Information Leaflet

Liverpool Women's
NHS Foundation Trust

An Explanation of the Care in the Last Hours or Days of Life for Families 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.

The dying process is unique to each person; it is important that we plan our care for your relative or friend according to their individual needs and wishes, your relative or friend may have already considered what is most important to them.

You will also be involved in the discussion regarding the plan of care with the aim that you fully understand the reasons why decisions are being made. If your relative's condition improves, then the plan of care will be reviewed and changed.

Nothing can take away the feelings of grief, however having information may help you cope at this anxious time. In most cases there are common changes which help to suggest that a person is dying.

This leaflet will hopefully explain these changes and answer some of your questions. However, if you have any more questions, please ask the nurses and doctors caring for your relative.

Reduced need for food and drink

Your relative may stop eating and drinking. This is a normal process during the last days of life; and it can sometimes be hard to accept. Your relative will be supported to eat and drink for as long as they want / are able to. The ward team will assess if your relative is alert and awake enough to eat and drink safely. This is not without an element of risk if the person is weak. This is often referred to as “risk feeding” and will be fully explained if this is to be considered.

If your relative is in hospital and cannot take fluids by mouth, a drip may be considered. Sometimes the benefits of a drip have to be weighed against the risks and will only be used where it is helpful and not harmful. These decisions will be explained to you. However, caring can be continued in many other ways, such as providing good mouth care and moistening of the lips which can help your relative feel more comfortable.

Changes in breathing

When someone is dying, their need for oxygen may lessen and the way they breathe may change.

Your relatives breathing may pause for a while and then start again. They will use different muscles to breathe, which means their breathing may look different, the abdominal (stomach) muscles will take over the work – the abdomen rises and falls instead of the chest.

Sometimes breathing can sound noisy or “rattling” largely due to a build-up of mucous because your relative is no longer able to cough or clear their throat. This can sound upsetting but is usually not distressing for them. If breathlessness is causing your relative distress, small doses of medicines can be given to help relax the breathing and relieve their distress.

Changes in consciousness and sleepiness

‘Withdrawal from the world’ is a gradual process. Your relative may spend more time sleeping and may be drowsy when awake. This is part of a natural process. Eventually, your relative will become unconscious and can remain in this state for a long time, for others, it is shorter.

During the process of dying, your relative’s skin may become pale and moist. Their hands and feet can feel very cold and sometimes look bluish in colour. They may still be aware of that family and friends are still with them so you can still talk to them.

Medication/treatment

In partnership with your relative and those identified as important to them, the nurses and doctors will develop an individualised plan of care to decide the care and treatments that will be of benefit. Investigations such as blood tests, blood pressure and temperature monitoring may be discontinued and medication will be reviewed, and any that are not helpful at this time may be stopped and some new medicines may be prescribed for treating symptoms such as breathlessness, pain, agitation, nausea and vomiting. The ward team will discuss the use of these medicines including any potential side effects to you. If swallowing medication becomes difficult, it may be given in a way that is easier for your relative, such as by an injection or sometimes by a continuous infusion using a small pump called a syringe pump. The nurses will aim to manage your relative’s symptom as best as possible.

Religious/Spiritual Needs/Comfort measure

It is very important to make sure all the staff who are providing care meet you and your relative's needs. This may include religious traditions, or rituals. Some families and friends may want to be involved in assisting the nurses with comfort and care, bringing in personal belongings such as blankets, photos and playing some of your relative's favourite music. If you would like to be involved, please tell the nurses.

Caring for you and your relative is important to us. The nursing team, doctors, specialist palliative care team and pastoral support team will provide support and care to you both. Please ask any of the team if you require any further support.

This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at pals@lwh.nhs.uk

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