



End of Life Care

Last Days of Life





Aim of this guide

Hearing the news that someone you care about is nearing the end of their life can be very difficult and distressing. You may feel overwhelmed and have feelings of disbelief or shock. The person you care about will be experiencing their own emotions which can be difficult to manage along with your own feelings.

You may have concerns about the future and feel depressed, tearful or angry that the person you care about is dying. You may be unsure how to cope with all the emotions and feelings you have. Family and friends can be a great support, but you may find it difficult to talk to them while they are dealing with their own feelings.

It is important to consider your own wellbeing and needs alongside the needs of the person you care about. You may have questions about what will happen when the time comes, or be unsure about the support available to you. This guide aims to explain the changes you may see in the person and in the care they receive in the last days of life.

Help and support is available from various sources, including those involved in the care of the person that is dying. Ward staff, the Chaplaincy and End of Life Care teams are here to help and answer any of your questions.

Our volunteer End Of Life Care Sitting Companions provide one-to-one support by listening, comforting and showing companionship to the dying person and those important to them. They can spend time with patients who may have infrequent or no visitors or those with emotional distress. They are able to assist with food and drink and mouth care. They can sit with the patient to enable family and friends to have a break from the bedside vigil or run errands to the hospital shop. They are happy to make refreshments for the family. Please ask the ward staff if you would like one of our volunteers to support you.

We hope this guide will provide information and sources of support that may be helpful to you at this difficult time.



Nearing the End of Life

Each person's experience of the last days of life will be different and it can be very difficult to predict what exactly will happen or how quickly the changes will occur.

Usually the person will gradually get weaker and have very little energy. Moving around becomes more difficult and they may need assistance to get in and out of bed. They may be in bed most of the time and become sleepier. You may notice that they have a reduced or no appetite for food. They may begin to withdraw from their surroundings and family.

For most people dying is very peaceful. They may become unconscious and it will be difficult to wake them. Others have periods when they are awake, can talk and then slip back into unconsciousness. Some people may experience some pain, agitation or difficulties with breathing. These symptoms can usually be managed with medications.

The aim of giving any medications is to keep the person settled and comfortable. These medications are not given to slow down or hasten death but to ensure the comfort of the person. If you feel that the person you care about is distressed, uncomfortable or in pain, please inform the staff.

Medications can be given by injections with a needle under the skin if the person is feeling sick, is unconscious or unable to swallow. Medications to manage symptoms commonly experienced in the last days of life will be prescribed and are given as and when needed. If the person is requiring medications regularly, the use of a syringe driver will be considered. A syringe driver is a small portable pump that can deliver medications continuously. A doctor or a nurse will explain the medications used and let you know if a syringe driver is being considered.

When a person is recognised as being at the end of their life, the End of Life Care Plan, an individualised care plan for last days of life, may be used. This helps us to fully assess the care needs and support required to both the person and those important to them. We want to understand if there is anything that would help you to cope at this difficult time. The care plan supports the staff to provide good end of life care and to manage symptoms.



Eating and Drinking

The person's appetite may already have reduced over the last weeks and months as they have become less well and their appetite is likely to be much reduced now. They may no longer wish to eat or drink anything. It may be because they have little or no need or desire for food and drink or they may find the effort of eating and drinking too much. Eventually the person will stop eating and drinking, and will not be able to swallow tablets.

It may be difficult to accept if someone stops eating and drinking, but it is a normal part of the dying process. The body's metabolism slows down and the person becomes unable to digest food or take any goodness from it. The effort of eating and drinking can become just too much. If they stop drinking, their mouth may look dry, but this does not always mean that they are dehydrated. There can be several other reasons for having a dry mouth.

If the person is conscious and they want something to eat or drink, you can offer sips of fluids and a spoonful or two of soft diet, provided they are still able to swallow. Sometimes using a straw or teaspoon may make it easier for the person to drink. A nurse will be able to help you to assess this. If someone is unable to swallow food or fluids, good mouth care & taste for pleasure can help your relative feel more comfortable. The nurses will explain to you how mouth care & taste for pleasure are given and may ask if you would like to help them give this care. There may be little or no apparent response from the person, this is likely due to weakness and not lack of appreciation. Just being together with the person may be comforting to you both.

Fluids given via a needle into a vein or under the skin are not routinely given in the last days of life. They are unlikely to improve comfort for the person you care about or make them better. As part of the natural dying process, the body's ability to manage fluids is reduced. Giving large amounts of fluids can lead to an unhelpful build-up of fluid on the chest or in the tissues of the arms and legs. Individual hydration needs will be watched closely. If you have any questions or concerns about this, please speak to a member of staff.



Breathing

As the person's body becomes less active they need less oxygen. People who suffer from breathlessness are often worried they may die fighting for breath, but often it is found that their breathing may ease during the dying phase and breathing can become easier.

Sometimes the person may sound chesty and their breathing may become noisy. This is likely because they are not able to swallow, or cough and clear, the normal fluids in their chest or throat which can cause a rattling sound.

A change in the breathing pattern is a normal part of the dying process. The breathing may become more shallow and rapid and, at times, can become noisier and sometimes rattly. However it generally does not seem to cause any distress to the dying person. It can be a bit like snoring – it affects those who can hear it more than the person who is making the sound.

Breathing difficulties can be made worse by feelings of anxiety or fear. Reassurance, medication and the comforting knowledge that someone is close by can make a difference. Someone familiar sitting with them may help, as knowing someone is there may reduce their anxiety. Also opening a window or using a fan may help. Giving added oxygen at this time is not usually necessary. If the breathing is very noisy, sometimes changing their position may help. The doctor or nurse may also suggest medication to try and reduce the mucus in their throat and chest. The medication may not always be needed and is not always helpful.

Reduced consciousness

For most, the process is a gradual one. It is normal for a dying person to sleep more. They are likely to spend more time sleeping and will often be drowsy even when they are awake. They become less interested in what is going on around them and also have less energy to take part. Some people become completely unconscious for a period of time before they die – this could be for a very short time or as long as several days. This does not always mean they no longer hear what you say to them. Even when the person appears to be sleeping or resting, they may still be able to hear you. Don't feel that you need to stop communicating with the person; you may want to carry on speaking quietly and calmly to them. You can also hold their hand, read to them or play their favourite music to let them know that you are there.



Changes that occur shortly before death

The dying process is different to each person, but in most cases there are some common signs which help to indicate that the person is dying.

The breathing pattern may change again. There may be long pauses between breaths or abdominal (tummy) muscles will take over the work - you can see the abdomen rising and falling instead of the chest. Breathing can appear difficult but this is more distressing for you to see than to the person who is dying. Medication can be given if there are any signs of distress, but these changes are an expected part of the dying process

Some people can become more restless and agitated as they are nearing death. Medication can be given (pain relief and/or sedative) to help ease any symptoms which may be causing distress.

You may note that the person's skin becomes pale, moist, and slightly cool prior to death. Most people do not wake from sleep and die comfortably and peacefully. Their breathing will get slower and eventually stop. Even if the death is expected, it still can be a huge shock when it actually happens.



What happens next?

There is no need to do anything immediately when someone dies. You may need a few minutes or longer to understand and take in what has happened.

Nursing staff will attend to the person who has died to make them comfortable. They will help to close their eyes and mouth and straighten them on the bed. A doctor, or a nurse who has received specialist training, will be contacted who will come and confirm the death. The nursing staff will allow you time to spend with the person and advise you how long the person can remain on the ward. This can be up to a couple of hours. The person will then be transferred to the hospital mortuary under the care of our bereavement and mortuary team.

The bereavement office will contact you when the relevant paperwork has been completed to arrange a convenient time for you to collect this. They will advise you about registering the death. Please phone the bereavement office on 01305 255125 if they have not been in touch with you within a couple of days after the death, or if you wish to arrange a viewing. You may wish to phone the funeral director, while you are waiting to hear from the bereavement office, as they will be able to provide you with further guidance at this difficult time.

You may wish to ring a friend or relative who can stay with you and offer their support. Ward staff, the Chaplaincy and End of Life Care teams are also here to help with any concerns and provide support at what can be a very sad time.

Further resources

[AtaLoss.org](https://www.ataloss.org)

AtaLoss.org aims to ensure that people in the UK affected by bereavement can access support. They have online resources to help people find support and have a range of resources which help people cope with bereavement. They currently have a range of projects which support people of different ages.



Bereavement Advice Centre

The Bereavement Advice Centre is a free helpline and web-based service. The service supports and advises people on what they need to do after a death. On their website there is a variety of information regarding practical issues that occur after a death.

If you need advice, call them on their Free phone number - **0800 634 9494**.

Days - Monday to Friday (excluding Bank holidays). Times - 9am-5pm

Cruse Bereavement Care

Cruse Bereavement Care is a national charity for bereaved people and offers confidential and free support, advice and information. Support is available face-to-face, over the telephone and online. Trained bereavement volunteers staff the helpline and provide emotional support for people affected by bereavement.

For telephone support call them on 0808 808 1677

Days - Monday to Friday (excluding Bank holidays). Times - 9.30am-5pm.

For information about local support go to their "[local services](#)" page.

Outlook Bereavement Support

Outlook Bereavement Support is a charity sponsored by Tapper Funeral Service which provides bereavement counselling and support across Dorset. The sole aim is to help the recently bereaved come to terms with loss and find a way forward in life. The early months of bereavement are inevitably difficult so Outlook Bereavement Support hopes that by extending a hand of friendship, it can help those who need it to rediscover a social life, provide practical advice and emotional support, plus help you start to build a new future. Outlook runs a programme of events which includes social functions, support and friendship groups plus practical, educational help forums. There is no charge for membership of this group and anyone is free to join or leave as they wish. For more information please call Leanne Adimi on 01202 338530 or John Taylor on 01202 338535. You will also find Outlook Bereavement Support on [Facebook](#) and [Twitter](#)



Samaritans

Samaritans is available round the clock, every single day of the year. You can talk to them at any time you like in your own way and off the record, about whatever is worrying or distressing you.

Call for free any time on 116 123 or email jo@samaritans.org

The Bereavement Services Portal

The Bereavement Services Portal is a useful website which provides a range of information regarding practical issues after a death. Information is provided on a range of areas including funeral planning, funeral directors and memorials.

<http://www.iccm-uk.com/portalindex.php>

The Bereavement Trust

The Bereavement Trust is a national free phone helpline which provides bereavement support in the evenings.

If you need support and practical advice please call their helpline on 0800 435 455. Lines are open every day from 6pm-10pm

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If you have feedback regarding the accuracy of the information contained in this leaflet, or if you would like a list of references used to develop this leaflet, please email pals@dchft.nhs.uk



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