

Supporting care in the last hours or days of life

Information for relatives
and carers



This supporting information has been written for relatives and carers who are supporting their relative or friend in hospital, home, care home or hospice.

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

They believe that the person you care about is now dying and in the last hours or days of life. This is a difficult and emotional time for everybody. It is often hard to know what to say to each other. The professional team are there to support you and to help you talk through your worries and concerns.

Comfort

The doctors and nurses will do their best not to disturb your time with your relative or friend. They will try to make sure that your relative or friend is comfortable and has everything they need so they will check on your relative. Please let the nurses know if you feel your relative or friend needs anything at any time.

You can still support your relative or friend at this time; spending time together, sharing memories and news of family and friends. Being cared for in this way helps people to feel that their lives have been worthwhile and that they will be remembered.

You and your relative or friend will be involved in the discussion regarding their plan of care. We hope this will help you understand the reasons for the plan of care. If, after a discussion with the doctors and nurses you do not agree with any decisions there is an option to obtain a second opinion.

All decisions will be reviewed regularly. If your relative or friend's condition improves then their plan of care will be reviewed and changed.

Medication

Medicine that is not helping your relative or friend may be stopped and new medicines prescribed. Medicines to control symptoms will be given when needed. When your relative or friend is no longer able to swallow, medication may be given by injection or by a syringe pump (small pump that allows medication to be given slowly over a 24 hour period).

Medication will be carefully monitored to make sure that:

- It is given at the right time.
- Just enough is given to ease the symptom.
- No more than is needed is given.

Religious/spiritual/cultural needs

As part of the plan of care the professional team will explore any needs, values, beliefs, wishes, desires or traditions that are important to your relative, friend or you. These may be about religious or spiritual needs. You may want to ask for specific support from a chaplain or religious adviser, regarding special needs now, at the time of death or after death.

Understanding the changes which occur before death

There comes a point in most people's lives when death and dying are contemplated. Perhaps we must face our own death or that of someone close to us, but we don't know what to expect.

In order to reduce the anxiety which often comes from the unknown, this leaflet describes some typical features of the process of dying. It anticipates questions you may want to ask and hopefully it will encourage you to seek further help and information.

The changes which occur before death

The dying process is unique to each person but there can be some common signs or changes that can show a person is dying. The changes are described below:

Reduced need for food and drink

At first the effort of eating and drinking may have become too much. At this time help with feeding might be appreciated. Your relative or friend will be supported to take food and drink by mouth for as long as possible.

When your relative or friend stops eating and drinking it can be hard to accept, even when we know they are dying. They may not want or need food or drink. If this happens the team will discuss this with you.

Decisions about this will be made in the best interests of your relative or friend for this moment in time. Fluids given by a drip will only be used where it is helpful and not harmful. This decision will be explained to your relative or friend if possible and to you too. It will be reviewed regularly by the doctors and nurses.

Good mouth care is very important at this time. The nurses will explain to you how mouth care is given and may ask if you would like to help give this care.

Changes in breathing

People who suffer from breathlessness are often concerned that they will die fighting for their breath. Towards the end of life, as the body becomes less active, the need for oxygen is greatly reduced. Carers often say that when a relative or friend is dying their breathing is easier than it has been for a long time.

Breathing difficulties can be made worse by feelings of anxiety. Knowing someone is close at hand is reassuring and can help reduce breathlessness caused by anxiety.

Your relative or friend may have noisy breathing in the last hours of their life. This is caused by a build-up of mucus in their chest, which they cannot cough up. Their nurses may give them medication to ease this and changes of position may also help.

Although you may find the noisy breathing upsetting it shouldn't distress your relative or friend.

Breathing mainly through the mouth is not uncommon at this point in life and the lips and mouth can become dry. Moistening the mouth with a damp sponge or cloth and applying lip salve can help to keep them comfortable.



Sleeping and drowsiness

Your relative may spend more time sleeping and will often be drowsy when awake. This change is a gradual process.

Try not to be upset if there is little response. This may be due to weakness and not lack of appreciation. Simply being together can be a great comfort to both of you. This natural process may go together with feelings of tranquillity. It is not a snub to relatives or friends.

Eventually they may lapse into unconsciousness and may remain in this state for a surprisingly long time, in some cases many days, and for others a shorter time.

When death is very close

When death is very close, within minutes or hours, the breathing pattern may change. Sometimes there are long pauses between breaths. The abdominal muscles (tummy) may take over the work and the abdomen will 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.

Their skin can become pale and moist and slightly cool prior to death. It is likely that your relative will not rouse from their sleep, but die peacefully, comfortably and quietly.

This leaflet has been developed by the Marie Curie Palliative Care Institute, Liverpool and the Leeds Teaching Hospital following consultation with patients and relatives. It has been adapted for local use by Specialist Palliative Care Services in Bradford, Airedale, Wharfedale and Craven.

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