



Information for  
patients and  
carers

When someone is dying

## What to expect when someone is dying

If you have been given this leaflet, it is likely that the team caring for your loved one believe that they are coming to the end of their life and may only have a few days, or even hours, to live. The decision that a patient is dying will involve a senior clinician and the multi-professional team. This will be based on the underlying diagnoses, medical history and evidence of clinical deterioration despite medical treatment. If you do not understand why this is happening, please ask to speak to a member of the clinical team looking after your loved one so that they can discuss this with you.

## Change in focus of care and treatment

As it is thought that your loved one is likely to die within the next hours or days, we will plan care and treatment accordingly. The care plan will be discussed with the patient, if possible, and those important to them, to ensure that you all understand how this is being developed.

Your loved one's wishes and those of you and your family are very important to us and we would like to make sure that we keep your loved one as comfortable as possible in the last hours / days of their life, so please make your views and wishes known to the team caring for them.

Often it is helpful to have a single nominated person who is important to the patient with whom to discuss these matters. The information should then be circulated to other family or friends who are involved in the patient's care. You may want to set up a group message or email to relay this information.

## Individualised care plan

In the last days of their life your loved one will have an individualised care plan. As part of this, the interventions and care they receive will be

reviewed. We will ask what is important to you and your loved one so that we are able to deliver the best possible care without causing unnecessary distress.

We will ask you if your loved one has any Advance Care Planning documents or a Lasting Power of Attorney. We will also ask about any religious, emotional, social, spiritual and cultural needs. This will enable us to deliver holistic care that is focused around your loved one.

You might notice that the nursing staff caring for your loved one may no longer be checking blood pressures and recording observations such as temperature and pulse rate so as not to disturb your loved one unnecessarily, and focus instead on making sure that they are kept as comfortable as possible.

This plan of care will be reviewed daily to ensure that we are meeting the needs of your loved one and that they are receiving the most appropriate care.

## Preferred place of care

Even though it is thought that your loved one is dying, there is often a choice of where your loved one can be cared for:

- Hospital – we will continue to provide the best possible care to your loved one here in the hospital
- Home – there is the option of discharge home to die with community support. We will discuss what level of support will be available in your area as this may vary. We can also refer to the Community Palliative Care Team for additional support if required
- Nursing home – if your loved one has previously lived in a nursing or care home, this option could be explored if you would like them to return there. Where a patient does not normally live in a nursing home, this can be explored but can take some time to put in place

- Hospice – referral to a hospice can be made. The choice of hospice is often dependent on the location of the person’s GP and there is usually a waiting list for admissions

Where the preferred place of care is not hospital, we need to ensure that your loved one is safe and well enough to travel.

## Symptoms in last days to hours of life

While many people have no distressing symptoms in the final days of their life, others may experience pain, breathlessness, agitation or restlessness, nausea and respiratory tract (chest) secretions.

If your loved one develops any of these symptoms, they will be assessed to establish the cause. Often there are a variety of ways in which symptoms can be managed without medications.

For ways in which you can help support your loved one, please see the section on ‘Changes in the last hours to days of life’.

Sometimes other interventions are required and your loved one may be prescribed injectable medications prescribed to help manage the symptom which the nurses can give if needed.

Occasionally, some symptoms can be difficult to manage and may require multiple doses of medications. In this instance, a syringe driver (pump) may be required to give those medicines throughout the day. This will be discussed with you before a syringe driver is introduced. We will use medications at doses that are required to control symptoms effectively, while aiming to reducing the possibility of side effects (eg. drowsiness) developing as far as possible.

If your loved one starts to experience any of these symptoms, we will do everything we can to improve things for them. There are different ways in which symptoms can be managed without the use of medication.

Please let the ward staff know if your loved one is suffering from any symptoms.

## Changes in the last hours to days of life

### **Reduced appetite or desire to drink**

As a person is nearing death, we often find that they do not eat and drink as normal. This may be because they have little or no desire for food and drink, or that they find eating and drinking too tiring. Eventually they may stop eating and drinking completely, and become unable to take tablets. This is very normal when a person is in the final days of their life.

Their doctor or nurse can look at whether extra nutrition or fluids are needed, and talk to family and friends about this.

### ***How can I help?***

If your loved one is conscious, offer food or drinks as wanted, do not attempt force and ensure they are able to swallow what is being given. Often, it is easier to have food and drink given on a teaspoon as it takes less effort to swallow. If you have any concerns around the risks of eating and drinking, or if this causes coughing or discomfort, please speak to a member of the medical or nursing team.

### **Mouth care**

The mouth may appear dry which can be due to a number of different reasons, and may in some people, cause discomfort.

### ***How can I help?***

Mouth care is important – you may want to give mouth care using special sponges soaked in water or drinks that the person enjoys. Mouth care gels are also available; they provide a moist coating to the

whole mouth and can also be used on the lips. Small pieces of ice can also be used to rehydrate the mouth.

## **Changes in breathing pattern**

When dying, it is common to see a change in breathing pattern. Often we find that the breathing rate slows down and becomes shallower before it stops all together. There may also be pauses in the breathing that last for several seconds. Your loved one will not be aware of this or be distressed by it.

Sometimes the breathing rate can also increase; this is often a normal part of the dying process, but if you are concerned that your loved one is distressed then please let the staff on the ward know.

Difficulty breathing or feeling breathless can make someone feel anxious. Not everyone who is dying will be aware of this.

## ***How can I help?***

Breathing difficulties can be made worse by feelings of anxiety. Sitting with your loved one and offering reassurance in a calm and quiet environment can be very helpful. Distracting them with memories from the past often helps them focus on something else and slows the breathing back to normal. Opening windows or using a fan across their body (rather than directly at them) is also very helpful. Please check with the ward staff about this, as this may not be possible at times due to COVID related restrictions.

The doctor or nurse may give medicine for breathlessness.

If your loved one is breathing mainly through their mouth, it is important to continue giving good mouth care and use lip balm as needed.

## Noisy Breathing

Sometimes breathing can be noisier than normal. This is caused by a build-up in saliva or fluid in the chest or throat that your loved one is not able to swallow or naturally absorb. This can be distressing to hear, but the dying person is usually not aware of it.

### *How can I help?*

Mouth care can help to remove secretions from the mouth. If there continues to be noisy breathing, please ask a member of staff to help – they can reposition your loved one onto their side which often helps if they are not distressed by moving. Injectable medication can also be given to help prevent new fluids (secretions) forming or slow down the rate of the breathing if this is distressing to your loved one. This will be given by a nurse. It is not always needed and is not always effective.

## The Mind and Emotions

Our thoughts and feelings are completely individual, and so are the mental and emotional experiences of people nearing the end of life. Changes in the body can also affect the brain, our behaviour and how we understand the world around us.

Common changes people experience include:

- Appearing calm or detached – interacting less with people around them
- Being confused – finding it difficult to concentrate and becoming disoriented
- Feeling restless or agitated – finding it difficult to feel comfortable and relaxed
- Being delirious – saying things that do not make sense to others, or seeing or hearing things that are not there. They may talk about relatives who have died being present – please do not be alarmed by this and provide reassurance.

These things can be difficult for friends and family members to see. Different things can cause these experiences, including medicines, pain, bladder or bowel problems, emotional distress, or other physical or psychological changes. It is sometimes a combination of factors.

You may find that your loved one is spending longer periods asleep than they are awake. They may also appear drowsy for the time that they are awake. This is very common in someone who is dying.

You may find that your loved one is less interested in what is going on around them; they may not have the energy to engage in conversation and may become unconscious. It is thought they are still able to hear you. Do not feel you have to stop talking to your loved one - this can often be very comforting to them.

### ***How can I help?***

Having someone offer reassurance, hold the person's hand and be close by may help. Being in a calm and quiet environment can also help. Some patients may seem to be more settled if they are not disturbed. Please speak to the nursing staff if you think that this is happening so that we can better support them and you in this.

The doctor or nurse may suggest using medicines to help treat underlying causes. They may give medicines to help the person feel calm and relaxed.

### **Changes to skin colour and temperature**

As a person is approaching death, you may find that they appear paler and that their hands and feet are cool or cold to touch. Sometimes skin can become mottled or appear blue. This is due to reduced circulation. There may also be instances where the hands and feet become swollen.



The nurses will want to change your loved one's position in bed to help relieve pressure to the skin and help prevent pressure damage. This will be discussed with you and their skin will be assessed on a daily basis.

### ***How can I help?***

Your loved one is unlikely to be distressed or aware of these changes, although they may be concerning to you. Holding hands or applying gloves and socks may be comforting to you. Gentle massage may also help if the hands and feet become swollen.

### **A person's final moments**

In the last few minutes the person's face muscles may relax and they may become very pale. Their mouth may open and their eyes may become less clear. Often, the person's body will completely relax. They may take slow, gasping breaths and then breathing will eventually stop – they will not be distressed or aware of this but it can be distressing to see.

Sometimes it can be difficult to identify the exact moment when the person died. There may be one or two last gasps a minute or so after what seemed like the last breath. This is always an emotional moment, even when death has been expected. You may suddenly feel overwhelmed with sadness; you may want to be alone, or you may want to ring family and friends. Often the emotion surrounding the final moments of death can take you by surprise. Please let us know what you need or prefer to happen at this time.

### **Keepsakes**

When your loved one dies, you will be offered the opportunity to collect keepsakes in their memory. It may be possible to gather a lock of your loved one's hair, or finger or thumbprint. Wards will be able to arrange

this for you, and the Bereavement and Donation Team can collect the keepsakes at the mortuary, so you do not have to make a decision straight away.

## Support offered by the ward and other teams

Please speak to the nurse in charge should you have any questions or concerns about your loved one. They will be able to answer your questions or redirect your questions or concerns to the appropriate person.

The Specialist Palliative Care Team are available 7 days a week and help support ward teams in caring for patients at the end of their life. Should you and your loved one feel you would like this, please speak to the ward doctors or nurse in charge who can explore this with you and make the appropriate referral.

The Hospital Bereavement and Donation Team are able to offer support both before and after your loved one has died. They can:

- Help you to understand the practical steps that are taken after death
- Help you to discuss the persons wishes for after death
- Discuss tissue and organ donation and support you as a family with your decision
- Offer you options for ongoing support, obtain keepsakes for you such as locks of hair/thumbprints
- Offer you the opportunity to assist in the care of your loved one before their care is taken over by the mortuary

The Hospital Bereavement and Donation Team are available from 9.00am to 5.00pm every day. If you would like to speak to them, please ask one of the ward nurses to contact them to arrange a visit.

The Chaplaincy Team are able to offer emotional, spiritual and religious support to patients and their loved ones at the end of life. Please ask

the nurse in charge if you would like a chaplaincy visit. If this is for religious support, please let us know your religion so that we are able to ask for the appropriate person to visit you.

## **Practical advice**

- Visiting times – when someone is thought to be in last days of life, there is open visiting. We would recommend a small number of visitors at a time to ensure your loved one is able to rest. Visiting times may be subject to change and we would recommend you check with the nurse in charge prior to your journey into the hospital
- Car Parking – please ask the nurse in charge for an arrangement of free car parking
- Fold away beds – we have a supply of fold away beds should you want to stay overnight with your loved one. Again, we would recommend a minimum number of visitors staying overnight to ensure your loved one is able to rest, and that you are also able to rest
- Refreshments – the ward team will be happy to offer you hot and cold drinks and snacks while you are visiting. Please do not hesitate to ask for them if needed. Vending machines are available throughout the hospital
  
- Food outlets – RPH
  - Charters restaurant – Burgundy Street, hot and cold foods and drinks. Open 8am – 2pm Monday to Friday; closed at weekends
  - Preston's Cafe – Main Entrance - hot and cold foods and drinks – Costa coffee. Open 7:30am – 7pm Monday to Friday; 8am – 7pm weekends
  - M&S shop – Main Entrance – Cold food and drinks, snacks and a small supply of toiletries, books, magazines etc. Open 7am – 9pm Monday – Friday; 9am – 7pm weekends

- Food outlets – CDH
  - RVS shop – Main Entrance – limited hot food menu, breakfast sandwiches, hot and cold drinks, sandwiches, snacks and a small supply of toiletries, books, magazines etc. Open 8am – 4pm Monday to Friday
  - The Courtyard Cafe – level 2 near X-ray department – sandwiches and limited toasted sandwiches – Costa coffee. Open 8am – 4pm Monday to Friday; 8am – 1pm weekends

\* ALL opening times subject to change.

## References

1. Marie Curie. (2019). What to expect at the end of someone's life. Liverpool: Marie Curie.
2. Marie Curie Palliative Care institute. (2013). An explanation of the plan of care in the last hours or days of life. Liverpool: Marie Curie Palliative Care institute.

## Contact details

Should you require further advice or information please contact Palliative Care Team, 01772 52 2055

## Sources of further information

[www.lancsteachinghospitals.nhs.uk](http://www.lancsteachinghospitals.nhs.uk)  
[www.nhs.uk](http://www.nhs.uk)  
[www.patient.co.uk](http://www.patient.co.uk)  
[www.accessable.co.uk](http://www.accessable.co.uk)  
[www.mariecurie.org.uk/help/support](http://www.mariecurie.org.uk/help/support)

All our patient information leaflets are available on our website for patients to access and download:

[www.lancsteachinghospitals.nhs.uk/patient-information-leaflets](http://www.lancsteachinghospitals.nhs.uk/patient-information-leaflets)

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If you want to stop smoking you can also contact the Quit Squad Freephone 0800 328 6297.

Please ask if you would like help in understanding this information. This information can be made available in large print and in other languages.

**Cantonese:**

如果你希望以另外一種格式接收該資訊，請和我們聯絡，不必猶豫。

**Gujarati:**

જો તમને આ માહિતી બીજી રચના કે ફોર્મેટમાં મેળવવાની ઇચ્છા હોય, તો કૃપા કરી અમારો સંપર્ક કરતા અચકાશો નહિ.

**Hungarian:**

Kérjük, vegye fel velünk a kapcsolatot, ha más formában kéri ezt az információt.

**Polish:**

Jeżeli chciał(a)by Pan/Pani otrzymać niniejsze informacje w innym formacie, prosimy o kontakt.

**Punjabi:**

ਜੇ ਤੁਸੀਂ ਕਿਸੇ ਹੋਰ ਫਾਰਮੈਟ ਵਿਚ ਇਹ ਜਾਣਕਾਰੀ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਸਾਡੇ ਨਾਲ ਸੰਪਰਕ ਕਰਨ ਤੋਂ ਨਾ ਝਿਜਕੋ।

**Urdu:**

اگر آپ اس معلومات کو کسی اور صورت میں حاصل کرنا چاہتے ہیں تو برائے مہربانی ہم سے رابطہ کرنے میں ہچکچاہٹ محسوس نہ کریں۔

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