

# Care and support in the last few days of life

## A guide for carers and relatives

Our intention is to deliver care and support that is sensitive to the cultural and religious needs and personal preferences of the dying person and their family.

## Important Contact Numbers

### Contacting your nurse:

0300 300 7777

### Specialist Palliative Care Nurses:

0300 300 7777

### Your GP:

### Out of hours GP:

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## Introduction

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This leaflet provides information and support for relatives and carers when a loved one is dying and is thought to be in the last few days of life. People are all different; not all of the things that are discussed happen to everybody or in the same order.

Some of this information may be new to you and if you have any questions or want to discuss anything contained in this leaflet, please speak with the attending nursing staff or your GP.

## Recognising someone is dying

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It is important to understand that for many people, dying is very peaceful. However it can be upsetting for family members who watch their relative go through these changes. This is a part of the natural dying process and does not necessarily mean that your loved one is in any discomfort or distress.

Although exactly what happens when somebody is dying is unique to each person, there are certain changes which we commonly see before someone dies. These changes can help us understand that somebody is likely to be in the last few days of their life.

Knowing what to expect may help to relieve anxiety and allow for better planning.

## Resuscitation

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When someone dies, their heart and breathing stops. For most patients who are recognised to be dying, trying to restart their heart or breathing (resuscitation) at this time will not work.

Everything will be done to ensure that the person receives appropriate treatments to help make them comfortable.

Please speak to your GP if you want to discuss this in more detail.

## Eating and drinking

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If your loved one is able and would like to eat and drink, the nursing team will support you with advice about how and what to give (i.e. soft food and liquids).

When a person is no longer able to swallow any food or fluids. On occasions a family member may want their loved one to have a drip/subcutaneous fluid, but at the end of life this offers little, if any benefit. The body cannot process fluid like a healthy body it can be harmful to artificially feed and hydrate. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems.

## **Stopping observations and medication**

All medications and treatments will be reviewed. Medication your loved one has been taking for many years may be stopped as these are no longer helping them. You may also notice that routine medical observations such as blood pressure are no longer done as these will not benefit your loved one and in fact may cause distress. An individualised plan of care for the person who is dying will ensure the best quality of care is provided with a focus on achieving your dying loved one's comfort and dignity.

## **Preferred place of care in the last days of life**

Some people have a clear idea about where they wish to spend their last days and may have already made their wishes known to you.

The earlier we know about any wishes, the sooner we can try to meet these, so please talk to your GP or the attending nursing staff. For other people, who they are with is more important than where they are when they die.

In some situations, where symptoms are difficult to control, the nursing team looking after you or your loved one may seek advice from the specialist palliative care nurses and LOROS the local hospice.

The views of the patient and their carers are very important, and will always be taken into account when reaching a decision. You may want to take a moment to discuss with your dying loved one what is important to them and to you/ and your family.

# What is important to me and my family/any questions or concerns/useful phone numbers

(a space for you to make notes)

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## Useful websites:

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Dying Matters:	<a href="http://www.dyingmatters.org/">www.dyingmatters.org/</a>
NHS End of Life Care:	<a href="http://www.england.nhs.uk/eolc/">www.england.nhs.uk/eolc/</a>
Loros:	<a href="http://www.loros.co.uk/">www.loros.co.uk/</a>
Marie Curie:	<a href="http://www.mariecurie.org.uk/help/support/">www.mariecurie.org.uk/help/support/</a>
Public Health England:	<a href="http://www.endoflifecare-intelligence.org.uk/">www.endoflifecare-intelligence.org.uk/</a>
Age UK	<a href="http://www.ageuk.org.uk/information-advice/">www.ageuk.org.uk/information-advice/</a>

## Religious, spiritual, emotional and cultural care

Many people might benefit from hearing familiar poems or words of comfort, or seeing images that bring feelings of peace and comfort. They may also value having someone from their own religious or belief community to sit and listen to them. A religious person may also find comfort in religious or cultural rites and rituals. The chaplains come from various religions and beliefs and include our non-religious chaplain. They offer non-judgemental listening support and are available to provide support to you and your family. Often family and friends are a great support but sometimes it helps to talk to someone else.

## End of life medication and syringe driver

It is common for people to become unable to take tablets and medicines by mouth. Many of the medicines used during the last days of life can be given by an injection. Your GP may arrange for the nursing team to have access to new medication quickly to ensure your loved one is comfortable and pain free.

There are a number of end of life medications that can be prescribed by your GP to relieve symptoms, the more common ones are:

**Morphine** – for pain relief and breathlessness

**Midazolam** – for agitation and restlessness

**Levomepromazine** – for nausea and vomiting

**Glycopyrronium** – for secretions in the chest

Depending on what your loved one needs, this may be a single injection or they may have medicines given continuously. When medicines are needed continuously, this is usually given via an infusion under the skin ('subcutaneously') that runs continuously. This is often known as giving medicines via a 'syringe driver' or a 'pump.' The use of needles is kept to a minimum.

## Symptoms and care

The following symptoms may or may not happen with your loved one, however it is important to remember that they are part of the natural dying process.

Common symptoms	Can I do anything to help?
<b>Pain</b> – your loved one may not experience any pain and even if they have difficulty communicating, the nursing staff will know if they are in discomfort.	In most cases this can be well controlled by the medication prescribed by the nurses and your GP.
<b>Reduced appetite</b> - your loved one may be struggling to swallow and may not want to eat or drink.	Offer drinks and fluids through a straw or a teaspoon or a syringe. You can moisten their lips with a damp sponge or place small ice chips in their mouth.
<b>Sleepy and lethargic</b> – your loved one may drift in and out of consciousness or spend more time sleeping because they lack energy and interest in what is going on around them.	Its important to remember that even though your loved one is unconscious or sleeping, they may still be able to hear you. You may want to continue speaking to them quietly and calmly, read to them, play some memorable or soothing music or just hold their hand.
<b>Changes in skin colour and feel</b> – your loved ones hands, feet and other extremities may feel cold to the touch or change colour and become mottled or patchy.	This is due to reduced circulation and it may be comforting to put on gloves or socks to make them more comfortable. You may also find that gently massaging their hands and feet may comfort them.

## Common symptoms

## Can I do anything to help?

**Agitation and restlessness** – your loved one may become confused and not recognise familiar faces, they may experience hallucinations and hear or see things and people that are not actually there.

Keep surroundings calm with minimal change, continue to reassure and speak calmly and clearly to them. Try not to correct them or tell them they are getting things wrong as this may upset them further and lead to increased agitation.

**Loss of control of bladder and bowel movements** – this is due to the muscles in that area relaxing and shutting down.

Your loved one may feel upset and embarrassed. It is important to keep them clean and comfortable.

**Changes in breathing** – during the final stages, your loved one needs less oxygen, their breathing may become shallower. Their breath may become noisy (this is often referred to as the 'death rattle') and is due to a build up of mucus in the chest which cannot be cleared through coughing.

If your loved one is conscious, they may be unable to clear their chest and feel anxious. It is important to keep them calm and you could open a window or use a small fan to circulate the air more. If your loved one is unconscious and lying down, it may help to change their position using a slide sheet and supporting pillows.

Your nursing team are there to help and support you and can advise on any of the symptoms and explain and/or demonstrate how you can help your loved one.

## Your nursing team

If there is an unexpected change in the condition of the patient or they are in pain or severe discomfort, please contact us on 0300 300 7777 (8am - 10pm). The nearest nurse may be some distance away treating others and is unlikely to be able to visit immediately – it can take up to two hours for the nurse to arrive and can be longer at night. If you feel the patient cannot wait and/or it is between 10pm and 8am phone NHS111.

## Your loved one's final moments

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Sometimes it can be difficult to recognise the exact moment your loved one dies. Their face muscles may relax and their jaw drop. Their breathing will eventually stop and often their body will relax completely.

You may feel overwhelmed with sadness and may want to be alone and take some time to process what has happened.

You may have a particular ritual or ceremony that is important to you, your family and the loved one who has died.

## What to do when your loved one has died

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Please speak to your GP/specialist nurse who will talk you through what you need to do next. A doctor/specialist nurse will need to visit and confirm that your loved one has died.

You will need to contact an undertaker who will advise you on the next steps.

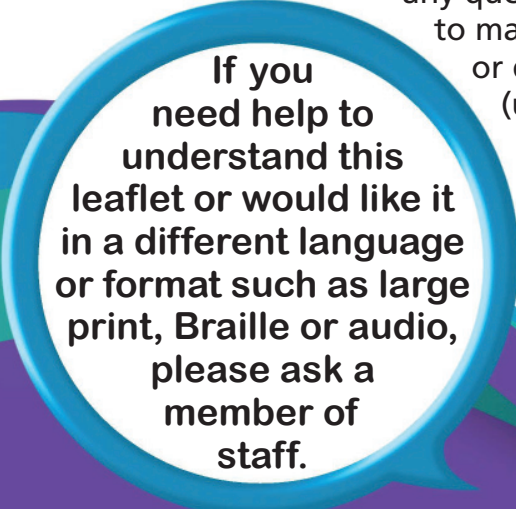
## Your worries and concerns

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Members of the nursing and specialist palliative care team are there to help you to work through your worries and concerns, and to offer you care and support. Please ask them if you have

any queries. You may find it useful to make a note of your concerns or questions as they arise

(using page 4) so that a member of the care team can go through them with you.



**If you need help to understand this leaflet or would like it in a different language or format such as large print, Braille or audio, please ask a member of staff.**

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