

Supporting care in the last days and hours of life

Information for patients,
relatives and carers





Some suggestions about how you could be more involved can be found throughout this leaflet in boxes like this. For the purpose of this leaflet, when we say relative, we refer to not only relatives of the patient, but also friends and carers.

The doctors and nurses will have explained to you that there has been a change in your relative's condition.

They believe that the person you care about may now be dying and in the last days or hours of life. This is a difficult and emotional time for everybody. It may be hard to know what to say. Nurses, doctors and other ward staff will work as a team to support your relative and are here to help you talk through any worries and concerns. This leaflet will provide you with some explanation about what your relative may experience at this time.

The ward staff will do all that they can to help, making sure that your relative is comfortable and always treated with dignity and respect. Staff will always try to respect your privacy.



Please share any known prior wishes with the ward staff. This may include what is important to your relative, for example, where they would wish to be cared for at the end of their life.

Planning care

Plans of care are made by ward staff, working closely with the patient and those who are important to them. Everyone has a care plan tailored to their needs and wishes. The care plan includes things that are important to your relative, and it helps to communicate these so that the care is consistent. You and your relative will be involved in discussions regarding the plan of care. All decisions will be reviewed regularly and changes made as needed.

Benefits and burdens

Hospital staff aim to do what is best for patients. However, all care and treatments come with both potential benefits and burdens. For example, some medications have side effects, taking blood tests could cause pain and getting out of bed might take a lot of physical effort. When a person is unlikely to get better, all care and treatments are reviewed to make sure that burdens of care and treatments do not outweigh the potential benefits.

Tell us anything you think may help the hospital ward staff care for your relative. For example, leaving a light on at night, or using a pillow from home.



Medicines

Your relative may have been taking some medicines for a long time. Ward staff will discuss with you whether some of these can be stopped if they are no longer helpful. Your relative will be monitored for symptoms. Medicines may be given, and common side effects will be explained. Enough medication will be given for the persons comfort, and no more than is needed will be given.

Syringe pump

If your relative has difficulty swallowing, medicines can be given as an injection or in a syringe pump (a small portable pump). A syringe pump gives a steady dose and may contain more than one medicine at a time. Medicines will not be given unless they are needed.

Symptoms

There are some common symptoms that someone in the last days and hours of life may have, although not everyone who is dying will experience them.

Pain

Even if your relative cannot tell us, it is often possible to tell if they are in discomfort by looking at their facial expressions and movements.

If they are in pain, ward staff will look for the cause. There are several ways of relieving discomfort, e.g. a change in position. Medication may also help and can be given when needed.

Restlessness and agitation

When people are dying, they may become confused or restless. They may experience hallucinations which can sometimes be familiar and comforting, however, if they are upsetting, these symptoms can usually be relieved.

Gently reassuring your relative by holding their hand, talking to them and reminding them of where they are and that they are safe can help. Sometimes your friend or relative may just want some peace and quiet. At these times you may help by keeping visitors, noise and physical contact to a minimum.

When reassurance or changing position doesn't help, nursing staff can give medicine to relieve the symptom. Staff should explain to you that the medicine is likely to make your friend or relative more sleepy.

Your relative may be reassured by some favourite music, or items from home, such as some photographs, a blanket or a radio. Some people are comforted by a hand or foot massage or hearing the voices of family and friends.



Noisy breathing

Your relative may have a noisy rattle to their breathing. This is caused by a build-up of mucus and saliva in their chest or throat, which they can no longer cough up or swallow. Listening to noisy breathing can be upsetting. However, much like a person who snores when they are asleep, it is unlikely to be causing distress to your relative. If your relative does become distressed by this, changing their position is often the best way to try and help. There are also medications that can be given.



If your relative becomes distressed with their breathing, press the nurse call bell or find someone to help. Sometimes reassurance, opening a window or using a fan can help.

Breathlessness

Should breathlessness be experienced there are simple measures that may help. These can include opening a window, using a fan or changing position. There are also medications that can be given to help with breathlessness. Oxygen requirements may be reassessed and whilst it may be useful for some patients, for others, oxygen may no longer be needed.



If you feel at any point that your relative is experiencing any symptoms or discomfort of any kind, please tell a member of staff as soon as possible.

Religious/spiritual/cultural needs

The plan of care for each person needs to include what gives shape and meaning to life. Please let staff know if there are values, beliefs, rituals and traditions that are important to your relative.

Tell us about any religious practices, rituals or music your relative likes, or if seeing a pet could help? Please talk to staff about anything that you think is important.



You may find support from a spiritual adviser or a chaplain helpful now, when your relative dies, and after their death.

The chaplaincy team provides spiritual care and pastoral support to people of all faiths and none. They can help you answer any questions that you may have or simply provide a listening ear. If you feel you would benefit from talking to a chaplain, please ask a member of staff to arrange this.

Your relative may prefer to be cared for in a side room. The ward staff will try their best to accommodate this. However a room may not always be available.



Respecting your privacy

Ward staff recognise that precious time you have with your relative is now short. Ward staff may not enter the room as often and limit interventions that are no longer helping. They will respect your privacy and try not to disturb you.



If at any point you need a member of staff, for your relative or for yourself, please press the nurse call button.

Comfort measures

Repositioning/Turning

If your relative is unable to move themselves, ward staff may need to help with a change of position. Regular repositioning can help prevent bedsores. However, if your relative is comfortable, ward staff may think that moving them regularly could cause some discomfort. In this case, your relative may only be repositioned when they are uncomfortable or need a wash and / or a change of clothing.

Observations

Some observations, for example blood pressure and blood tests, may no longer help and may cause distress. Where this is the case they will be stopped. Ward staff will focus on those observations necessary for comfort.

Going to the toilet

Your relative may not be strong enough to use a toilet or commode. The bowels can slow down and do not open as often. The bladder can pass less urine, which can be very dark in colour. Occasionally, your relative may lose control of their bowels and bladder. Pads may be used by ward staff to keep your relative as clean, dry and dignified as possible.

Sometimes people who are dying are unable to open their bowels or pass urine and this may cause them distress. The ward staff will monitor your relative for constipation and may give pain killers or suppositories if needed. If your relative is unable to pass urine, it may be more comfortable for them to have a urinary catheter inserted.

Mouth care

Your relative's mouth may become dry. This is usually because they are more sleepy and breathing through their mouth, rather than as a sign of dehydration. Moistening the mouth with water, brushing the teeth and applying lip salve can help. Ward staff will provide mouth care regularly.

If you would like to help with mouth care for your relative, please tell the ward staff. Some people who cannot swallow may want to have mouth care given with their favourite drink rather than water.



Changes which can occur before death

It can be worrying if you don't know what to expect at this time. Every person's death is different. However, there are some signs or changes that can show when a person may be near to death.

Changes in Breathing

The breathing pattern can change as the body slows down. Breathing may be fast, shallow or deep and there may be pauses between breaths. You may notice the abdomen (tummy) muscles rise and fall instead of the chest. If breathing appears laboured, remember that this is more distressing to you than it is to your relative.

Appearance

A dying person's skin may change colour, it can also change temperature and become hot, moist or slightly cool before they die. Sometimes when a person stays in bed for a long time or their organs aren't working normally, fluid can collect in the arms or legs and they become swollen.

Reduced need for food and drink

As people approach the end of their life, some may find the effort of eating and drinking too much. Your relative will be supported by ward staff to eat and drink for as long as they are able and wish to do so.

When your relative no longer needs or wants to eat and drink it can be hard to accept, even when we know they are dying. Their body may not need or be able to use food and fluid in the same way anymore. In this case, your relative may not feel hungry or thirsty and may be more comfortable not eating or drinking at all.

Some people may benefit from fluids given by a drip, but for some people, fluids might make them uncomfortable. The doctors will decide whether or not fluids may make your relative more comfortable and will discuss this with you.



You can help by offering your relative food and drink if they want it and letting them refuse it if they don't.

Sleeping and drowsiness

Your relative may spend more time sleeping and can sometimes be drowsy when they are awake. This change can be gradual, but sometimes it can happen more quickly.

It can be upsetting if your relative is sleeping when you're visiting. However, simply being together can be a great comfort to you both.

Eventually your relative may become unconscious. Sometimes this may be for a few hours; some people can be unconscious for a few days.

It is widely believed that people who are dying may still be able to hear. It may be comforting for your relative to be spoken to, read to or to listen to music, even when they are no longer awake.



Care after death

After a person has died the ward staff will speak to you about what happens next and provide you with an information booklet called 'What to do after someone has died'. You will be given time to spend with your relative. Please speak to the nursing staff if there are any spiritual, cultural or practical wishes you wish to discuss.

Please speak to the nurse or doctor if you have any concerns or questions.



At Leeds Teaching Hospitals Trust, we don't just care for our patients, also we care about the people close to our patients as well. We are here to support you, in any way we can.

How can we **SUPPORT** you?



Supporting care leaflet - we hope you have found this leaflet helpful at this difficult time. If you would like this information leaflet in another language, please visit: <https://www.leedsth.nhs.uk/patients-visitors/patient-and-visitor-information/patient-information-leaflets/> and select the BrowseAloud™ Icon.



Understanding your needs - please inform the ward staff of any specific needs you have. There is space on page 14 and 15 for you to write down any questions or concerns.

Ward Contact Number:.....



Parking Permit - a free car parking permit is available. Please ask a member of staff.



Personal Space - should you wish to spend some time away from the bedside. Please ask about the family room, prayer and quiet room locations.
Location of Room(s) for your use:

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Offer a comfort care pack - a comfort care pack can be offered if you are staying overnight or for long periods throughout the day. Visiting should not be restricted, please discuss with ward staff. Overnight accommodation may be available. Please speak to a member of staff.



Restrooms - please ask staff where the nearest toilets for your use are located.



Tea & Coffee - please feel free to ask staff for a cup of tea or coffee.
Nearest place to obtain food and drink:

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Please ask a member of staff to help complete the information on pages 12 & 13

This leaflet has been developed by following consultation with patients, relatives and the Specialist Palliative Care Team at Leeds Teaching Hospitals NHS Trust.

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Care and support in the last days of life:
Information Leaflet.

Palliative Care Guidelines: Patient Information Leaflet NHS Lothian.

If you have a problem or concern

The Patient Advice and Liaison Service (PALS) can also support you and can be contacted by e-mailing:

patientexperience.leedsth@nhs.net or ringing **0113 206 6261**



What did you think of your care?

Scan the QR code or visit **bit.ly/nhsleedsfft**

Your views matter



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