

Patient information

Care in the Last Hours to Days of Life

Palliative Care Department

Information for those important to the dying person

The dying process is unique to each person; it is important that we plan our care for your loved one according to their individual needs and wishes.

We will involve you and your loved one, if able, to plan the best quality care and understand the reasons for this plan.

It can be difficult to take in lots of information at one time. We will do our best to ensure any questions are answered, that you understand and feel supported during this difficult time. We hope this leaflet helps. If you need any more information, please ask a member of staff.

SWAN model of care for End of Life and Bereavement

We use the Swan model to support and guide the care of dying patients, and to give personalised care. A Swan sign is put up near the place where the dying person is to remind staff to maintain a peaceful and personal environment. Resources are available to you and your loved one such as mementos and additional comfort measures, speak to a member of staff for more information.

How will I know when a person is dying?

Reduced need for food and drink

We will continue to help your loved one eat and drink for as long as they are able. People will gradually lose interest in eating and drinking. As part of the natural dying process, the body no longer needs the same amount of food and drink.

Decisions about the use of medical treatments e.g. artificial fluids (a drip) will be made on an individual basis. Research studies show that giving artificial hydration in the last days of life does not affect life expectancy, may improve some symptoms but also cause harm with swollen limbs or fluid in the lungs or other areas.

Decisions about the risks and benefits of assisted hydration will be explained to you and reviewed on a regular basis.

If the dying person has assisted nutrition, such as feed by a drip or through a tube into the stomach or intestine, this will also be reviewed. Continuing this feed when someone is dying risks poor digestion of food and potential harm such as risk of vomit going to the lungs.

It is very important we maintain good mouth care to ensure the mouth is clean and moist. Dry mouth can occur due to mouth breathing and medications rather than dehydration. We will provide mouth care and you can help with this should you wish.

Becoming sleepier

The natural process means that people often spend more time sleeping. They may be disorientated or drowsy even when they are awake. It is common to drift in and out of consciousness. People will often become unconscious for a period of time before they die; this can vary and be for hours, a number of days or longer.

Changes in the skin

Skin may feel cool to the touch and change colour due to changes in the circulation.

Symptoms

At times a person may become restless and agitated; they can sometimes appear confused and even hallucinate. This can be distressing, which is why it is important we assess for any causes and treat if it is appropriate. Restlessness and agitation can be caused by physical symptoms such as pain or discomfort, difficulty passing urine and changes in the environment. We will observe your loved one for such symptoms and provide appropriate care, and medications if required.

Breathing changes

As a person approaches the end of their life they require less oxygen and breathing may become shallow. There can be pauses between breaths and at times the breathing can become noisy at the back of the throat. This happens because the person is no longer able to re-absorb or swallow natural saliva and mucus which can cause a rattling sound called secretions, your loved one is unlikely to be aware or distressed by these secretions, but we can give medications to help dry them up. In the very last moments of life, breathing can become slower again with more frequent pauses. Changes in breathing pattern are a normal and an expected part of the dying process.

Medication and treatments

Medications and treatments will be reviewed and it may not be appropriate to continue with some tests at this time. These may include blood tests and monitoring of blood pressure and temperature. Any medications that are not helpful at this time may be stopped. It may not be possible to give medications by mouth, so medications will be tailored to individual needs and may be given by injection or if needed, by a continuous infusion pump called a syringe driver.

We will monitor for signs of pain, sickness, breathlessness and any other symptoms and if needed administer injectable medications. These medicines may have side effects such as dry mouth and sometimes sleepiness. They will only be given if and when they are required and only enough to alleviate symptoms, they do not speed up the dying process.

What else do I need to know?

Comfort and personal care

We will continue to help with personal care needs, repositioning in the bed and use of a special mattress and regular mouth care throughout the day and night.

We recognise it is often important for you to ensure your loved one has their own personal items. Should you have any specific preferences please let a member of staff know and we will aim to meet these wishes. If you want to help with personal care, let the nurses know and they will advise and support you to do so.

Prevention of Pressure Ulcers and Pressure Area Care

A pressure ulcer is an area of damaged skin (sometimes known as "bedsores")

Pressure ulcers can cause pain and discomfort and can develop quickly. They may present as discoloured skin, blisters, or open sores.

A pressure ulcer can result from remaining in one position for too long. They can also be caused by medical devices such as catheter tubing.

To minimise potential pain and discomfort, we will continue to check your loved one's skin and help with position changes, these can be small and subtle, often a 30-degree tilted move is all that is needed to relieve pressure.

We recognise that you may not want your loved one, or your time spent with them to be disturbed too often. The nurses will endeavour to coincide position changes with other aspects of care such as personal hygiene and medical device monitoring.

If you have any concerns or questions about changing of position, please speak to the nurses who will be able to explain further.

Spiritual and religious support

We want to support the spiritual needs of both you and your loved one. We have a chaplaincy team who offer support for those of all faiths and also those with no specific religious beliefs but who recognise their own spiritual journey. Ask a member of staff should you wish to access this. Please highlight any preferences that we need to be aware of to ensure we meet any religious, spiritual or cultural needs in the last days of life or after death.

Volunteers

We have an end of life volunteer companionship service available for emotional support. This service is provided by trained volunteers who can sit with you and your loved one. They are able to listen and support you whilst showing understanding and compassion. They can spend time with your loved one to offer you a break if required or if you are unable to attend the ward in person.

Visiting

Each ward has specific times for general visiting. Please speak with the nursing staff on the ward as we will provide flexible visiting times. Speak to a member of staff for advice regarding facilities for visitors and overnight stays.

Side Rooms

You may have a preference that your loved one is cared for in a single room if they are not in one. We will always aim to meet this request, however at times this may not be possible. Your request will be reviewed on a daily basis and accommodated wherever possible.

Car parking

For visitors using hospital parking, in some instances a free pass may be available. Please speak to a member of ward staff.

Visitor food and drink

There are coffee shops, dining areas and vending machines across the hospital. Each has different opening times. Ask a member of staff for further details. Staff on the wards should also be able to provide you with some drinks.

Mobile phones

We are aware you will need access to mobile phones to keep in contact with family members. There are plug sockets available for chargers beside every bed. Please do not unplug any medical devices. Please be considerate to other patients and staff when using your phone.

Organ Donation

There are several ways in which we can support donation of organs and tissue depending on the circumstances and wishes of you and your loved one. Should you or your loved one wish to have further information, leaflets are available, and you can also ask to speak with the medical team.

We aim to provide a high standard of care and support for all involved at this difficult time, should you have any concerns or questions please speak to a member of ward staff.

Further information

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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