickly; hence this period can be short days.

It is important to remember that, even when the person is or appears to be sleeping or resting, they may still be able to hear you. Do not feel that you need to stop communicating with the person.

The patient may find it comforting for someone to read to them or play some of their favourite music. Or they may prefer someone to sit quietly with them. Try to do whatever you think would give the person the most comfort. We encourage you to keep talking to them as they may well be able to hear you, even if they cannot respond.

3. Changes in breathing

A change in the breathing pattern is a normal part of the dying process. When someone is dying, the body becomes less active and their need for oxygen reduces. The knowledge that someone is close at hand can be a real help in preventing breathlessness caused by anxiety. So, just sitting quietly and holding the person's hand can make a difference. Medication can also be used to help relieve these feelings of breathlessness. Please discuss this with the person's GP.

Things that might help if someone is breathless:

- Opening a window or door can help keep the room cool.
- Cooling the face by using a cool flannel or cloth can help.
- Portable fans are not recommended for use during outbreaks of infection

Occasionally in the last hours of life, breathing can become noisy. This is caused by secretions in the throat and upper chest, which may build up as someone becomes sleepier and less able to clear them. It may be helpful to change the person's position so that they are on their side if they agree or do not seem too disturbed by being moved.

The GP may also suggest medication which may help to reduce the fluids in their chest or throat. This is not always needed, and it does not always make a difference. The noisy breathing can sound alarming but this doesn't usually distress the dying person.

In the very last moments of life, the person's breathing pattern may change. Breaths may become much slower and quieter before they stop altogether.

4. Changes that happen just before death

When death is very close (within minutes or hours), the patient's breathing pattern may change. It can become rapid, shallow or with long pauses between breaths.

The patient's skin may become pale, and moist and slightly cool.

Most people do not wake from sleep in the final moments of life but die peacefully and comfortably. Breathing will usually gradually slow and then stop altogether. This may take a long time in some people and it can be difficult to pinpoint the exact moment of death.

Symptoms that might occur:

Please liaise with the patient's GP regarding 'Just in Case' (sometimes called 'as required') medications. The aim of these medications is to relieve symptoms and not change the natural course of the dying process. They are supplied in a variety of forms, for example: injections, under the tongue (sublingual) or between the gum and cheek (buccal). If medication has not been prescribed for a symptom please liaise with the patient's GP. If a medication is prescribed, the symptom is causing distress and you have assessed as a Registered Nurse that medication is required please administer following the prescribed instructions.

1. Pain:

- People may experience pain due to existing illnesses and may also develop pain as a result of excessive coughing or immobility. At the end of life they may grimace or groan to show this
- Not being able to pass urine can cause pain
- Check their position in the bed to see if this might help

2. Agitation/Distress:

- Some people may become agitated and confused towards the end of life. They may seem confused at times and then seem their normal selves at other times.
- People who become delirious may start behaving in ways that are unusual for them- they may become more agitated than normal or feel more sleepy and withdrawn.
- Pain may worsen agitation
- Not being able to pass urine may also worsen agitation

3. Nausea & Vomiting:

- Sometimes people may feel nauseated or sick when they are dying
- If they are vomiting and unable to sit up, turn the person on their side to protect their airway.

Symptoms related to suspected or confirmed COVID-19

1. Fever:

Fever is when a human's body temperature goes above the normal range of 36-37° Centigrade.

Signs and symptoms of a fever:

- shivering
- shaking
- chills
- aching muscles + joints
- other body aches
- may feel cold despite body temperature rising

Things that might help:

- Try a cool flannel applied across the face
- Reduce room temperature - open a window or door
- Wear loose clothing
- Oral fluids if able to drink

2. Cough:

Cough is a protective reflex response to airway irritation.

To minimise the risk of cross-transmission:

- Cough Hygiene: cover the nose and mouth with a disposable tissue when sneezing, coughing, wiping & blowing the nose
- dispose of used tissues promptly into clinical waste bin used for infectious or contaminated waste

Things that might help:

- humidify room air
- oral fluids
- honey & lemon in warm water
- elevate the head when sleeping

This symptom information has been adapted from:

- 1) NICE. COVID-19 rapid guideline: Managing symptoms (including at the end of life) in the community. NG163. Published 3/4/20
- 2) COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care. Role of the specialty and guidance to aid care. NHS Northern Care Alliance NHS Group. Association of Palliative Medicine of Great Britain & Ireland. V3. 6/4/20

What happens after the person has died

You will need to phone the patient's GP surgery to inform them of the death. Out of hours please contact 111/Sirona SPA.

During the COVID-19 pandemic there have been some changes to the legislation regarding Verification of Death. Please liaise with Sirona SPA 24/7 03001256789 if you would like advice/support.

Staff should continue to follow infection prevention and control measures. This is due to the ongoing risk of infectious transmission. Please refer to the local BNSSG guidance.

Please find further guidance from Public Health England about the care of the deceased with suspected or confirmed coronavirus (COVID-19) here:

<https://www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased/guidance-for-care-of-the-deceased-with-suspected-or-confirmed-coronavirus-covid-19>