

End of Life Care in hospital

An information guide for relatives,
friends and carers



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Introduction

Being informed that a person is approaching the end of their life, can be very distressing to hear. You may feel shocked, angry, overwhelmed, or worried about how you will cope or maybe unsure of what to expect.

We aim to provide a high standard of care for the dying person and those who are important to them by ensuring their symptoms are well controlled, communicating with kindness and compassion and involving you in decisions about changing the focus of care to ensure comfort and dignity is maintained at the end of life.

Once decisions have been made, a plan of care will be created specifically to meet the person's needs, preferences and wishes.

The plan of care will be reviewed daily and adjusted accordingly to ensure the person receives the most appropriate treatment and care when they are dying. The nurses, doctors and members of staff are here to help answer any questions or concerns you may have.

We know that caring for someone in their last days can have an impact on relatives, friends and carers. It can be easy to ignore your own needs when your attention is focused on the person who is dying, however, it is important to remember to prioritise your needs too.

This guide for relatives, friends and carers aims to explain some of the changes you might see when someone is dying. It describes the care and support available in the hospital for those at the end of life and for those important to them.

♥ What is End of Life Care?

End of life care is treatment, care and support for people who are approaching the end of their lives.

It can be difficult to know when a person is entering their final days and hours. Potential signs that someone is coming to the end of life include, amongst other things: having an incurable illness that is progressing despite treatment, worsening generalised weakness, reduced alertness and appetite.

When the team caring for a person believe that the person is dying, they will gently try to explain this to the person. If the person is not able or not well enough to communicate, they will speak with you as the relative, friend or carer. They will ask you, your views, thoughts, and feelings as these are significant in planning and giving the best care to the person that is dying.

♥ The care you can expect to receive in the final days

Staff may suggest using an end-of-life care plan to try to ensure the dying person receives holistic care.

This may include the prescription of medicines that can be used to ensure physical and psychological comfort, and a change from monitoring of blood tests, blood pressure, oxygen saturations to monitoring comfort levels.

Staff aim to individualise care to ensure physical, psychological, social and spiritual needs are met and that the people important to the dying person are supported.

♥ Changes you may see as part of the dying process

Each person's experience of the last days of life varies. It can be hard to predict exactly what will happen or how fast the changes will occur. Death can occur gradually over a period of short weeks or rapidly over a period of days or hours.

Even though it can be difficult to predict when someone is dying, there are some common characteristics and changes which a person may show when they are approaching death:.

Withdrawing from the world

For most, this is a gradual process. Spending more time asleep and often drowsy when awake. Showing less interest in what is going on or their usual daily activities. This natural process can be accompanied by feelings of calmness. Some people may be able to speak a little but as their condition deteriorates, they will communicate less. The sense of hearing may remain and it can be comforting for the dying person to hear familiar voices.

Poor appetite

When someone starts to die, their body no longer has the same need for food or drink. The body's metabolism slows down and the body cannot digest the food so well or take up the goodness from it.

The person will be supported to take food or fluids by mouth for as long as they want to and are able to swallow safely. Losing interest in food and drink and a reduced need for these is a normal part of the dying process. When a person stops eating and drinking it can be hard to accept, even though we know they are dying.

People sometimes ask if artificial fluids (a drip) will be given. These are not usually helpful and may cause more harm and increased burden of symptoms when someone is dying. An assessment is made on an individual basis and decisions made according to the dying person's needs.

Difficulty swallowing

As the dying person becomes weaker, the muscles used in swallowing can lose strength, making it difficult to control the swallowing action. This may lead to having difficulty swallowing medication, food or drinks. Signs of difficulty swallowing include coughing or choking when eating or drinking or the person may have a sensation that the food is stuck in the throat or chest.

There are several ways to support the patient with difficulty swallowing such as:

- a thickening agent being prescribed which is mixed with drinks to make it easier for the dying person to swallow.
- a small spoon or syringe can also be used to give small sips of their favourite drinks.
- If the person is awake and it is safe to give (please check with nursing staff) ice cream or an ice lolly can be brought into the hospital by the family or carers to help the person with a dry mouth.
- regular mouth care can help to moisten a person's dry mouth, lip balm or Vaseline can help to moisturise dry lips. Please speak to nursing staff if you would like to help provide mouth care.

Losing control of their bladder and bowels

A person who is near to death may lose control of their bladder and bowels. This can be managed by using incontinence pads, a conveen (in men) or a catheter. Using a conveen or a catheter can help to maintain dignity and protect the skin from becoming sore or irritated from elimination.

Limited mobility or bedbound

The person may complain of feeling weaker and having little energy. Moving around becomes harder and the person may require assistance to get in and out of bed. They may be in bed most or all of the time or start to sleep more. Nursing staff will monitor the person's skin, provide equipment and regular repositioning to help prevent pressure sores developing.

♥ Symptoms and changes that may occur just before death.

For most people dying is very peaceful. Breathing becomes slower and more irregular with long gaps in between breaths. This may take place over a few minutes although it can be a longer process. Some people may experience pain, anxiety, agitation, or difficulties with breathing. These symptoms can be managed with good nursing care and medication if needed, to ensure a comfortable and settled death.

♥ Symptoms and changes that may occur just before death include:

Changes in breathing

Towards the end of life as the body becomes less active, the demand for oxygen may become less. Oxygen masks may cause discomfort or feel irritating. If oxygen is needed it can be given through nasal prongs that sit at the base of the nostrils. Often oxygen is no longer required, and it can be stopped. Breathlessness can be a frightening symptom. The person will benefit from calm reassurance, holding hands or a fan blowing in the face can be helpful. Medications can also be used to ease breathlessness and the feelings associated with it.

There may be changes in breathing levels and sounds of breathing. For most, the final moments will be peaceful, breathing may become slower or intermittent before finally stopping. It is not unusual to have long pauses between breaths when death is close.

Respiratory secretions

Sometimes in the final hours of life breathing can incorporate a noisy rattle due to build up of secretions. Medication along with change of position may help to reduce this. The noisy breathing is unlikely to cause any distress to the dying person but can be distressing for others to hear.

Pain

Most people die comfortably and peacefully without pain. Regular checks to ensure the dying person is settled are made. If required, pain relief can be given to ensure the patient is comfortable and their dignity and respect is maintained. Please inform the ward staff if you have concerns that the person may be in any discomfort.

Anxiety

There may be several reasons why the person may feel anxious at end of life such as:

- Worrying about getting pain at end of life
- Worrying about being a burden or leaving their family behind after
- Family or money worries
- Spiritual distress

Talking about what is important to the person at end of life can help to identify any issues that may be causing distress. We aim to find out what we can do to support the dying person and those important to them. Providing emotional, practical and spiritual support can significantly help to reduce or alleviate anxiety. Sometimes, medications are also needed to ease anxiety to ensure comfort and relief.

Restlessness or agitation

Some people may become restless or agitated before they die, this is usually due to the chemical changes in the body that affect the brain. Nursing staff will check to see if there is a physical reason causing the agitation such as urinary retention. If this is not the case, medication can be given to relieve and ease the restlessness for comfort care.

Changes in skin

The dying person's circulation starts to slow down and fingers, toes, ears, and the person's nose may feel cool to touch and turn bluish in colour. In dark complexions, the skin can become darker rather than bluish. The skin may become pale prior to death.

Medications

The doctors will review the medications and may stop those that are unlikely to bring benefit. They will prescribe new medications called "just in case" medications so that if any symptoms should occur the nursing staff will be able to give the appropriate drug in a timely manner. These medications are prescribed on an "as required" basis and are aimed at controlling the following symptoms:

- Pain
- Nausea and or vomiting
- Anxiety, restlessness or agitation
- Respiratory secretions.

If the person is requiring medications regularly the use of a syringe pump will be considered. The aim of giving any medications is to alleviate pain or any other distressing symptoms to ensure the dying person is comfortable at end of life, it is not to slow down or hasten death in any way.

It may not be possible to give medication by mouth at this time, so it may be given as an injection under the skin, or sometimes, if needed, by a continuous infusion in a small battery-operated pump, called a syringe pump. This helps to provide a slow continuous infusion of medication over 24 hours. Once a syringe pump is in place, the person may still require additional injections to be given to provide effective symptom control.

Additional medications will be prescribed on an individual basis, for example if a dying person has epilepsy, medication will be prescribed and administered in the event of a seizure occurring.

♥ The kind gestures we offer at end of life

Comfort Blankets and Shared Hearts

Our community of volunteers have extended their kindness in crocheting comfort blankets, each unique to create a cosy, homely, less clinical feeling in hospital. You are welcome to keep this as it is for individual use only.

Our Shared Hearts, was an initiative created when visiting was completely restricted during the pandemic. Our volunteers knitted a Pair of Hearts. One heart given to the dying person; the other heart sent to you. A keepsake to remain with each forever. We have continued to offer this keepsake for relatives/friends or those who are unable to visit. Please ask a member of staff if you would like the person to receive a Comfort Blanket or Shared Hearts.

Free Car Parking

Parking exemption can be offered. The ward staff can complete a parking form which needs to be taken to Level 0 of the yellow multi-storey car park.

The Rose Symbol

The Pink Rose symbol is a trust initiative to promote compassion, dignity, and respect for the dying person. Our aim is to alert those hospital staff not directly involved in caring for the person or you, that this is a sensitive and precious time for you. With your consent it may be displayed at the nurse's station, bedside curtain or side room door.

Rose Volunteers

Specially trained volunteers who offer support to the person or you as end-of-life approaches. They offer compassionate, listening, comfort and companionship. They can help by reading aloud, offering mouth care, sitting service to offer respite for relatives or friends if they would like a break from the bedside or just by simply sitting and being with the person.

♥ Services available to support

Caring for Carers Service

This service provides confidential advice and support for unpaid carers who are using any of our hospital services. The team are available to listen and support with any queries or concerns relating to your caring role.

The Carer service can help support you if you choose to stay with your loved one outside of visiting times, offering a meal voucher in the hospital restaurant, encouraging you to have a break off the ward and have something to eat/drink.

If you feel you would like ongoing support following the loss of your loved one, the service can refer or signpost you to Carers in Hertfordshire. Through them you can access services such as bereavement and emotional support, for a period of up to three years.

Specialist Palliative Care Team

This is a team of Specialist Palliative Care Consultants, Clinical Nurse Specialists, Discharge Nurses, Support Worker, Administrator and End of Life Care Nurse Educator.

The Specialist Palliative Care Team do not see all patients who are at the end of life but can be called in to support if there are challenging symptoms or other more complex needs.

The Hospital Palliative Care Team based at Watford General Hospital work seven days a week and can be contacted by your ward nurse if we can be of help or support at this time.

Telephone: 01923 217930

Spiritual Care

We embrace both religious and non-religious perspectives on life. The Chaplaincy and Spiritual Care Team in the hospital are an integral part of the support available and are often called upon to provide spiritual and pastoral support. This involves lending a listening ear to anyone in need, without judgement, whatever a person's faith or beliefs.

Needs vary and the emphasis is always on a welcome for everyone that requires compassionate care. The Chaplaincy and Spiritual Care Team can be contacted by any member of staff. Please inform them should a visit be required.

There are multiple spaces in the trust that can be used as a place for sanctuary for quiet reflection, prayers or meditation. Please ask a member of staff for further information.

♥ Facilities

Usually there are no restrictions at this precious time but due to ongoing COVID-19, there may be times when visiting restrictions may be applied. Please speak to the nurse in charge for up-to-date guidance.

Open compassionate visiting for relatives/friends/carers is offered and every effort will be made to ensure you are supported and comfortable should you wish to stay.

Visitor toilets are available throughout the hospital. Please ask a member of staff for details of the nearest facilities for you to access.

Some wards do have a small number of side rooms and ward staff will do their best to try to arrange for end of life care patients to be nursed in these rooms to maintain privacy and dignity if this is your wish. Unfortunately, this is not always possible and we cannot guarantee a side room will be available. There is limited space on the wards, so please arrange with relatives and friends, if staying, for one to two visitors at the bedside at one time.

Should you choose to stay overnight please discuss with the nurse in charge. A relatives recliner chair can be arranged for your comfort.

Refreshments

Please help yourself to hot drinks available from the drinks machine on each ward. Cold water bottles are also available on request.

The Dining Room restaurant: behind Dermatology department, adjacent to disabled car park.

Monday - Sunday	7am - 8pm
Breakfast Served	7am - 11am
Hot Meals	11.30am - 4/5pm

The Dining Room coffee shop: at the back of The Dining Room restaurant

Monday - Friday	8am - 4pm
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Light refreshments of sandwiches, rolls, snacks, jacket potatoes, hot and cold drinks available.

Peabody's coffee shop: At the main entrance of the hospital on Level 2 Princess Michael of Kent (PMOK).

Monday - Friday	7am – 6pm
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Light refreshments of sandwiches, rolls, snacks, hot and cold drinks available.

Vending Machines: For hot/cold drinks and snacks.

Acute Admissions Unit:	Reception
Emergency Department:	Entrance
Maternity Unit:	Reception

There is also a vending machine on Level 2 PMOK beside the lifts by the main foyer, where you can purchase phone chargers and leads if required.

♥ Care after death

Even when death is expected it can still be a shock. The ward staff will support you and allow privacy and time to say goodbye. A trained health care professional will need to be called to verify the death, this is usually a doctor or senior member of staff.

Once you feel ready, the nursing staff will talk through with you what to do next. They will give you a booklet called 'Help for Bereaved Relatives' which gives guidance about arrangements for the death certificate, registering the death, funeral guidance and signposting to Bereavement Support Services.

Patient Affairs will contact the next of kin within 24 hours, to inform them when the death certificate will be ready to be collected.

Telephone number is 01923 217114.

♥ Organ and tissue donation

West Hertfordshire Teaching Hospitals NHS Trust supports both organ and tissue donation. Many people benefit from the kind generosity of donors and their families who are willing to consider this. Please speak to staff if you wish to have more information about this. The donation of one cornea could help up to four people to have their sight restored or improved.

If you would like to discuss tissue donation in more detail, you can contact a specialist nurse on:

Tel: 0800 432 0559 (freephone).

We hope this guide has been helpful to read, if you have any questions or concerns, please ask a member of staff for further information.

♥ Resources

Anne Robson Trust

The Anne Robson Trust is a pre-bereavement charity offering company and support to anyone who is facing the end of life or the death of a loved one. The telephone helpline service was created to provide support to people who are dying, and their families, friends and colleagues across the UK.

Free National Helpline: 0808 801 0688

Website: annerobsontrust.org.uk

Cruse Bereavement Support

Helpline: 0808 808 1677

Website: Cruse.org.uk

Samaritans

Helpline: 116 123

Website: <https://www.samaritans.org/how-we-can-help/contact-samaritan/talk-us-phone/>

Hertfordshire County Council – Bereavement Services

Website: <https://www.hertfordshire.gov.uk/services/births-deaths-marriages-and-citizenship/deaths/bereavement-services.aspx>

West Hertfordshire Hospitals NHS Trust

Watford General Hospital

Vicarage Road
Watford
Herts
WD18 0HB

If you need this leaflet in another language, large print, Braille or audio version, please call **01923 217 187** or email **westherts.pals.nhs.uk**



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