

What to expect in the last days and weeks of life:

When your loved one is
staying in hospital

Information for family, friends and carers



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We have written this booklet as a source of information for family, friends and carers who will be supporting a loved one in hospital during their last days and weeks.

It provides information on aspects of care of the dying person, including care needs, physical symptoms and the dying process. The booklet also outlines the importance of looking after yourself and signposts to some sources of support.

Each person's care, needs and symptoms are unique, so this booklet may not provide all the information you need. If you have questions or concerns, please ask the ward nurse or medical team.

Looking after yourself

Supporting someone in their last days of life can be a huge challenge, both emotionally and physically.

You might feel sad, tearful, angry or guilty. You might have a sense of grief for the loss of the future you had together.

You might feel frightened about what will happen and how you will cope. Remember, you are likely to be more of a support to your loved one than you realise, just by being there.

You do not have to do this on your own:

- The ward team is here to support you.
- We have a pre-bereavement support service and a spiritual care team who can also support if needed.
- You may want to ask other family members, friends, and carers what they are able to do to help. This might be making meals, helping with cleaning or running errands.
- The UHS carers support service can offer a range of support to you. You can contact them through the patient support hub on telephone **0800 484 0135** or by email at: carersupport@uhs.nhs.uk (opening hours: Monday to Friday, 10am to 4pm).

It is very important that you take the time to look after yourself. Eat regularly, rest, and talk to or meet friends or relatives.

If you are staying in hospital to provide care for somebody overnight, we may be able to arrange a temporary 'Z' bed for you. Ask a member of staff on the ward to request this for you from the patient support hub.

Parking

If you or the person you are caring for has a blue badge, you can park at our hospitals for free. Please have your badge number ready as you approach the exit gate, then press the call for assistance button on the ticket machine. You will be asked to provide your badge number to exit the carpark.

If the person you are caring for is dying and they or you do not have a blue badge, ask the clinical team about long-stay parking options. Seven-day, fourteen-day and thirty-day parking tickets are available from the Travelwise office.

Plan of care

With your loved one's consent, the medical or nursing team will offer you an opportunity to discuss the plan of care and answer any questions.

We may give you advice about what to expect in the coming days, the medications to control symptoms, and how to access support if you need it.

Please feel free to share as much of the physical care as you and your loved one want. Nursing staff will be happy to show you what you can do, or they will be happy to provide all the care so you can concentrate on just being there.

It can be difficult to take lots of information on board at a time like this, but we will do our best to explain things to you simply and clearly. If you have questions, or just want to talk things over with one of the nurses, doctors, pre-bereavement counsellors or spiritual care team, please let us know.

Your loved one may have been prescribed new medications to help manage their symptoms, including medications 'just in case' symptoms develop. These may be medications given by mouth, or injection, as needed, to manage pain, sickness, restlessness or respiratory secretions (bubbly breathing).

The medications given for pain and agitation will be given at the lowest effective dose for your loved one. These medications may cause drowsiness, but increasing drowsiness is also a normal part of the dying process.

Your loved one may already have an advance care plan which describes their wishes and treatment preferences. This can be helpful to guide families and healthcare professionals to deliver treatment and care in accordance with the patient's wishes if they are not able to communicate this.

Your loved one will have a treatment escalation plan to support decision-making around appropriate treatments as they are deteriorating.

If your loved one wishes for their care to be focused on comfort and for a natural death to be allowed, the medical team will complete a Do Not Resuscitate (DNACPR) form. The DNACPR form only relates to how they will be cared for if their heart or breathing stops. Decisions about other treatments, such as antibiotics, for example, are separate from this and will be considered on an individual basis.

Spending time with others

Your loved one may wish to spend some quality time with you and the other people who are important to them, to reflect, make memories, make plans or say important things. They may also wish to have some quiet time where they are not disturbed.

They may prefer to have short periods of conversation or short visits from you as they can become tired very easily.

You may notice that your loved one starts to gradually withdraw from the world.

Resting and sleeping

Feeling weak and tired is common. Energy levels reduce and more time is spent resting or sleeping.

In the final days, your loved one may spend most of the time asleep and they may lose consciousness, which may be for spells of time or may persist.

Sometimes your loved one may not respond to you either because they are tired and have no energy to respond, or because they are deeply asleep or unconscious.

Mobility and safety

Your loved one may find it more difficult to move around independently. They may be spending more time in bed and need help to get in and out of bed or move in the bed.

Your loved one may be at an increased risk of falling, due to loss of strength, slower reflexes, being in a less familiar environment and dizziness. We will assess their risk of falling and put a plan in place to reduce the risk as far as is possible.

Eating and drinking

It may be more comfortable for your loved one to eat little and often. They may need support to use cutlery or drinking cups.

As they become weaker, it may be easier for them to swallow softer or creamy texture foods.

It is safest if your loved one eats and drinks when they are alert and sitting up. If they are sleepy or lying down, it may be harder for them to swallow safely. This risks them possibly breathing in the food or drink (aspiration) or choking.

It may become difficult for them to swallow medications in tablet form. We will change these to liquids where possible, or stop the medication if it is not helping with comfort.

It is normal for appetite and thirst to reduce. In the final days your loved one may not eat or drink anything, either because they are too sleepy, or because they have lost their appetite or thirst. Usually this does not cause distress, but if you are concerned about discomfort due to hunger or thirst, please ask the nursing or medical team.

A dry mouth can usually be helped by sips of water and sucking on ice chips or lollies. Sometimes we can use moistened mouthcare swabs to help clean and moisten the soft parts of the mouth. If your loved one needs this, we will show you how to do this safely. We will provide saliva replacement gel or spray if needed.

Invasive treatments such as intravenous fluids or artificial nutrition do not usually help to manage symptoms during the dying process. The clinical team will regularly assess the benefits or harms of these treatments and advise on ongoing management.

Bladder and bowels

Due to weakness or fatigue, it may become difficult for your loved one to get to the toilet on time. They may need equipment to make it easier to pass urine or stool at the time of need (for example, a urine bottle, commode or bed pan).

It may become more difficult for them to control their bladder and bowels due to weakness or fatigue. They may wish to use incontinence pads or pants, or bed pads. They may wish to consider a urinary catheter which is a tube passed into the bladder connected to a bag to collect the urine (inserted by the nursing team). Sometimes a urinary catheter is needed to manage a full bladder if the person is unable to pass urine (urinary retention).

There may be constipation due to reduced mobility, reduced intake of food and drink, medications and loss of strength. We can manage this with laxative medications taken by mouth if your loved one is able to swallow these safely.

If the bowels have not moved for more than three days it may be necessary to have a suppository or enema (medication given via the back passage (anus)). It is important to keep the bowels working for comfort as constipation may cause pain, restlessness and urinary retention.

Skin and pressure area care

The skin can become dry or irritated. We can apply an alcohol-free lotion to relieve this.

The lips can become dry and cracked. A lip salve or petroleum jelly can help with this. However, if your loved one is on oxygen it is important that the lip treatment is water-based, not petroleum-based.

Sitting or lying in one position for a period of time can put pressure on the skin. This can lead to the development of pressure sores, which may cause discomfort or pain. We will help your loved one to move or turn in bed every few hours, to prevent pressure sores.

Pain

Not everyone who is dying will experience pain. Longstanding pain may remain the same, or it may change. If the usual pain is worsened by movement, this may improve with reduced activity levels. If a new pain develops or a longstanding pain worsens, we will assess and treat this.

If your loved one is in the last days of their life, they may not be able to tell us that they have pain.

We will assess for signs of pain such as:

- confusion
- furrowed brow
- grimacing
- guarding a painful area
- moaning
- fast breathing
- restlessness
- agitation

We use the Bolton Pain Assessment tool to support the recognition of pain when a patient is unable to report this themselves. If we suspect your loved one is in pain, we will offer treatment for this.

Usually, pain can be relieved with regular paracetamol. If this is not effective, we will prescribe a stronger pain-relief medication such as immediate release morphine or oxycodone where appropriate. These medications are started at a low dose which usually helps the pain without causing any ill-effects (for example, morphine at a dose of 2.5mg every four hours or oxycodone at a dose of 1.25mg every four hours as needed). If this pain-relief medication does not help, we will reassess.

If your loved one is in pain but unable to take pain-relief medication by mouth, we will assess the situation and offer to give pain-relief medication by injection.

Morphine and oxycodone can cause nausea (feeling sick) which usually settles after three to five days of use. This can be treated with anti-sickness tablets. Morphine and oxycodone can cause constipation which usually requires a mild daily laxative. If you are concerned about any new symptoms that started after your loved one began to take morphine or oxycodone, please tell the nursing or medical team.

Shortness of breath

If your loved one usually gets short of breath because of their medical condition, they may already know what helps their breathing. It can be useful to write this down so that this information can be used to support them if their breathing becomes difficult.

Simple measures that may help include:

- noticing the shortness of breath, being still, resting and allowing their shoulders to relax
- sitting upright or leaning forward resting, their hands or arms on a table
- having cool air from an open window or door
- having a fan blowing air across their face
- concentrating on having a good breath out before breathing in, trying to keep focusing on the 'out', rather than the 'in' breath
- focusing on distractions, such as looking at a picture that is calming or brings back nice memories, or TV, or music

If your loved one has new or worsening shortness of breath and this is causing discomfort, we will assess them and offer treatments to support their comfort, such as inhalers, a nebuliser or oxygen.

We may give your loved one other medications to reduce the feeling of breathlessness, such as morphine at a dose of 1.25 to 2.5mg or oxycodone at a dose of 1 to 2mg, every two to four hours as required. If they are anxious, we may offer them lorazepam tablets. We would usually place half a tablet under the tongue (two to three times a day as needed, usually with at least four hours between doses).

If your loved one is unable to swallow, we may offer them morphine or oxycodone by injection to reduce the feeling of breathlessness. Alternatively, we may offer injections of midazolam or levomepromazine to help with any anxiety caused by the breathlessness.

Nausea (feeling sick) and vomiting (being sick)

If your loved one develops nausea and/or vomiting we will assess and treat the underlying cause if appropriate. We will also offer anti-sickness medication which can be given by mouth or injection depending on the situation and their preference.

We may give your loved one any of the following anti-sickness medications:

- metoclopramide
- cyclizine
- haloperidol
- levomepromazine
- prochlorperazine
- ondansetron

Confusion

If your loved one has been getting weaker and is showing signs that they are in their last days of life, confusion or restlessness may be part of the dying process. We will make sure that this is not being triggered by pain, a full bladder or a full bowel.

If the person is feeling restless or agitated, you can support with simple measures such as:

- reassuring them
- letting them know the time of day, where they are and who they are with (orientation)
- creating a calm environment
- distracting them, such as looking at pictures or photos, reminiscing or playing soft music

Sometimes we give medication to help the restless or agitated person to relax. We may recommend a tablet such as lorazepam, or a tablet or injection of haloperidol or levomepromazine.

Syringe drivers

A syringe driver is a pump used to give medication continuously to manage symptoms. The medication is delivered through a small tube placed under the skin.

Most people die comfortably without the need for a syringe driver. We would use a syringe driver if the patient cannot take the medications they need to control their symptoms by mouth. This might be because of swallowing difficulties or sickness, or because medications are no longer being absorbed by the digestive system.

A syringe driver can deliver medications to control pain, nausea and vomiting, restlessness and agitation, seizures and respiratory secretions (bubbly breathing).

It will take approximately four hours for any medications to have an effect when they are given by a syringe driver. If your loved one is experiencing a difficult symptom when the syringe driver is being set up, they may need an extra injection of medication first.

The syringe driver is put in place only to manage symptoms and promote comfort. This is not aimed at altering the time course of the natural dying process. If you have any concerns about the use of a syringe driver, please ask a healthcare professional.

If your loved one experiences uncontrolled symptoms while the syringe driver is in place, they may need an extra injection of medication. If they need one or two extra injections, this does not mean that the syringe driver is not working. We will re-assess the symptoms and medications in the syringe driver on a daily basis.

When the syringe driver runs out it will sound an alarm. We aim to replenish the syringe within an hour or two of it running out to prevent the symptoms returning.

There will be a small pool of the medications under the skin, so when the pump runs out, your loved one will continue to absorb the medications already there for an hour or so. Please tell a member of staff if you notice the alarm sounding. The syringe driver may also sound an alarm if the tubing is kinked or blocked, or if the infusion site needs changing.

The last days of life: psychological and emotional needs

Talking about dying

You and your loved one may have already talked about them dying and can continue to do so openly.

However, it is also normal for talking about dying to feel difficult. You may not always know what to say, and this is normal and OK. Sometimes just knowing you are listening to each other is a great comfort and support.

Having these conversations may be sad, painful and upsetting, and expressing this through crying is a very normal reaction that can release a lot of feelings or emotions.

It may be difficult to know how to open a conversation about dying with your loved one. It could start with a question such as:

- I wonder if there is anything you would like to talk about?
- I'm really happy/comfortable for us to talk about anything you'd like to.
- I'm wondering if there is anything playing on your mind?
- Thinking about the coming days and weeks, is there anything important to you about that time or how you are cared for?
- Thinking about the coming days, what matters most to you?
- Is there anything that you would like me to know about your wishes, if you were to become more unwell and be unable to tell me at that time?

Creating opportunities to share their feelings and worries, and yours, can help everyone involved to understand each other better. It may be easier to understand what is and is not important to your loved one, and to identify and address any concerns or fears. It may also allow time to get professional support, if needed.

Your loved one may need encouragement or a sense of permission from you to talk openly as they may be worried about upsetting you. If you can, be inquisitive and ask about your loved one's feelings or worries. If they say something where the meaning is unclear, say that you are interested to hear more about it.

Try not to change the subject if your loved one is talking about dying or the future. They may have something very important or meaningful to share with you.

Not talking about death can create tension, lead to misunderstandings, and increase fear, sadness, loneliness and anxiety. Opportunities can be missed to say important things such as 'I love you', 'I appreciate you', 'I'll miss you', or 'I'm sorry'.

If your loved one does not want to talk about dying, that is also OK. It may be that they want to focus on something else, that it feels too uncomfortable for them, that they want to protect you, or that they want to talk to a healthcare professional about it.

As you talk, there may be opportunities for reminiscing, memory making, and preparing. There may also be opportunities to confirm wishes around the funeral or belongings.

If you or your loved one would like support to help you talk together, or you would like to talk about how you are feeling, we have a pre-bereavement support service and a spiritual care team. Your ward team can put you in touch with either of these services if you would like.

Talking about organ donation

It may be possible for your loved one to give the gift of sight through eye (corneal) donation after their death. They may already be on the organ donor register or have spoken about this with you.

If you, or your loved one, would like some more information about this, please speak to the ward staff who can make a referral to the specialist team.

Being there during dying

Your loved one may feel great comfort from you being with them. You may not need to say or do anything in particular. You could offer physical contact, such as holding hands, a gentle massage or a hug. We will ask the dying person what they need and what will offer them comfort, and provide this where possible.

We will ask about any religious or spiritual needs and support these if possible. This may involve arranging a visit from our spiritual care service.

The last days of life: physical changes in the active dying phase

Your loved one is now likely to be spending most or all their time in bed and a lot of the time asleep or unrousable (not waking up). They may be taking minimal amounts of food and drink, or none at all. They may be unable to take medications by mouth.

Your loved one will naturally become more drowsy and sleep for longer periods of time, before becoming unrousable as they are dying. If medications are needed to help with symptoms, it is possible that they may also cause drowsiness. The medication doses are often well-tolerated and help with comfort, but if you are concerned that your loved one is drowsy because of the medications, please tell a member of nursing or medical staff.

If your loved one's mouth is dry, you can help with mouth care. Please see the eating and drinking section on page 7.

Your loved one's breathing pattern may become irregular, or they may have a cycle of fast breathing which slows to a pause (Cheyne-Stokes respiration). The pauses may become longer, there may be very occasional gasps, and eventually the breathing will stop. These changes in breathing do not usually cause any distress for the dying person.

Your loved one may make breathing noises. They may snore which might be normal for them or new. This does not usually cause any distress. The breathing can start to sound wet or rattly because of saliva and other secretions not being coughed up in the usual way. This does not usually cause the person any distress but can sound unpleasant to those at the bedside. We can help with this by repositioning the person onto their side and using a medication injection to dry up the secretions.

Your loved one's hands and feet may become cooler, pale, blue-tinged or mottled. Their face may become pale, with pale or blue lips.

After your loved one has died, the ward staff will support you, explain what has happened and provide written information about what happens after someone has died. This information will also include details of sources of emotional and practical support.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

www.uhs.nhs.uk

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