



Royal Papworth Hospital
NHS Foundation Trust

Last days of life

Information for
family and carers



There comes a time in life when each of us has to think about death and dying, whether it is our own death or the death of someone close to us.

The last few days or hours of life will be different for each person: it can be difficult to predict what will happen or how quickly changes will occur. Some people may have concerns or anxieties due to previous experiences around death. It is important you feel able to ask questions in order to understand what is happening. The information in this leaflet may help, but do speak to the doctors and nurses as well.

The natural process of dying is one in which the body's systems wind down; it is not unusual for people to lose interest in the world, to lose concentration, to lose interest in food and drink, and to become drowsy, until eventually they cannot be roused.

Eating and drinking

As a person becomes weaker they may find the physical effort of eating and drinking too much, and they may need help.

When someone stops eating and drinking, it is natural for them and those around them to find this difficult as it indicates that their condition is deteriorating and it becomes more evident that they are dying.

You may wonder if fluids or food would be given artificially; this is an individual decision for each patient and needs to be discussed and decided with the medical team.

A dry mouth will make the person feel thirsty, so it is important that attention is given to mouth care. Using water/mouth wash to moisten the mouth and applying lip salve to the lips can be very beneficial and comforting; please ask the nursing staff if you wish to help with this.

Personal care

During the last few days of life the dying person will have a greater need for assistance with personal care.

Their position will need to be changed on a regular basis. Their skin will need to be cleaned and moisturised to ensure that they are comfortable and do not become sore.

Special mattresses and cushions, etc. may be provided by the nursing team to ensure that they are comfortable.

There may be times when a dying person prefers not to be moved and wishes to be allowed to lie quietly and peacefully. Nursing staff will respect their wishes but there may be occasions when they need to be moved to prevent pressure and soreness, and to maintain their comfort and care.

Symptoms

All symptoms will be reviewed regularly and medications to treat them will be available as required.

Medication will be given in the most appropriate way; this may include injection, use of a 'syringe pump' or 'patches'. How the medication is to be administered will be carefully considered and fully explained to you.

Changes in breathing

People who have experienced breathlessness in their day-to-day life may become fearful that this will worsen as their condition deteriorates. As they become weaker and rest more, this may not happen. If they do become distressed by their breathing, they can be given medication to relieve this.

Some patients develop rattly breathing due to secretions that they can no longer clear by coughing. Usually this is not distressing for the dying person. Medications and repositioning may help to reduce the sound.

Often, as the patient deteriorates, the pattern of breathing changes. It may become slower or more irregular with pauses between breaths. In some people, it may seem to take a long time for the breathing to finally stop but in others it can occur quite quickly.

Restlessness

Sometimes the dying person may become agitated or restless and may call out. This is known as terminal restlessness. This may be due to discomfort, for example, due to a full bladder or bowel. This will be reviewed by the staff.

Sometimes the discomfort is not physical but emotional. In this case the dying person may find comfort in the presence of a family member or friend, or someone else important to them, such as a spiritual or religious leader.

If medications such as sedatives are required to relieve restlessness, the team will discuss this with you.

Spiritual needs

Many people who are dying have religious or spiritual needs and may have asked for support as the time of death draws closer.

Family and friends may also have religious or spiritual needs.

The hospital has a chaplaincy team you may call (through the ward nurses) but you are welcome to invite anyone who has supported you previously. If you need a quiet space to reflect, ask the nursing staff for directions to the chapel where you will find a multifaith space.

In this situation it is useful if someone has a note of anyone that the dying person wants with them at this time.

Care of the bladder and bowels

Sometimes the person may have difficulty controlling his/her bladder or bowels. Nurses will check on a regular basis to ensure the person is kept clean, dry and comfortable. They may discuss the use of aids such as pads or a catheter.

Pain

Not every dying person has pain. If the person has had pain controlled with medications, these will be continued. If they appear to be in pain (restless or grimacing), the medical and nursing staff will assess and discuss the need for additional medication.

The natural process

It is natural for the dying person to withdraw gradually from the world, spending more time asleep, talking less and taking less interest in things when awake.

Even if they are not interacting with you, they will hear you and will be aware that you are there. If possible, ask them whether they would like you to be there. Eventually they will sleep for longer periods of time and slip into unconsciousness.

At this time, it is uncertain how long it will be until death, but the medical and nursing staff will be there to support you and to answer any questions you may have.

Support

Hospital staff are there for you as well as the patient. Please ask for support and feel free to ask questions.

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