

If you have any comments about this leaflet or would like to receive more information please contact:

Karen Hagreen
Clinical Educator in End of Life Care
Telephone: 01422 379151

Julie Williams
Macmillan Nurse Specialist for Palliative Care Education
in Care Homes
Telephone: 030 3330 9767 Mobile: 07976 484768



Calderdale and Huddersfield 
NHS Foundation Trust



The Care and Support of the Dying Person in Calderdale

Information for the Dying Person and
Relatives/Carers



The doctors, nurses and carers in our hospitals, hospices, care homes and in the community are dedicated to caring well for people who are dying. We also want to support their relatives/friends at what can be a very difficult time.

It is vital that we get the important things right for the dying person. This will be different for each person, so we use an individualised care document for people in the last few days of life.

We are happy to discuss anything that is not clear or answer any questions. We hope this leaflet supports information that has already been discussed with you.

It is very important that you know that the very best care is being provided for your loved one

If there is anything you wish to discuss with a Doctor/Nurse/Carer please use the space below to make notes.

What type of care will my loved one receive?

We want to assure dying people and their families that high quality care will be delivered with compassion following clear discussion with families. A care document for people who are dying is used to help staff meet these needs and guide them in delivering the best care that they can at this time. It is also a way of recording the special care that dying people and their families need.

When is the Individualised Care of the Dying Document used?

The Individualised Care of the Dying Document is used when the team of doctors and nurses:

- have treated any reversible causes for a person's deterioration, and
- consider the person to be dying from their illness and in the last few hours or days of life.

What happens when the Individualised Care of the Dying Document is started?

We will continue to offer our care and support as before. Medicines that are no longer helpful will be stopped but the doctors will ensure that important medicines (for pain, sickness or breathlessness) are given by different means if the person cannot swallow (by using syringe pumps for example). Nursing staff/ care home staff will ensure that care continues with an emphasis on keeping your loved one comfortable

How will a relative or carer know if the Individualised Care of the Dying Document is being used?

The fact that the person's illness is worsening should always be discussed with the main carer or key family members. Where possible it will always be discussed with the person, although they may be too ill to talk.

We will ask you if there is anything that is of special importance for your loved one at the end of life. This might be good pain or symptom control, any religious or emotional needs, knowing that you are supported, or special requests at the point of death or after death. The doctors or nurses will be happy to answer any of your questions

After death

The person is entirely unresponsive, breathing, heartbeat and pulse has stopped, the eyes are fixed and may be open or closed and there may be a loss of control of urine or bowels. There may be a loss of saliva from the mouth.

What to do after the death

Do not call 999 - this is not necessary when a death is expected.

Call your District Nurse or doctor so that the death can be verified.

Call family, friends and any spiritual advisor you would like to come.

Call the funeral director when the nurse or doctor has verified the death.

There is no rush to call the funeral director if you wish to spend time with the person who has died.

When death is very close

When death is very close, within minutes or hours, the breathing pattern may change. Sometimes there are long pauses between breaths. The abdominal muscles (tummy) may take over the work and the abdomen will rise and fall instead of the chest. If breathing appears laboured, remember that this is more distressing to you than it is to the dying person. The skin of the dying person can become pale, moist and slightly cool prior to death. It is likely that they will not rouse from their sleep, but die peacefully, comfortably and quietly.

What will happen when my loved one dies?

We will do everything we can to make sure that your loved one is comfortable, pain-free and not in distress when they die. When someone dies from a natural process, we cannot resuscitate them, and the doctors will already have made a decision not to attempt resuscitation (DNACPR) when they die.

How often will the person be reviewed?

The dying person will be reviewed as often as needed. It is important to give all necessary care whilst giving you some private time as a family. If you feel we aren't quite getting this balance right for you please let the clinical/care team know.

If the person improves, what will happen?

If the person's condition improves, use of the Individualised Care to the Dying Document will stop and care will return to our usual care following discussion with your family. Should the person deteriorate again, we will check to make sure the right care is given and will explain things to you again.

What if a relative or carer disagrees with the use of an Individualised Care of the Dying Document?

It is important that you feel supported and have the opportunity to talk with us about personalised care. We encourage persons and carers to share their views with us about any aspect of care, including the Individualised Care of the Dying Document. We are happy to discuss this and answer questions about it. If you would like to see a copy of the paperwork on which we record the care we provide, please ask to see this.

It is very important that you know that the very best care is being provided for your loved one

Medication/Treatment

Medication will be reviewed and any that is not helpful at this time may be stopped and new medication prescribed. Medication to control symptoms will be given when needed.

This will be carefully monitored to make sure that:

- It is given at the right time;
- Just enough is given to ease the symptom, and
- No more than is needed is given

It may not be possible to give medication by mouth at this time so medication may be given by injection or sometimes, if needed, by continuous infusion by a small device called a syringe pump. This will be tailored to individual needs.

It may not be appropriate to continue some tests at this time; these may include blood tests or blood pressure and temperature monitoring. The team looking after your relative/friend will make regular assessments of his/her condition.

The staff will talk to you about maintaining the person's comfort; this will include discussion regarding position in bed, use of a special mattress and regular mouth care. You may want to be involved in elements of care at this time

Religious/Spiritual/Cultural needs

As part of the plan of care nurses and care staff will explore any needs, values, beliefs, wishes, desires or traditions that are important to the dying person and relative/friend. These may be about religious, spiritual or cultural needs. You may want to ask for specific support from a religious or spiritual advisor, regarding special needs now, at time of death or after death.

Not everyone that dies has a formal religious tradition or belief but any specific needs at this time should be explored.

Do you promote euthanasia?

No - We will neither do anything to speed up someone's death nor artificially prolong life. We want to provide the best possible care in the last hours or days of life, and will tailor this to each person and their family.

Changes in bladder or bowel patterns

Do not worry if the need to pass urine or to have bowels opened decreases. This is normal when someone is dying.

Changes in breathing

People who suffer from breathlessness are often concerned that they will die fighting for their breath. Towards the end of life as the person becomes less active, the need for oxygen is greatly reduced. Relatives and friends often say that when the person is dying their breathing is easier than it has been for a long time.

Breathing difficulties can be made worse by feelings of anxiety. Knowing someone is close at hand is reassuring and can help reduce breathlessness caused by anxiety. The dying person may have a noisy rattle to their breathing in the last hours of their life. This is caused by a build-up of mucous in their chest, which they cannot cough up.

The nurses may give them medication to ease this and changes of position may also help although you may find the noisy breathing upsetting it shouldn't distress the dying person.

Understanding the changes which occur before death

The dying process is unique to each person but in most cases there are common characteristics or changes which help to indicate that person is dying.

In order to reduce anxiety which often comes from the unknown, this leaflet describes some common features of the process of dying. It anticipates questions you may want to ask and hopefully it will encourage you to seek further help and information.

Any one of these signs can be attributed to something other than dying, so remember that the events described here are happening to a person whose illness is already so severe that life is threatened.

The many changes which indicate that life is coming to an end fall into three main categories:

1. Reduced need for food and fluids
2. Withdrawing from the world
3. Changes in breathing.

Reduced need for food and drink

Initially as weakness develops, the effort of eating and drinking may simply have become too much and at this time help with feeding/drinking might be appreciated. Your relative/friend will be supported to take food and fluids by mouth for as long as possible.

Offer small helpings of their favourite food or drink, but do not try to force them to take food or fluids.

Good mouth care is very important at this time.

When someone stops eating and drinking it can be hard to accept, even when we know they are dying. It may be a physical sign that they are not going to get better. Your relative/friend may not want or need food and/or drink.

For some people the use of artificial fluids can add to a risk of developing distressing symptoms. Decisions about the use of artificial fluids (a drip) will be made in the best interests of your relative/friend if they cannot make a decision for themselves. This will be explained to you and reviewed regularly. If they wish to remain in their home/care home to die then artificial fluids (a drip) would not be offered.

Sleeping, drowsiness, restlessness and confusion

The dying person may spend more time sleeping and will often be drowsy when awake. This change is a gradual process.

Save conversation for when the person seems more alert.

Sometimes they may be confused about the time, date and place and not recognize familiar people.

Speak calmly and remind the person of the day, the time and who is in the room, if they seem distressed by being disorientated.

The dying person may become restless, pull at the bed clothes and see people or things that are not in the room

Reassure the person and avoid physical restrictions when possible. Use enough covers so that the person seems comfortable

The dying person may have difficulty in hearing and seeing and may have a fixed stare

Leave a soft light on in the room. Assume that the person can hear you at all times.

Try not to be upset if any of these symptoms happen or there is little response. This natural process may go together with feelings of tranquillity. Eventually they may lapse into unconsciousness and may remain like this for a surprisingly long time, for some people it may be quite a number of days, and for others a shorter time.