



Care and Support In the Last Days of Life

An Information Guide

Care and Support **In the Last Days of Life**

Introduction

This booklet provides information for families and others in relation to caring for a person in the last days of their life. This includes information about symptoms that may be experienced, the care and support which may be given, and some questions that are frequently asked at this difficult time.

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What to Expect When a Person Is Dying

Individual experiences in the last days of life can vary from person to person; it is very difficult to predict what exactly will happen. Some common signs and symptoms may show that a person is entering the last days of life. Knowing what to expect may help to relieve anxiety and allows for better planning.

- They may become very sleepy and spend most or all day in bed resting and sleeping. Periods of being awake may reduce and eventually the person may be deeply asleep all of the time
- They may have difficulty swallowing and may not want to eat or drink
- They may struggle to take tablets or medicines by mouth
- They may lose control over their bowels or bladder
- They may show signs of distress or restlessness
- Their breathing may change and can sometimes become noisy
- They may become confused or disorientated
- They may become emotional and have spiritual questions
- They may lose interest in their surroundings and withdraw from people

For many people, dying is very peaceful. We understand that it can be very upsetting to watch a person go through these changes. This is part of the natural dying process and does not necessarily mean they are uncomfortable or in any distress.

The doctors and nurses looking after a person in the last days of life will be checking for any changes and will do all that they can to make the person as comfortable and dignified as possible.

Stopping Observations and Medicines

A person 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.

Routine observations such as blood pressure monitoring, regular blood sugar measurements or blood tests may no longer be done. In the last days of life these may not be of benefit to the person and may cause unnecessary distress.

Symptoms and Care

Changes in Breathing

The breathing pattern can change as the body slows down. Breathing may be fast, shallow or deep and there may be pauses between breaths.

Should breathlessness be experienced there are simple measures that may help. These can include opening a window, using a fan or changing position.

The patient may require a small dose of morphine. Morphine is usually given for pain but it can also be used for breathlessness and can be very effective. This may be given by an injection under the skin or as a medicine by mouth.

Oxygen requirements may be reassessed and whilst it may be useful for some patients, for others, oxygen may no longer be needed.

Chest Secretions

Everyone makes secretions (fluid) in their chest and throat. When someone is in the last days of their life, the normal secretions that they have cannot be cleared and they may make the person sound “chesty”. This is due to a build-up of fluid in the air passages.

The breathing can sound noisy, but is not normally distressing for the person. Changing the position of the person may help. Medications can also help to dry up some of the secretions and these can be given by injection.

Pain

Not everyone who is dying will have pain. Even if the person has difficulty communicating it is usually possible to tell if they are in discomfort and the doctors and nurses can check for this.

If there is pain, it is reassuring to know that there are several ways of relieving it. Changes in position may help. 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 as a medicine by mouth or by injection when needed. Medications will not be given unless they are needed.

Distress and restlessness

As part of the natural dying process the person may become confused, distressed or restless. Sometimes hallucinations may occur. This can be difficult for family and others to see, but measures can be taken to improve these symptoms.

It can help to keep the environment calm and quiet and to gently reassure the person by holding their hand and talking to them.

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

Sickness and Vomiting

When a person is in the last days of life they may feel sick. There are many possible reasons for this which the doctors and nurses will assess on an individual basis. The person may feel sick when they are moved or certain smells may trigger sickness. Medicines can be prescribed to help relieve this symptom via an injection.

Bowels

As a person becomes weaker and their 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, the person may lose control of their bowels. If they are very weak and are unable to get out of bed, pads may be used.

Bowels will be assessed by the doctors and nurses with the aim of maintaining dignity and comfort. This may be done by 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 the person 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 the person on and off a commode or toilet. In order to maintain dignity and comfort pads can be offered.

For some people it may be kinder 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 distress and restlessness.

Eating and Drinking

In the last days of life a person's need to eat and drink becomes less. Some people may be able to take small amounts of food and drink; others may only be able to take sips of fluid. Some may not wish, or be able, to take anything at all.

When a person is close to dying, though it is possible to give fluids by a drip into the veins (IV) or under the skin (subcutaneous), it is uncertain that this will prolong their life or help them feel better. The risks and potential benefits of fluids given by a drip will vary from person to person. The team looking after your loved one will assess this regularly.

It is comforting to provide good mouth care and ensure that the mouth is clean and moist. Gels and saliva sprays may be given to help with this. Families and others can be taught to clean the person's mouth if they wish. If a person is unable to drink, frequent care of the mouth and lips should be offered.

For patients who are very close to dying, there is no definite evidence that feeding via tubes or drips lengthens survival or improves their quality of life. In addition, there are risks and potential discomfort related to inserting feeding tubes.

If you have any concerns or questions related to this then please discuss with the clinical team.

Giving Medicines Using a Syringe Pump

Sometimes a small portable pump called a syringe pump may be set up by your doctor or nurse. 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.

A very small needle will be inserted just under the skin in the tummy or arm through which the medicines will be given.

If the person is at home, the District Nurse will bring the syringe pump with them. The family or others would need to collect any medicines from a chemist. This would be arranged by the GP and District Nurses.

Common Medicines Used to Relieve Symptoms

Medicine	Reason for Use	Notes
Morphine	Pain or breathlessness	Medicines can be given to help with side effects. Similar medicines may sometimes be used as an alternative such as Oxycodone or Fentanyl.
Midazolam	Agitation and restlessness	
Levomopromazine	Nausea and vomiting	Different anti-sickness medicines may be used depending on why a person is feeling sick.
Glycopyrronium	Secretions in the chest	Sometimes a degree of chest secretions may persist even when medicine is given.

Side effects related to each medicine can be discussed with the Nursing and Medical Staff.

Place of Care in the Last Days of Life

The person and their family may have wishes about where care should be when they are dying. Some people may have made their wishes about this known in advance. It is important that we talk to you about this and where possible we would like to meet their wishes.

If cared for in hospital, the person's family can stay by the bedside. The ward staff will discuss with you the facilities available e.g. car parking, food and drink.

People can also be cared for in their own home or care home in their last days of life. If the person is in hospital when this decision is made, the doctors and nurses will make arrangements with the aim of getting the person home as quickly as possible. District Nurses will be arranged to visit at their home. The District Nurses are available and can be contacted in an emergency, both night and day. Other services in the community may be available including Hospice at Home and Community Palliative Care Nurses. The out of hours GP service can also support care at home or in the care home.

Hospice care may also be provided in some circumstances. The ward or Palliative Care Team can make a referral to your local hospice as appropriate.

Individual Wishes and Preferences

Each individual and their family will have different needs and wishes when they are dying. If there is anything of particular importance to you please speak to nursing staff about this. If the person is in hospital, this may include the privacy of a side room if this is possible.

Please feel free to ask the nurses to remove unwanted equipment from the room to ensure you can make the room more

personal. You may wish to bring the person's own night wear, blankets or dressing gown. It may be possible for a camp bed to be placed next to the bed for you, please speak to ward nursing staff. Some families and others may want to be involved in assisting the nurses with comfort and care. If you do, please tell the nurses.

Emotional, Spiritual and Religious Needs

When we or someone we know is dying, we may find talking to someone can provide the support we need.

Often, this support comes from family and friends but sometimes it helps to talk to someone who is independent.

At this difficult time, people may wish to have their religious, spiritual, cultural or emotional needs supported. Hospital Chaplains are approachable and non-judgmental and are available 24 hours a day, 7 days a week to provide support for patients, families and others in the hospital.

If a person has spiritual or religious concerns at home, the nurses can contact local churches and appropriate faith groups to support them.

For further information regarding specific denominations and support available, please contact the Chaplaincy Department on 01254 733632.

Families may want to record familiar sounds such as children, grandchildren or family members who cannot be present, either singing or talking to the person. Playing favourite music may also be soothing.

Children are very welcome to visit to say goodbye to a loved one.

If you wish to have a memento, such as a lock of hair, the nursing staff will be able to help you with this.

Care after Death

The death of someone close to you is very significant and everyone reacts very differently to the situation. After a person has died they will be seen by a doctor or nurse. The nursing staff will then ensure the person is cared for before being taken to the mortuary.

The nurses will ask if anyone in the family wishes to assist with this care (washing/dressing).

It is possible to visit patients in the mortuary and arrangements can be made. Please ask the nursing staff for advice.

If the death of the person is at home or in the care home, they will be seen by their GP or nurse who will ensure that the person is cared for before going to the funeral directors of your choice.

Should you have any spiritual, cultural or practical wishes following the death, such as urgent release for burial or cremation, this can be discussed and the person's needs met wherever possible.

The intention would be to deliver care that is sensitive to the cultural and religious needs and personal preferences of the dying person and their family and others.

Frequently Asked Questions

What happens if my relative gets better?

Occasionally a person's condition can improve. If a person gets better, the care they need will be reassessed by the doctors and nurses caring for them. The care and treatment will be discussed with you.

What will happen to my loved one's personal belongings?

The personal belongings may be taken as appropriate by the next of kin.

What do I tell the children?

Talking to children about a person dying can be challenging and exactly what you tell them often depends on their age. Generally it is best to be as honest as possible with children.

This may be distressing and hard, but it can help children deal with things after the death a little better.

What would happen if the person deteriorated and I wasn't around?

If you are not around when they deteriorate the nurses on the ward will call you to inform you as you may wish to come in. The nurses will observe them closely and comfort them until you get there. If the person is at home then someone will need to be at home with them at all times.

Can the person hear and communicate with us even if they seem deeply asleep?

This can vary. Some people communicate by squeezing hands until they are too weak to do so. Some may still be able to communicate a little.

As their condition deteriorates further, they will be able to communicate less. Sense of hearing is a fairly strong sense and it can be comforting for them to hear familiar voices from friends and family.

Is it best to let them rest and not disturb the person?

It is generally best to ensure calm, quiet surroundings for them. Nurses may try to locate a side room for your loved one. However, this is not always possible, so as much as possible will be done to ensure a calm ward environment.

If they are at home as calm an environment as possible is preferable.

If you have any further questions or concerns please contact:

Ward/Community Team: _____

Contact Number: _____

The Consultant/GP responsible for the care of your relative/friend is: _____

If you require this **document** in an alternative format or language, please contact: Tel: 01254 732652

Polish

W celu otrzymania tego **dokumentu** w innym formacie lub języku, prosimy o kontakt z

Punjabi

ਜੇ ਤੁਸੀਂ ਇਸ ਦਸਤਾਵੇਜ਼ ਨੂੰ ਕਿਸੇ ਵਿਕਲਪਿਕ ਫਾਰਮੈਟ ਜਾਂ ਭਾਸ਼ਾ ਵਿੱਚ ਲੈਣੀ ਦੇ ਹੋ, ਤਾਂ
ਕਿਰਪਾ ਕਰਕੇ ਸੰਪਰਕ ਕਰੋ

Urdu

اگر آپ کو اس دستاویز کی ایک متبادل شکل (فارمیٹ) یا زبان میں ضرورت ہے تو براہ
مہربانی رابطہ کریں

Bengali

আপনি যদি এই **প্রচারপত্রটি** অন্য কোন আকারে বা অন্য ভাষায়
চান, তাহলে যোগাযোগ করবেন

Romanian

Dacă aveți nevoie de acest document într-un format sau limbă alternativă,
vă rugăm să contactați

Lithuanian

Norint gauti šį **dokumentą** kitu formatu ar kita kalba, prašome susisiekti su
mumis

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