

Care in the last days of life

Care homes with nursing

Information for family and friends

If the nurses at the care home believe your relative or friend is the last hours or days of life they will have explained this to you. The information below describes the care given in the last days of life, how you can be involved and some of the changes you may see in your relative or friend. The nurses and carers will check their condition frequently and will want to make sure they are comfortable and have everything they need. They will also want to make sure you feel supported.

Priorities at this time are to:

- Let you know of any change in your relative or friend's condition
- Agree a plan of care to meet your relative or friend's needs during the day and night. This will include:
 - Food, drink and mouth care
 - Comfort and symptom control
 - Emotional, social and spiritual support
- Ensure care decisions reflect your relative or friend's wishes and are regularly reviewed
- Involve you and your relative or friend in decisions about care to the extent they and you want
- Support you, and wherever possible respect your wishes, as well as those of your relative or friend
- To be compassionate and sensitive at all times

How you can help

If you are aware of any wishes your relative or friend has that may help at this time, or if you would like to be involved in giving care please let the staff at the home know. You may prefer not to discuss this or be involved in giving care. This will be respected.

Your relative or friend may have spoken to you about things that are important to them at this time. These may include any religious, cultural or spiritual beliefs, or other wishes such as music photographs and who they would like to be with them. If staff need to be aware of these please speak to them. If you would like support from a chaplain or other religious leader at this time and do not have any contact details please ask for this information.

You can support your relative or friend in important ways such as spending time with them, sharing memories and news of family and friends. If needed, the nurses may confirm your contact details with you, so they can keep you updated about what is happening.

Please ask if you are unsure about anything.

Who will be providing support?

The team providing care will vary depending on your relative or friend's needs but typically may include:

- GP
- Registered nurses and carers in the care home
- Specialist palliative care nurse from a hospice
- End of life (EOL) care facilitators for care homes
- Health case Manager or Social Worker

Changes in the last days of life

The care each person needs is unique; however there are some common signs or changes in the last days and hours of life.

Food and drink

The staff at the home will support your relative or friend to eat and drink for as long as possible. As they become weaker they may find swallowing and the effort of eating and drinking too difficult, or they may not want to eat and drink. When a person stops eating and drinking good mouth care is very important to stop their mouth feeling dry. The nurses will explain to you how mouth care is given and may ask if you would like to help give this care.

If there are concerns that your relative or friend is uncomfortable because they cannot eat or drink, giving artificial fluids (drip) may be considered. This is not common and will only be used where it is helpful and not harmful. In these circumstances it would be discussed with you, the GP, other members of the care team and your relative or friend, where possible, before making a decision. This decision will be reviewed regularly.

Comfort and symptom control

The nurses and carers will assess how comfortable your relative or friend seems, provide personal care and change their position when needed. They will look for any changes in their eating and drinking, sleepiness, breathing and whether they seem in any discomfort, pain or distress.

A doctor or nurse will assess your relative or friend's medication needs and decide on suitable drugs, the correct dose and when this should be taken. Medicine that is not helpful at this time may be stopped and new medication prescribed. Your relative or friend may not experience any discomfort, however if they do the priority is to control their symptoms, having medication available will enable the nurse to respond promptly. The nurse would be able to explain how the medication is given and the likely effect.

If your relative or friend is unable to swallow, an injection or a syringe pump may be needed to give medication to keep comfortable. If you have any concerns or queries about medication please ask the nurse.

Sleeping and drowsiness

Your relative or friend may spend more time sleeping or be drowsier when awake. As they become weaker they are likely to become unresponsive. This change is a gradual, natural process and simply being there can be a comfort. If they show signs of distress or restlessness the nurse can give medication to help with this. The medication used can be sedating, however only enough to control the symptom will be given and no more.

Changes in breathing and colour

In the last hours of life breathing patterns may change and sometimes there are long pauses between breaths. Breathing can also appear laboured. The skin can become pale, moist and slightly cool to touch. This is part of a gradual, natural process as the body becomes weaker and it is unlikely your relative or friend is aware of these changes.

You may hear a rattle when your relative or friend breathes. This can be caused when mucus or secretions build up in the airways. Changing their position or giving medication may help with this. The noise itself is not a sign of distress, though we understand that some people may find it upsetting.

If you have any concerns or queries about any aspect of your relative or friend's please ask.

Further information

www.leedspalliativecare.org.uk

Help us get it right

If you have a complaint, concern, comment or compliment please speak to a member of staff.

We can make this information available in large print, audio or other languages on request.