

Even if the person is unresponsive, keep communicating and touching as they may still be aware of your presence 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 indicate death is getting near. The heart struggles to pump properly which can result in swelling of the arms and legs. Urine may become darker in colour and decrease in amount. The person may also become incontinent and need a catheter or incontinence pads to prevent their skin becoming sore.

### **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 again before they die. Sometimes they may appear confused and may not recognise familiar faces. They may hallucinate and see or hear things that are not actually there – for instance they may see pets or people that have died. Simply 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.

### **Comfort**

The staff will aim to keep your relative or friend comfortable so please feel free to discuss any preferences they may have such as their position in bed.

### **Spiritual care**

We embrace both religious and non-religious perspectives on life. We support anyone who wishes to explore personal thoughts and feelings that have arisen as a result of past and recent experiences. There is a leaflet about the hospital chaplaincy service available on the wards. Please ask a member of staff if the patient would like to see a chaplain or faith community leader. 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 loved one**

We can support you if you want to stay on the ward area, so please talk to the nurse in charge. There should be no restriction on visiting and we encourage children to visit, but again please speak to the nurse in charge to check that it is appropriate at that time. We will try and accommodate the patient and family in a side room whenever there is a room available, though if the patient does not want to move then we will support them in a bay.

### **The person's final moments**

Particularly in the last few minutes, the person's face muscles may relax and they may become very pale. Their jaw may drop and their eyes become less clear. The breathing will eventually stop. Often, the person's body will completely relax. Sometimes it can be difficult to identify 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. However, you should note down the time as close as possible to the moment they died.

This is always a profound moment, even when death has been expected for days. You may suddenly feel overwhelmed with sadness; you may want to be alone or you may want to phone family and friends.

By this time you will be exhausted with the caring and the waiting and the relief and finality of the moment of death can take you by surprise.

### **Care after death**

Caring for a patient at the end of their life, and after death, is enormously important and a privilege. There is only one chance to get it right, and so knowledge of the appropriate practice will ensure the key elements of care are undertaken. Total care after death demonstrates our respect for the patient and is focused on maintaining privacy and dignity and fulfilling religious and cultural beliefs. Therefore if there are any religious or cultural wishes of the patient, please let the nurses know. Also if the family would like to participate in the final care of the patient, or wish to dress them in specific clothing, please let the nursing staff know that too. Once the final care has been completed the family can take the belongings if they would like to.

If you do not wish to help in the final care then please spend some time with your loved one, you can pack the belongings if you wish and then once you are ready to leave, the nursing staff will then give you a leaflet titled 'What do I do now?', which will inform you of what happens next.

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.

### **What is cardiopulmonary resuscitation (CPR)?**

Cardiorespiratory arrest means that a person's heart and breathing stop.

If someone is very weak and is given fluid by mouth it may go down the wrong way and make them cough and splutter.

Good mouth care is very important at this time to ensure the mouth remains moist and comfortable. The nurses will explain how this is given and may ask if you would like to help. The doctors and nurses will assess regularly the need for artificial hydration and if the person cannot take fluids by mouth, fluids given by a drip may be considered but only where it is helpful and not harmful and if started it will be closely reviewed 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 efficiently as before – giving drips can sometimes make things worse by overloading the delicate fluid balancing mechanisms of the body. If this happens the person may experience 'chestiness' or noisy breathing, and swelling of the arms or legs, as their body cannot process the fluid from the drip.

### **Changes in breathing**

When death is approaching the breathing pattern 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 the person can no longer cough up but this does not cause distress. Medication or a change of position may help but will often have only limited success. We try to avoid suction as it can be more distressing. If a person is breathing through their mouth, moistening the lips and tongue and applying lip salve will help.

### **Withdrawing from the world**

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 surprisingly long time (in some cases, many days) although for others this time will be much shorter.

If your relative/friend is no longer able to take medication by mouth, it may be given by injection or by a small pump called a syringe driver.

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 loved one is too hot or cold, adjusting the bed covers may help or tell the nursing staff who can give paracetamol to reduce a high temperature.

### **Coping with dying**

The dying process is unique to each person, but there are common changes that may take place. Knowing about these changes may help you cope during this time.

### **Reduced need for food and drink**

Loss of interest in and a reduced need for food and drink are 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, to build itself up. This is why the appetite gets smaller – the body seems to recognise 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 or friend will be supported to eat and drink by mouth for as long as possible.

It is normal for people who are dying from advanced cancer and other illnesses, to eventually stop drinking and to stop feeling thirsty. As the body weakens and the systems start to work less well, there is less need for fluid. It is also important to remember that it is the illness which is making the body systems fail, not a lack of fluid.

When this happens, it is sometimes possible to try to restart their heart and breathing with emergency treatment called CPR. This might include:

- repeatedly pushing down very firmly on the chest
- using electric shocks to try to correct the rhythm of the heart
- inflating the lungs with a tube inserted into the windpipe or a mask on his or her face.

A person's heart and breathing can stop working as part of the natural process of dying. If people are already very seriously 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 patients 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.

### **If it is decided that CPR will not be attempted, what then?**

The healthcare team will continue to give the best possible care. The healthcare professional in charge of your relative's care wants you to be involved and to understand why the decision has been made. There will be a note in the health records that your relative is “not for cardiopulmonary resuscitation”. This is called a “do-not-attempt-resuscitation” or DNACPR decision.

### **Organ and tissue donation**

Colchester Hospital University 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 patients 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.

Tissue donation (eg eyes, bone, skin, connective tissues), especially in cases where organ donation is not possible, can offer the opportunity for relatives to fulfil their loved one'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, therefore 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 loved ones 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.

To join the organ donation register contact [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk) or telephone: 0300 123 23 23

### **Colchester General Hospital facilities**

- Senses restaurant can be found on the first floor of the main building. Opening hours:  
Breakfast: 8am - 11.15am      Lunch: Midday - 2.15pm  
Supper: 5pm - 8pm              Snacks: 8pm - 10pm
- Shops  
The hospital has League of Friends shops located in the main entrance of each wing where a selection of confectionery, newspapers, magazines, soft drinks (hot and cold), toiletries, sandwiches, fresh fruit and hot snacks can be bought.

- ensure that symptoms such as pain, nausea, agitation, shortness of breath and respiratory secretions are managed
- support the intake of food and fluids by mouth for as long as possible
- ensure that physical needs such as bowel care, mouth care, passing urine, pressure area care and personal care are assisted with whenever required
- assess and review effectiveness of medication.

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/friend. Please feel free to ask questions at any time although you may also find answers to your questions within the "Coping with dying" section.

### **Communication**

We would like to discuss regularly with you 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 or friend's condition deteriorates or improves.

This information booklet has been written to support what you have been told because it is sometimes difficult to remember everything at this difficult time. The doctors and nurses will ask you for your contact details, because keeping you updated is our priority.

### **Medication and treatment**

Regular medication that is not helpful at this time may be stopped and new medicines may be prescribed to keep your relative/friend comfortable. Medicines for symptom control will be given only when needed to help relieve the symptom they are experiencing.

## **Coping with dying**

You may wonder what the dying process involves – what actually happens in the very last days and hours of a person's life? This process is unique to every single person. It is not always possible to :

- know for sure that a person is in the last days of life
- predict exactly when a person will die
- know exactly what changes the person you are caring for will experience when they are dying.

There are certain bodily changes that signify a person is likely to be close to death. It is normal for these signs to come and go over a period of days, and if they do go, this does not usually mean that the person is recovering.

Some of these changes may be distressing, but the following information may re-assure you that many of these changes are not unusual and suggest how you can help or seek guidance. As a carer, if any of these signs do start to overwhelm or distress you, you may wish to take a break and leave the bedside for a period. It is important to think about your own feelings as well as the person you are caring for.

## **Our aims now are**

- to provide care for these days that reflects their personal need
- to promote care that prioritises their wellbeing
- to promote the patient's involvement and that of the family/carers if they so wish, in the planning of the care.

To achieve these goals we will

- communicate to the family/carers information regarding the current condition and care as often as is needed by them, but at least daily
- assess regularly and document our assessments in their care record

The biggest shop is in the Main Entrance next to the Outpatients Department which is open 8am - 8pm weekdays and Midday - 5pm at weekends and bank holidays. There are also shops in Gainsborough Wing, Constable Wing and Elmstead Day Unit with more restricted opening times. If you or your visitors cannot find what you need in any of these shops, ward staff can direct visitors to nearby supermarkets.

- Cash-point

There is a cash-point machine at the hospital on the main corridor leading from the Main Entrance.

## **Car parking**

All visitor car parks are pay-on-exit and unauthorised parking will result in a parking fine. You can obtain a weekly ticket from the General Office at the front of Colchester General Hospital at a reduced rate

## **Comments, compliments or complaints about your care?**

Please call PALS (Patient Advice Liaison Service) on 01206 742683, pick up a leaflet or visit [www.colchesterhospital.nhs.uk](http://www.colchesterhospital.nhs.uk)

## Coping with dying

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*This booklet is supported by:*

*What to expect when someone is dying, NCPC 2015*

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

Please ask if this  
leaflet is required in  
an alternative format

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best.*