Wrightington, Wigan and Leigh Teaching Hospitals
NHS Foundation Trust

# Care at the end of life

Version number: **7**
Last modified date: **12th November 2026**

# Care at the End of Life

## Information for Relatives and Carers

## Supportive & Palliative Care Service

- Author ID: EG
- Leaflet ref: PC 004
- Version: 7
- Leaflet title: Care at the End of Life
- Last review: February 2025
- Expiry Date: February 2027

## Introduction

There comes a point in most people's lives when death and dying have to be considered.  Perhaps we must face our own death or that of someone close to us, but we don't know what to expect.  Those involved may find it easier to support each other if they know what may happen during this time.

In order to reduce the anxiety which often comes from the unknown, this booklet hopes to anticipate the questions you may want to ask, and where you can get further help and information if needed.  It contains details about the care and support which may be given, symptoms that may be experienced and some questions that have been asked frequently at this difficult time.

## Care of the dying person

The doctors and nurses have explained to you that there has been a change in your partner/relative/friend's condition.  These professionals believe that the person you care about is now approaching the end of their life and has only a few days or hours to live.

## Care

We aim to care for your partner/relative/friend with respect, dignity and compassion at all times.  Whenever possible, their needs will be anticipated and managed by the doctors and nurses.  An individual plan of care will be discussed in detail with the person themselves (where possible) and with those closest to them.  This includes provision of food and drink, symptom control, psychological, social and spiritual support. The care will be delivered with compassion and respect.

Please tell us about anything which is particularly important to you, or to the person who is dying, in order to help us to provide the best possible care.

## Communication

Communication is vital in the individualised care of your partner/relative/friend. The doctors and nurses have a responsibility to keep you well informed and involved in on-going decisions about treatment and care. If you would like to discuss this care in more detail, please ask a member of the team.

## Comfort

The doctors and nurses want to ensure that the person who is dying is as comfortable as possible. Please let them know if you feel their needs, or your own, are not being met for any reason. Please tell us if you wish to be involved in any aspect of your partner/relative/friend's care, as wherever possible a member of the nursing staff will be willing to support you with this request.

The care of the dying person will be assessed regularly and reviewed by the doctors and nurses. The outcome of these regular reviews will be explained to the person who is dying (where possible) and to those they have agreed the information can be shared with.

## Understanding the changes which occur before death

The dying process is unique to each individual but in most cases there are common characteristics or changes which help us to know that a person is dying.  These fall into four main categories:

- Reduced need for food and drink
- Changes in breathing
- Withdrawing from the world
- Changes which occur close to death

## Reduced need for food and drink

When someone becomes weaker and less well, eating and drinking often become too much effort.  Your partner/relative/friend will be supported to take food and fluids by mouth for as long as they want these and are able to swallow them. 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 is not always easy to accept this change, even when they are very unwell.  People sometimes ask if artificial fluids (a drip) will be given.  These are not usually helpful when someone is dying and in some cases may cause more harm than good.  An assessment is made on an individual basis.  Decisions will be explained to you and reviewed regularly.

## Changes in breathing

Towards the end of life, as the body becomes less active, the demand for oxygen is much less. People who suffer from breathlessness are often concerned that they may die fighting for breath, but in fact breathing often eases as they start to die. However breathing problems can be made worse by feelings of anxiety. The knowledge that someone is close at hand is not only reassuring, but it can be a real help in preventing breathlessness caused by anxiety. Just sitting quietly and holding the hand of your partner/relative/friend can make a real difference to them.

Sometimes, in the last hours of life, there can be a noisy rattle to the breathing. This is due to a build-up of mucus in the chest, which the person is no longer able to cough up. Medication may be used to reduce it and changes of position may also help. These measures may have limited success, while this noisy breathing may be worrying for relatives or carers; the dying person doesn't usually appear to be troubled by it and is often unaware that it is happening.

## Withdrawing from the world

For most, the process of ‘withdrawal from the world’ is a gradual process. The person will spend more time sleeping and will often be drowsy when awake. This apparent lack of interest in one’s surroundings is part of the natural process of dying and may even be accompanied by feelings of tranquillity and peacefulness.

Eventually the person may lapse into unconsciousness and remain in this state for a period of time. This can be up to a few days, although for others it can be shorter.

## Changes which occur close to death

When death is very close, (within minutes or hours) the breathing pattern may change again. Sometimes there are long pauses between the breaths, or the

abdominal (tummy) muscles will take over the work, with the tummy rising and falling instead of the chest. Breathing may appear laboured, but it does not usually cause distress to the person who is dying.

The skin may become pale, moist, slightly cool or mottled and discoloured prior to death.  It often becomes more delicate and vulnerable to developing pressure/moisture damage, skin tears, bleeding and infection, with changes sometimes occurring quickly, despite optimal nursing care.

Most people do not rouse from sleep, but die peacefully, comfortably and quietly.

## Simply being together

The end of someone's life can be a difficult and painful time and it can be hard for those close to the person who is dying to know what to say to them or to each other.  Simply being together, sharing company in silence, may be comforting and all that is needed.

Nurses, doctors and other staff are here to help you work through your worries and concerns and offer you care and support. If you have any questions, please speak to a healthcare professional, who will be able to advise and give you more information.

## Place of care in the last days of life

Some people may have particular wishes about where they are cared for at the end of their life.  Please speak to the staff involved in the person's care if they have expressed any specific requests about where they would like to be cared for, as we would like to meet their wishes if at all possible.

## Care at home

If your partner/relative/friend chooses to be cared for at home, the District Nursing service provide support at home.  However, 24-hour care is not provided in the community, therefore many partners/relatives/friends choose to have a care package for additional support. We can assess for fast-track continuing healthcare, to support any financial costs for the additional support. The frequency of visits may vary depending on individual needs.  The service operates a "call out" service outside of usual working hours (08:30 – 17:00). The District Nurses will aim to respond promptly and appropriately to calls.  Response times can vary; hence calls will be prioritised.

**Times of working:**

08:30 – 17:00 (day service)

17:00 – 08:00 (Evening/Night service).  There is usually four or fewer staff on duty overnight. This is similar to other health services (e.g.  GP out of hours)

Any medication the Doctor has prescribed needs to be kept safe, especially out of the reach and sight of children.  Some of the prescribed medication may not need to be used; however, it is good practice to have medication available in case your partner/relative/friend needs it.  The District Nurse will be able to give you advice.

Some medication may need to be counted, and stock levels recorded daily (this is a legal requirement). The District Nurse will monitor the quantity of stock medication remaining and will inform you if you need another prescription.

## Memories and keepsakes

Sometimes families and others close to the patient may want to record familiar sounds, or children, grandchildren or family members who cannot be present either singing or talking to the person. Playing favourite music may be soothing. This will be an individual choice.

If you wish to have a keepsake such as a handprint or a lock of hair or a photograph, please speak to the nursing staff, who will be able to help you with this. In the community, the staff will be able to support you in taking a lock of hair or a handprint.

## Religious, Spiritual, Emotional and Cultural Needs

When we, or someone we know, is at the end of their life we may find talking to others can provide all the support we need. Often this support comes from a partner, family or friend but sometimes it helps to talk to someone who is independent. At this difficult time some people may wish to have their religious, spiritual, cultural or emotional needs supported.

Please speak to the staff if you, or the person who is dying, have any needs or wishes in this area.

**You may wish to make a note here of anything which is important to the person who is dying, as well as those who are close to them.**



# Care after death

The death of someone close to you is very significant and everyone reacts very differently to the situation.  Please speak to staff if you have any needs or wishes at this time.  This section explains what happens in each setting, when a person has died.

**At the hospital:**

After a person has died they will be seen by a doctor or nurse.  Nursing staff will then ensure that care after death is given before the person is taken to the hospital's mortuary.  This care may include washing the person and changing their clothes.  The nurses will ask if any members of the family or others close to them wish to assist with this care.  The person will be taken to the mortuary and a family member may wish to go with them.  It is possible to see the person in the mortuary if you wish.  Please ask the nursing staff for advice.

**At home or in a care home**

After a person has died they will be seen by a doctor or nurse.  Nursing staff will provide care after death before the person is moved to the funeral directors of your choice.  This care may include washing the person and changing their clothes.  The nurses will ask if any members of the person's family or others close to them wish to assist with this care.

**At a hospice**

After a person has died they will be seen by a doctor or nurse.  Nursing staff will then ensure that care after death is given before the person is taken to the cool facility.  This care may include washing the person and changing their clothes.  The nurses will ask if any members of the person's family or others close to them wish to assist with this care.  However, once the person has been moved from their room to the cool facility it is no longer possible for them to be viewed until they have been transferred to the funeral director's premises.

**Information for all settings:**

In the majority of deaths that occur, the Medical Examiner will need to be notified. It is a legal requirement that this step happens as soon as possible after the death has been confirmed. In some instances, the coroner may need to be notified when death occurs. It is all dependent on circumstance of death.  If the person is at home or in a care home and an advanced plan re expected death is not in place, the police will be notified and decide if they need to be in attendance/involved. If they deem, they do not need to be involved, you will be advised to instruct a funeral director of your choice. If they deem, they do need to be involved, your loved one will be taken to the local hospital mortuary. Please do not be alarmed by this, it is normal for this to happen.

If you have any spiritual, cultural or practical wishes following the person's death, such as urgent release for burial or cremation, please let staff know and we will endeavour to meet these needs wherever possible.  Our wish is to deliver care that is sensitive to the cultural and religious needs and personal preferences of the dying person, their family and others close to them.

## Organ and tissue donation

When a person has died they may be able to donate organs or tissues (such as eyes or skin) for transplant.  This may be possible even if the person has had cancer, as long as they have not had radiotherapy or chemotherapy within the past

six months. It may be possible for this donation to take place up to 24 hours after their death.  Please speak to the staff if you wish to have more information about this.

Organ and Tissue Donation

## What happens if my relative's condition improves?

Occasionally a person who appeared to be dying can improve. Often any improvement is only temporary and the person's condition then deteriorates again after a few hours or days. However, there are circumstances when it becomes apparent that the person is not dying at that time and on rare occasions a person may live for several weeks or months after they were thought to be dying.

The person's condition and their care needs will be reassessed regularly by the doctors and nurses caring for them.  Any changes in their condition or care will be discussed with you.

## What do I tell the children?

Talking to children about a person approaching the end of life can be challenging and what you decide to 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.  The team caring for the person can advise you further regarding specialist support and offer booklets to help you decide what to say.

## What would happen if the person in the hospital or hospice deteriorated, and I wasn't around?

If you are not around when the person who is dying deteriorates, 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 with them at all times.

## How long can we stay with the person in the hospital or hospice after they have died?

You may stay with the person as long as you feel you wish to, following their death. Staff will be available if you need support during this time.

## In the hospital or hospice, what will happen to the person's personal belongings?

Staff will pack up the person's personal belongings and they can then be taken by the next of kin when convenient.

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

People vary.  Some people communicate by squeezing hands until they are too weak to do so.  Some people may still be able to speak a little but as their condition deteriorates further, they will be able to communicate less.

Their sense of hearing may remain until near the end and it can be comforting for the person to hear familiar voices from friends and family.  You may wish to play some quiet music, especially if there are pieces of music which the person particularly enjoyed.

## Is it best to let them rest and not disturb them?

It is generally best if the environment is calm and quiet and staff will try to support this where possible.  You may wish to speak to the person quietly.  If several family members or friends wish to spend time with the person, you may wish to consider taking it in turns to sit with them.

## Facilities available etc

Whilst you stay with your relative, friend or loved one on the ward, the following will also be available to you:

**Comfort Packs**
Containing toiletries and essentials.

**Relative ‘Zed-Beds’**
To allow you to rest, at your relative or loved one’s bedside, should you wish to do so.

**Refreshments**

Hot and cold drinks and meals

**Exemption from Car-parking costs**
Please ask the staff about this facility.

You will be provided with a Patient and Family diary - please use this to tell us ‘What Matters to You’, for example your partner, relative, friend or loved one’s favourite flavours (for mouth care), possessions, memories, etc.

## Key Contacts

GP (out of hours)..... 111

Community Hospice Specialist Nurses..... 01942 525 566

Wigan and Leigh Hospice..... 01942 525 566

Hospital Supportive & Palliative Care Team..... 01942 822 008

Chaplaincy Team..... 01942 822 324

Bereavement Team..... 0300 707 2524

Bereavement Liaison Nurses..... 0300 707 3548

Medical Examiner Officer…… 0300 707 3654

District Nurse Out of Hours ..... 0300 707 1266

District Nurses…… 0300 707 7700

Organ donation & transplantation ..... 0300 123 2323

## Useful National Organisations

| | |
|---|---|
| Marie Curie | www.mariecurie.org.uk<br><br>0800 716 146<br><br>Monday to Friday 9am to 5pm |
| Macmillan | www.macmillan.org.uk<br><br>0808 808 0000<br><br>Monday to Friday 9am to 8pm |
| Childhood Bereavement | www.childhoodbereavement.org.uk<br><br>0207 843 6309 |
| Winston’s Wish | www.winstonswish.org.uk<br><br>01242 515 157 |

| | |
|---|---|
| Carers UK | www.carersuk.org<br><br>Email: adviceline@carersuk.org<br><br>0808 808 7777<br><br>Monday to Friday 10am to 4pm |
| Hospice UK | www.hospiceuk.org<br><br>0207 520 8200 |
| Age UK | www.ageuk.org.uk<br><br>0800 678 1602 |
| CRUSE | www.cruse.org.uk<br><br>Email: helpline@cruse.org.uk<br><br>0808 808 1677 |
| NHS | www.nhs.uk |

## Acknowledgements

Coping with Dying. Understanding the changes that happen before death. Marie Curie Palliative Care Institute. Salmon I, Griffiths C, Bridson J.

End of Life: A Guide. Macmillan Cancer Support and Marie Curie Cancer Care, 4th edition June 2013.

Care and support in the last days of life. Salford Royal NHS Foundation Trust, 2014.

This booklet was developed by the Wigan Borough End of Life Care Task Force Best Practice Group.

NHS
Wigan Borough
Clinical Commissioning Group

Wigan & Leigh Hospice



Version number: **7**
Last modified date: **12th November 2026**

All rights reserved © 2026
WWL Teaching Hospitals NHS Foundation Trust