



East Suffolk and
North Essex
NHS Foundation Trust

Care in the last days of life

***Palliative Care team
Colchester Hospital***

Tel: 01206 746272

***Palliative Care team
Ipswich Hospital***

Tel: 01473 704932





Choosing the right term for all situations, such as loved one, relative, partner, friend etc is difficult. In order to make this leaflet as easy to read as possible we have chosen the term 'relative' but the leaflet is intended for anyone with a connection to the patient.

Death is a sensitive subject and one that many people are not comfortable discussing. This leaflet will give you some information about questions that we are frequently asked. We hope that you will find it useful during this difficult time. The doctors and nurses looking after your relative believe that their condition has deteriorated and that they may be in the last few days of life.

There are bodily changes that could mean that they are likely to be close to death. It is normal for these changes to come and go over a period of days and if they do go it does not usually mean that they are getting better. Knowing about these changes may help you cope during this time.

Some of these changes may be upsetting but the following information may help you to understand that these changes are not unusual.

It is very important for everyone involved to be clear about the plan of care and have their needs understood and met. We would encourage you to tell us what is important to both you and your relative. Please feel free to ask questions at any time although you may also find answers within this leaflet.

Communication

We would like to talk regularly to you about the plan of care so that you fully understand the reasons why decisions are being made. The plan of care will be reviewed and changed if your relative's condition gets better or gets worse.

This leaflet has been written to help you because it is sometimes difficult to remember everything that the doctors and nurses will tell you.

Medication and treatment

Regular medicines that are not helpful at this time may be stopped and new medicines may be given to keep your relative comfortable. Medicines for symptom control will be given only when needed to help relieve the symptom they are experiencing. If your relative is no longer able to take medicines by mouth, it may be given by injection or by a small syringe pump.

It is unlikely doctors will continue with tests such as blood tests and blood pressure monitoring as they are no longer appropriate at this time. If you believe your relative is too hot or cold, try moving the bed covers as this may help. A person's heart and breathing can stop working as part of the natural process of dying. If people are already very ill and near the end of their life, there is usually no benefit in trying to resuscitate them each time their heart and breathing stop. This is particularly true when people have other things wrong with them that mean they do not have long to live. In these cases, trying to re-start the heart and breathing may do more harm than good by prolonging the pain or suffering of a terminal illness.



Reduced need for food and drink

Not wanting to eat and drink is part of the normal dying process. It may be a physical sign that they are not going to get better and in advanced illness, people can start to lose weight even when their appetite is still fairly normal because the body is no longer able to use the food it is given. This is why the appetite gets smaller – the body seems to know that it can no longer cope with food. When a person stops eating and drinking, it can be hard to accept even when we know they are dying. Your relative will be supported to eat and drink by mouth for as long as possible. If someone is very weak and is given fluid by mouth it may go down the wrong way and make them cough and splutter, and they may not want to continue.

Good mouth care is very important at this time to ensure the mouth remains moist and comfortable. The nurses will explain how this is done and may ask if you would like to help. The doctors and nurses will assess daily if they cannot manage fluids by mouth, then a drip may be considered but only where it is helpful and not harmful. If started it will be closely checked to make sure there are no side effects from it. In the last few days or hours of life the body cannot handle fluid as well as before – giving drips can sometimes make things worse. If this happens the person may experience ‘chestiness’ or noisy breathing, and swelling of the arms or legs, as their body cannot get rid of the fluid from the drip.

Changes in breathing

When death is approaching their breathing may change. Sometimes there are long pauses between breaths or the breathing may become fast and shallow. Occasionally a 'bubbly' noise may develop as a result of a build-up of fluid that they can no longer cough up but this does not cause distress. Medicines or a change of position may sometimes help. If a person is breathing through their mouth, moistening the lips and tongue and applying lip balm will help.

Spending more time asleep

A person who is reaching the end of their life will spend more time sleeping and may eventually become unconscious. This is part of the natural process and they may remain in this state for a long time (in some cases, many days) although for others this time will be much shorter.

Even if the person doesn't respond, keep talking and touching them as they may still be aware that you are there which can be a great comfort to them.

Appearance

Skin can change in colour and become clammy or slightly cold. The eyes may stay open and seem to stare which can tell you that death is getting near. The heart doesn't pump properly which can mean there may be more fluid in the body and so the arms and legs appear bigger. Urine may become darker in colour and they will pass less.



Restlessness and agitation

The person may become more restless and agitated. This may happen in the last few days of life, though the person may become more peaceful before they die. Sometimes they may seem confused and may not recognise familiar faces. They may see or hear things that are not there – for instance they may see pets or people that have died. Sitting with the person may often help to calm them down. Keeping things as normal as possible may help comfort the person.

Bowel and bladder

The person may lose control of their bladder or bowels. This happens because the muscles in this area relax and don't work as they did. They may also have fewer bowel movements as they eat less and their urine may get darker as they drink less. The person may also become incontinent and need a catheter or incontinence pads to prevent their skin becoming sore.

Comfort

To keep your relative comfortable we may discuss any preferences they may have such as their position in bed. We don't move patients regularly, it depends on if they would like to be moved and if they are uncomfortable.

Spiritual care

We embrace both religious and non-religious perspectives on life. We support anyone who wishes to talk about personal thoughts and feelings that have arisen as a result of past and recent experiences. Please ask a member of staff if your relative would like to see a chaplain or faith community leader.



Chaplains provide spiritual and pastoral support for the family, friends and carers of patients throughout the hospital, for people of all faiths and of no faith. Chaplains and Chaplaincy volunteers visit wards and departments regularly. Chaplains operate a 24-hour on-call service and can be contacted via the switchboard by any member of staff. Chaplains can also arrange emergency marriages or blessings, so please ask the ward to contact them if this is required.

Your needs are also important so please tell the staff of anything that can be done to help and support you at this time.

Staying with your relative

Usually there would be no restrictions on visiting your relative at this time, but due to COVID-19 there are restrictions on the number of family and friends who can visit. Please speak to the nurse in charge if you need further information. We would also encourage children to visit but please check this is possible. We can support you if you want to stay on the ward area, so please talk to the nurse in charge. We will try and accommodate your relative and family in a side room whenever there is a room available, though if they do not want to move then we will support them in a bay. Please also ask the ward about a free parking permit and they will advise how you get one. This allows you free parking for seven days, and then you would need to request a new permit when this runs out.

The person's final moments

In the last few minutes, the person's face may relax and they may become very pale. Their jaw may drop and their eyes become less clear. The breathing will eventually stop and their body will completely relax.



Sometimes it can be difficult to be sure of the exact moment when the person died. There maybe one or two last gasps a minute or so after what seemed like the last breath.

This is always an emotional time, even when death has been expected for days. You may suddenly feel very shocked and sad. You may want to be alone or you may want to phone family and friends.

Care after death

When someone dies, a trained healthcare professional needs to verify the death which means to confirm that the person has died. This could be a nurse or doctor. They have to record the time they have verified and not the time of death so this may be some time after your relative took their last breath.

After death you may see a purple butterfly on the door or curtain of the bed space where your loved one is in. This is to assist other staff that may come to the ward, to recognise that a patient has died and that the family may still be present, therefore ensuring that you are not disturbed unnecessarily whilst with your loved one.

After they have died you can spend some time with your relative, and pack up their belongings. If your relative has any specific religious or cultural wishes, please let the nurses know. If you would like to participate in the final care of your relative or wish to dress them in specific clothing, please let the nursing staff know that too.

Once you are ready to leave, please take all your relatives' belongings and then the nursing staff should give you a leaflet titled 'What do I do now?' which will inform you of what happens next and how you register your relative's death.



Organ and tissue donation

East Suffolk and North Essex NHS Foundation Trust supports both organ and tissue donation. Organ and tissue transplantation saves and enhances people's lives. For instance, donated corneas can give sight to people blinded by cataracts and donated skin is used for skin grafts for burns victims. Many people each year benefit from a transplant, but this depends entirely on the generosity of donors and their families who are willing to consider organ and tissue donation.

For patients not in Critical Care, tissue donation (such as eyes, bone, skin, connective tissues), can offer the opportunity for relatives to fulfil their relative's wishes. When tissue has been donated, it is used for transplantation and offers huge benefits to many people.

Tissue can be donated up to 48 hours after death, so it is important to let medical or nursing staff know your wishes as soon as possible. Funeral arrangements are not delayed and family members are still able to view their relative's body after donation occurs.

A specially trained nurse from NHS Blood and Transplant will contact you and can give you more information.

Alternatively, you can phone them directly on

0800 432 0559.



Please use this space for any notes you wish to make.



Please ask if you need this
leaflet in an alternative format.

Issued by:
East Suffolk and North Essex NHS Foundation Trust
Ipswich Hospital, Heath Road, Ipswich IP4 5PD
Colchester Hospital, Turner Road, Colchester CO4 5JL
www.esneft.nhs.uk



Issue 3: October 2020 Review date: September 2023
© East Suffolk and North Essex NHS Foundation Trust, 2014-2020.
All rights reserved. Not to be reproduced in whole, or in part,
without the permission of the copyright owner.