Supporting care in the last hours or days of life

Information for relatives and carers
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 may be hard to know what to say. Nurses, doctors and other staff are there to support you and are there to help you talk through your worries and concerns.

**Comfort**

The doctors and nurses looking after your relative or friend in the last days of life will be checking for any changes. They will do all that they can to make your relative or friend as comfortable and dignified as possible. Please let the nurses know if you feel your relative or friend needs anything at any time.

You can support your loved one 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.

**Communicating the plan of care**

You and your relative or friend will be involved in the discussion regarding their plan of care. If, after a discussion with the doctors and nurses, you are unclear or have any concerns please raise this with the ward staff. If you are still unsure you may want to ask for a second opinion from another doctor or nurse.
If your relative or friend’s condition improves then their plan of care will be reviewed and changed. All decisions will be reviewed regularly.

**Medicines**

Your relative or friend may have been taking some medicines for many months or years and these may need to be stopped or changed if they are no longer helpful. The doctors and nurses will discuss this with you.

Medicines to manage symptoms will be given when needed. *This will be carefully monitored to make sure that:*
- It is given at the right time;
- just enough is given to ease the symptom, and
- no more than is needed is given.

**Using a syringe pump**

Sometimes your relative or friend may not be able to take their medicines by mouth. A syringe pump (a small portable pump) may be set up to continue some regular medicines or if they are requiring lots of individual injections to manage symptoms.

The syringe pump is used to deliver a constant dose of medicines usually over 24 hours and may contain more than one medicine at a time.
Observations
We may no longer be doing routine observations, for example blood pressure, blood sugar measurements or blood tests. These may no longer be of benefit to your relative or friend and may cause unnecessary distress.

Religious/spiritual/cultural needs
As part of the plan of care the staff will explore any needs, values, beliefs, wishes, desires or traditions that are important to your loved one 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 or at the time of death or after death.

Symptoms and Care
Pain
Not everyone who is dying will have pain. Even if your relative or friend has difficulty communicating it is usually possible to tell if they are in discomfort and the doctors and nurses can check for this. If you have any concerns about your relative or friend being in discomfort please let the nurse or doctor know.

If there is pain it is reassuring to know that there are several ways of relieving it. Changes in position may help some. However for others it may be best not to change the position. This will be assessed on an individual basis. Drugs such as morphine, can be useful and can be given in a medicine or by injection when needed. Medicines will not be given unless they are needed.
Restlessness and distress
As part of the natural dying process your relative or friend may become confused, restless or distressed. Sometimes hallucinations may occur. This can be difficult for the family and others to see but these symptoms can be helped.

It can help to keep the environment calm and quiet and to gently reassure your relative or friend by holding their hand and talking to them.

Medicines are available which can help relieve these symptoms. The doctors and nurses caring for your relative or friend will check for any other causes that may be contributing to the distress.

Bowels
Due to weakness and as the person’s condition deteriorates they may not be strong enough to use a toilet or commode. Often the bowels slow down and do not work as normal. Occasionally, due to muscle weakness your relative or friend may lose control of their bowels. If they are very weak and unable to get out of bed, pads may be used.

Bowel function will be assessed by the nurses and doctors with the aim of maintaining dignity and comfort. This may be related to ensuring the patient is not distressed when having a bowel movement. If they are uncomfortable then pain killers could be given. Suppositories could be considered to ensure a regular bowel pattern if needed.
Bladder
As the body naturally slows down your relative or friend may pass little or no urine and the urine may become very dark in colour. Due to weakness, it may be too distressing to assist your relative or friend on and off a commode or toilet.

In order to maintain dignity and comfort, pads can be offered. For some people it may be more comfortable to have a catheter, to drain urine from the bladder. This will preserve their energy and ensure they remain dignified and comfortable. If appropriate this will be discussed with the family and others.

Catheters can also be used for people who have signs of retaining urine, which can cause restlessness and distress.

Mouth Care
Regular mouth care should be given to your relative or friend. If they are breathing through their mouth, the lips and mouth can become dry. Moistening the mouth with water using a soft small tooth brush or foam mouth swabs and applying lip salve can help keep them comfortable. If you would like to provide mouth care for your relative or friend please discuss this with the nurse caring for them.
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 section 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 dying process is unique to each person but there can be some common signs or changes that can show a person is near to death. 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 loved one 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 we may discuss artificial fluids (a drip).

This decision 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. The need for artificial fluid will be reviewed regularly.
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 from your relative or friend. This may be due to weakness 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 loved ones.

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

Although it is not scientifically proven, it widely believed that hearing is the last of the senses to go. It can be comforting for your relative or friend to be spoken to or read to even when they are no longer responsive.

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 loved one 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 loved one may have a noisy rattle to their 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. The nurses may give them medication to ease this and changes of position may also help.
Although you may find the noisy breathing upsetting is unlikely to be causing distress to your loved one.

**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.

It is likely that your relative will not rouse from their sleep, but die peacefully, comfortably and quietly. Their skin can become pale and moist and slightly cool before death (any one of these signs can be attributed to something other than dying).

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

*Below is some space if you would like to write anything to remind you of any questions you would like to ask.*

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Other Information - facilities
The following services are available for you and your family.

Car Parking Permit
Ward staff can give you a car parking permit for hospital car parks which will last up to seven days.

Accommodation
We are sometimes able to offer overnight accommodation in Bexley Wing hotel (SJUH) or Take Heart rooms (LGI). Please speak to the nurse in charge.

Open Visiting
You should not be restricted to ward visiting times. Please speak to ward staff for further details.

Chaplains
The Trust currently employs chaplains for all major religious groups as well as a non-religious chaplain. If you or your relative/friend would like to see a chaplain, please speak to ward staff who can arrange this.

Refreshments
Please feel free to ask staff for a cup of tea or coffee. If you wish to purchase meals staff will let you know where the nearest restaurant or food outlet is.
The nearest female toilet for you to use is:

The nearest male toilet for you to use is:

The nearest disabled access toilet for you to use is:

The nearest baby change facility for you to use is:

The nearest prayer facilities are located at:

There is a quiet room for you to use located at:

The nearest public telephone is:

You are able to obtain food and drink from:

The ward can be contacted at any time on:

www.leedspalliativecare.co.uk
This leaflet has been developed by the Marie Curie Palliative Care Institute Liverpool and adapted following consultation with patients, relatives and the Specialist Palliative Care Team at Leeds Teaching Hospitals NHS Trust.

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Palliative Care Guidelines: Patient Information Leaflet NHS Lothian.