



Royal Cornwall Hospitals
NHS Trust

Caring for people in the last days of life

How we will care for you and your family



One + all | we care

Throughout this booklet we will refer to families to mean all those close to the patient, whatever their relationship.

If you have been given this leaflet it is likely that your family member is in hospital, and that the healthcare team believe that they are very unwell and are now in the last days of life.

We recognise that these are often the most difficult times for patients and their families. This leaflet has been written to try to help you understand what may happen, and how the doctors, nurses and other staff in the hospital team will care for you and your relative over the next hours, and days.

In caring for your relative our aim will be to try and deliver the right care, whatever their circumstances. We will strive to maintain their comfort, promote privacy and dignity and stop any medicines or tests which are unnecessary. Above all we want to communicate well with you to find out what matters most to you and your relative.

Recognising dying – how do we know?

It may be that your relative was admitted to hospital for treatment and care with the hope of recovering and returning home. It can be hard to understand why the doctors and nurses believe that death is now approaching.

The team delivering treatment and care will have been monitoring any changes in your relative carefully. In situations where a person does not respond to treatment, and where further choices for treatment are very limited, this is an important sign of declining health. People may become increasingly unwell despite treatment and care, either in how they feel, or how physically able they are. In some instances tests may reveal very serious problems that cannot be treated or made better.

Though every person is an individual, there are often common signs of deteriorating health. People may become drowsier, less interested in eating and drinking, and more withdrawn.

Some families feel understandably confused about the sequence of events. It is important that you have the information that you need. Please ask if you would like further explanation, or if you simply have more questions or concerns that you would like to share.

Preferred place of care

Some people have clear preferences for where they wish to be cared for when they are dying. This may be at their home, the home of a family member or somewhere closer to home, either a community hospital, nursing home, or hospice. Please tell us as soon as possible if hospital does not feel like the right place for you, so that we can work with you to plan what choices may be available. If you are a relative who would like to care for your family member at home, there may be additional support available. Securing help can take time, so early discussions are important.

Planning important care

In hospital we have a specific plan of care for patients in the last days of life. The team caring for your relative will discuss with you what you both feel is important, so that what matters most to you both is central to the plan of care. The care plan ensures that all aspects of care are addressed, and that each patient is treated individually. We will ask who is important to the patient and how they are best communicated with.

We will monitor your relative regularly and review and change their care plan to suit their needs. This should happen at least daily, or more frequently if needed. We will be thinking about their comfort, ensuring that we are delivering good quality nursing care. This includes personal care and symptom control, communicating regularly, clearly and with compassion throughout.

As death is expected, we will not attempt to revive or resuscitate your relative when the heart and breathing eventually stop. This will enable death to be as peaceful and gentle as possible. Our doctors may talk to you about including these decisions in the plan of care. At our hospital this is called a treatment escalation plan (TEP).

Occasionally, the situation for a patient can stabilise or even improve. If this happens, we will review and change the plan of care in discussion with you and your family.

Maintaining comfort

People in the last days of life are monitored very regularly, and their level of comfort recorded. Any obvious cause of discomfort should be addressed, for example re-positioning a patient in bed if they seem uncomfortable. People are often nursed on a special mattress to protect their skin, and attention is given to make sure they are clean and dry.

We will review usual medication and may stop those medicines that are no longer helpful. Medicines are prescribed 'as needed' for symptoms that people may experience at this time, either as a normal response to the changes within their body or as a result of illness. Medicines are prescribed for pain, breathlessness, nausea, restlessness or agitation and noisy throat secretions. The medicines used at the end of life not only relieve physical symptoms, but can also relieve any emotional distress and suffering. It is important to know that although these medicines are made readily available, they are not given routinely as many people do not experience symptoms.

When symptoms such as pain or nausea are present, the person may need medication to be more comfortable. We have safe and effective medicine plans, drawn up by our specialist palliative care doctors and nurses. Medicines used at this time include opiate painkillers, and relaxing medicines called benzodiazepines. These medicines may cause sleepiness in some people. To avoid this where possible, the smallest effective dose is prescribed to achieve symptom relief.

As people become less able to swallow or more sleepy, medicines are given as a small injection under the skin. If patients need injections frequently, or continuous symptom control is needed, medicines are given using a device called a syringe driver.

Balancing the need to maintain comfort and the use of medicines at this time may be an understandable source of worry for you or your relative. Please speak to the healthcare team if you have questions or concerns.

Eating and drinking

As people approach the last days of life, it is normal to eat and drink less. When the body is becoming weaker, this affects the swallow muscles, so eating and drinking become more of an effort. The body is less able to digest and absorb food and drink. When this happens, people frequently lose their appetite and may stop eating and drinking. This can be upsetting for families because it is our natural instinct to provide food and drink as a way of nurturing those we care for. It is common for families to worry that their relative will suffer from a lack of nourishment. It is important to remember that it is the illness that causes these changes, and that feeling less hungry or thirsty are a normal response. It is rarely uncomfortable for the dying person.

Where people are still able to take food and fluids, this can be offered regularly, but don't be surprised if your family member only wants a few sips or mouthfuls at a time. As eating and drinking becomes more of an effort, they may need help to take sips of fluid. A drinking beaker, short straw or plastic syringe may make it easier. Fluids can also be thickened to make swallowing them easier. People who are wakeful may choose to continue taking small amounts of food and fluids, even if it makes them cough or splutter.

When people become unable to swallow safely without choking, caring for the mouth becomes an important part of maintaining comfort. A soft toothbrush or plain swab soaked in water can be rubbed gently and regularly around the mouth and lips. Other fluids such as tea, squash or even a favourite alcoholic drink can be used if this is something your relative might like. Water soluble mouth gels should also be available at the bedside to keep the lips and the inside of the mouth moist. Families can have an important role in delivering mouthcare at this time.

You may have questions about the role of artificial food and fluids, and whether this would be beneficial. Artificial food and fluids do not prolong life in dying patients and rarely promote comfort. For some patients, giving food or fluids artificially may cause symptoms of breathlessness, restlessness, swelling, nausea and vomiting or excess throat secretions. We will always consider what would be most helpful to your relative, and discuss with you to weigh any benefits against the disadvantages. These considerations are important, and individual to each situation. Please discuss any concerns or questions you may have with the healthcare team.

Physical changes

As the last days of life approach, most people become gradually less wakeful, spending longer periods of time sleeping, and becoming drowsier and less engaged when they are awake. At this time your relative may still be able to hear your voice and be comforted by your presence. You can reassure them by speaking gently, using their name, holding their hand, or doing something that you know will comfort them, like playing familiar music.

It is common for people to experience changes in their breathing pattern, with breaths becoming shallower and/or more rapid. Though these symptoms may be understandably concerning, in most cases this is not a sign of distress and usually means that the person is deeply unconscious. We will monitor carefully for signs of discomfort so that medicines to relieve breathlessness and anxiety can be given promptly. As time progresses, it is usual for there to be longer pauses between breaths.

As people become less wakeful and more relaxed, they may experience a build-up of secretions in their throat. Changing position or specific medicines may help improve this. Gentle suctioning in the mouth can also be used to remove secretions if your relative is unable to swallow. For deeply unconscious patients these secretions are not troubling.

When death is close, the person's skin may become pale and cool, or mottled. These changes are all part of the natural process of dying. Most people remain peacefully unconscious.

Spiritual and cultural needs

There may be cultural, spiritual, or religious preferences that are important to your relative at this time. These may relate to:

- the way we deliver care
- the things that will bring comfort in the last days of life
- the way in which we care for your relative after death.

These details will be individual to each person and their family. Some patients or families may wish to meet with a member of our Pastoral Care team. This support is available to all people regardless of their beliefs. This skilled team provide the opportunity to talk through any needs, fears or worries.

Supporting the person who is dying

If you are able, just sitting alongside the person who is dying can provide real support. Careful listening may help the person to share their feelings. It may also help you to understand their concerns. Most people just want to be listened to as they express their hopes and fears. They may just want to know that they are not alone.

Caring for yourself during this time

The time approaching death is likely to be an emotional experience for families. The person who is dying, and people who care about them, like you, may go through a range of emotions. These may include shock, distress, fear, denial, helplessness, relief or sometimes anger. These feelings can come and go at different times. Both you and the person you care about may go through all of them, or some of them, or none of them.

Your own needs may be the last thing you are considering. It is important to try and keep up your strength so you can spend time with your relative or other family members. You may have some of your own ideas about what will help you at this time. Practical and emotional support from family and friends can be an important and welcome comfort. It is important to eat and drink regularly, take any usual medications, sleep as best as you can and get some fresh air.

When someone dies

Death often feels deeply shocking, even where it is expected. We are here to offer you support.

For those families who are at the bedside, a doctor or nurse will gently examine your relative to confirm that death has occurred. If you wish to, you will be supported to remain with your relative during this time. You will be given a Bereavement booklet containing information and advice about what will happen next.

Your relative will be cared for gently and respectfully in preparation for transfer to the care of our bereavement services on the hospital site. This is often called 'laying out', or 'last offices'. Please tell us if you would like to help deliver care to your family member at this time.

Cover photo courtesy of Tony Armstrong-Sly



If you would like this leaflet in large print, braille, audio version or in another language, please contact the General Office on 01872 252690

