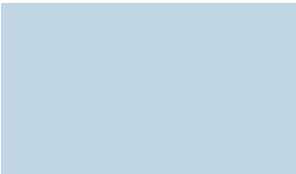


NHS

The Royal Wolverhampton
NHS Trust



Care and Support in the last days of life





Contact:



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Introduction

This booklet provides information for families and others in relation to caring for a person at the end of their life. It contains information concerning symptoms that may be experienced, the care and support which may be given and also some questions that have been frequently asked at this difficult time. The booklet has a space for you to write down any other questions that you may have for the health care team. Finally, there is space that you may find useful to communicate between family members and others, or perhaps to write down your feelings about anything specific that you may wish to share. It is important for the doctors and nurses to understand what it is that is important to you and your family/others and there is space in the booklet to write this down and discuss this with the team. It may also help to write down any concerns or questions that the professionals may be able to help you with.

What is important to you?

To enable us to provide the best care and support possible to you and your loved one, we would like to offer you the opportunity to tell us what is important and matters to you and how we can best support you.

What happens when a person is dying?

Individual experiences in the last days of life can vary from person to person and it is very difficult to predict exactly what will happen. However, there are some common signs and symptoms which may indicate that a person is entering the last days of life. Knowing what to expect may help to relieve anxiety and allows better planning.

- The dying person may become very sleepy and spend most or all day in bed resting and sleeping. Periods of being awake may reduce and eventually the person may be deeply asleep all of the time.
- They may have difficulty swallowing or not want to eat and drink.
- They may struggle to take any tablets or medicines by mouth.
- They may lose control over their bowels and bladder.
- Sometimes the person may show signs of being distressed or restless.
- Their breathing may change and can sometimes become noisy.
- Their hands, feet, legs and arms may feel cold to touch.
- The person may become confused or disorientated.
- They may experience a variety of emotions.
- Their beliefs, faith or religion may become particularly important at this time.
- They may lose interest in their surroundings and withdraw from people.

For many people, although dying is very peaceful, it can be upsetting to watch a person go through these changes. This is part of the natural dying process and does not necessarily mean they are uncomfortable or in distress. The doctors and nurses looking after the person in the last days of life will be checking for any changes and will do all that they can to make the person as comfortable and dignified as possible.



Why might observations and medicines be stopped?

A person may have been taking some medicines for many months or years and these may need to be stopped or changed if they are no longer helpful. The doctors and nurses will discuss this with you. We may no longer be carrying out routine observations, for example blood pressure, blood sugar measurements or blood tests. These may no longer be of any benefit to the person and may cause unnecessary distress.

What symptoms might a person who is dying experience?

Changes in Breathing

The breathing pattern can change as the body slows down. Breathing may be fast, shallow or deep and there may be pauses between breaths. Should breathlessness be experienced there are simple measures that may help, these include opening a window, using a fan and changing position. The person may require a small dose of morphine. Morphine (or a similar medication) is usually given for pain but it can also be used for breathlessness and can be very effective. This may be given by an injection, under the skin. Oxygen requirements may be reassessed and for some people oxygen may no longer be needed. However, for some it may be helpful.

Chest Secretions

Everyone makes secretions (fluid) in their chest and throat. When someone is in the last days of life, the normal secretions that they have cannot be cleared and they may make the person sound “chesty”. This is due to a build up of fluid in the air passages. The breathing can sound noisy but is not normally distressing for the person. Changing the position of the person may help. Medications can also help to dry up some of the secretions and these can be given by injection.

Pain

Not everyone who is dying will have pain. Even if the person has difficulty communicating, it is usually possible to tell if they are in discomfort and the doctors and nurses can check for this. If there is pain, it is reassuring to know that there are several ways of relieving it. Changes in position may help the person in pain. However, for others it may be best not to change the position. This will be assessed on an individual basis. Medicine such as morphine (or a similar medication), can be useful and can be given by injection if needed. Medications will not be given unless they are needed.

Distress and restlessness

As part of the natural dying process the person may become confused, distressed or restless. Sometimes hallucinations may occur. This can be difficult for the family and others to see but these symptoms can be helped. It can help to keep the environment calm and quiet and to gently reassure the person by holding their hand and talking to them. Medicines are available which can help relieve these symptoms. The doctors and nurses caring for the person will check for any other causes that may be contributing to the distress.

Sickness and Vomiting

When a person is at the end of their life they may feel sick. There are many possible reasons and the doctors and nurses will assess this on an individual basis. The person may feel sick when they are moved or certain smells may trigger sickness. Medicines can be prescribed to help relieve this symptom via an injection.

Bowels

Due to weakness and as the person's condition deteriorates, they may not be strong enough to use a toilet or commode. Often the bowels slow down and do not work as normal. Occasionally, due to muscle weakness the person may lose control of their bowels. If they are very weak and are unable to get out of bed, pans or pads may be used. Bowels will be assessed by the doctors and nurses with the aim of maintaining dignity and comfort.

Bladder

As the body naturally slows down the person may pass little or no urine and the urine may become very dark in colour. Due to weakness, it may be too distressing to assist the person on and off a commode or toilet. In order to maintain dignity and comfort, pads can be offered. This will preserve their energy and ensure they remain dignified and comfortable. If appropriate this will be discussed with the family and others. Catheters can also be used for people who have signs of retaining urine, which can cause distress and restlessness.



How might eating and drinking be affected?

Based on the person's condition their need to eat and drink may become less. Some people may be able to take small amounts of food and drink, others may only be able to take sips of fluid and some may not wish, or be able to, take anything at all. Drips may be reduced or stopped based on the person's needs. Each person will be individually assessed by the doctors and nurses to make sure their comfort is maintained, therefore it is important to provide good mouth care and ensure that the mouth is clean and moist. Gels and saliva sprays may be given to help with this. Families and others can be taught to clean the person's mouth if they wish.

Clinically-Assisted Nutrition and Hydration

Clinically-Assisted Nutrition and Hydration (CANH), sometimes called 'Artificial Nutrition and Hydration' refers to providing food or fluid by tube. It does not refer to help given to people to eat and drink by mouth, such as spoon feeding.

It is possible that the decision to withdraw Clinically-Assisted Nutrition and Hydration may be made in the last days of life when the risks and burden of continuing outweigh any gains for the person.

A judgement will always be made on an individual basis, looking at the individual needs of each person. The decision will be regularly reviewed. Your nurses and doctors will be happy to discuss this in more detail if you wish.



How might a syringe pump be used to give medicines?

Sometimes a syringe pump (a small portable pump) may be set up by your doctor or nurse. The syringe pump is used to deliver a constant dose of medicines usually over 24 hours and may contain more than one medicine at a time. A very small needle will be inserted just under the skin in the tummy or arm through which the medicines will be given. A syringe pump means that the person can have the medicines they need and so will not need to have lots of individual injections. The medicines and their doses will be reviewed each day before the pump is refilled to make sure the person is receiving the best medicine for them at that time. If the person is at home the district nurse will bring the syringe pump with them and this will be left in the person's home, should it be needed. The family or others would need to collect any medicines from a chemist. This would be arranged by the General Practitioner and District Nurses.



Where can care be given in the last days of life?

The person and their family may have wishes about where care should be at the end of life. Some people may have made their wishes about this known in advance. It is important that we talk to you about this and where possible, we would like to meet their wishes.

Hospital care

If cared for in hospital the persons family can stay by the bedside and the ward staff will discuss with you changes to visiting hours and the facilities available, for example, shower, car parking, food and drink.

People in hospital may wish to be cared for in their own home or care home at the end of their life. If this is the case, the doctors and nurses will make arrangements with the aim of getting the person home as quickly as possible and if appropriate care and support can be arranged.

Care in the person's own home or in a care home

District nurses will visit depending on the persons need. The district nursing services vary according to area but most are available 24/7 and can be contacted both night and day. Other services in the community may also be available. These may include:

- Night sitting service
- Community specialist palliative care team
- Social service carers
- Your General Practitioner
- Out of hours General Practitioner
- Community Rapid Intervention Team (RIT)

Hospice In patient care

Some people may wish to be cared for in a hospice at the end of their lives and the Specialist Palliative Care team looking after you can arrange this if needed.

What are end of life comfort measures?

What matters most to you and your loved one is essential information to help ensure all the staff who are providing care meet you and your family's needs. You may find it helpful to write down what is important in the diary section of this booklet. If the person is in hospital this may include the privacy of a side room on the ward or unit if this is possible. Please feel free to ask the nurses to remove unwanted equipment from the room and ensure you can make the room more personal. You may wish to bring the person's own night wear, blanket from home, or dressing gown. Some families and others may want to be involved in assisting the nurses with comfort and care, if you do please tell the nurses. Families may want to record familiar sounds, children, grandchildren or family members who cannot be present either singing or talking to the person. Playing favourite music may be soothing. Children are very welcome to visit to say goodbye to a loved one.

Keepsakes

If you wish to have a keepsake such as a hand print, lock of hair or a photograph of hands, the nursing staff will be able to help you with this.



How can religious, spiritual, emotional and cultural needs be met?

When someone is approaching the end of their life they may find talking to someone can provide support. Often this support comes from family and friends but sometimes it helps to talk to someone who is independent.

You or your loved one may also wish to have any religious and spiritual needs supported by your own faith representative. Please make this clear to those involved in the care of your loved one.

If your loved one is being cared for in one of our hospitals or in a hospice there are chaplains from different religions who are available to support you and your loved one.

All of our Chaplains are approachable and non-judgemental and within our hospitals are available 24 hours a day, 7 days a week, to provide support and care. If you would like a member of the multi faith chaplaincy team to visit then please ask for this to be arranged.



What happens after a person has died?

The death of someone close to you may be very significant and everyone reacts very differently to the situation

What happens when death is in hospital?

After a person has died they will be seen by a doctor or nurse who will verify their death. This involves a physical examination to confirm that the person has died. The nursing staff will then ensure the person is cared for before being taken to the Swan Suite (mortuary). If anyone in the family wishes to assist with this care (washing/dressing) or if there is any particular clothing you would like your loved one dressed in for their transfer to the Swan Suite, please let the nursing staff know.

It is possible to arrange to visit your loved one in the Swan Suite. This is by appointment only and can be organised by telephoning the Bereavement Centre (01902 695091). The intention is to deliver care sensitive to the cultural and religious needs, and personal preferences of the dying person and their family and others. Further information regarding the next steps after your loved one's death can be found in the bereavement information pack which the nursing staff will provide.

What happens when death is in a care home?

If the death of the person is in a care home they will be seen by a nurse or doctor who will verify their death before going to the funeral directors of your choice.



What happens when death is at home?

After your loved one has died, you should in the first instance contact your district nursing team and general practitioner. The district nurses will be able to attend if you wish to assist with care (washing and dressing) and remove syringe drivers if they are in place. The intention is to deliver care sensitive to spiritual, cultural or practical wishes following death; please inform the district nurses of any preferences of the dying person or their loved ones.

A doctor or nurse will need to attend in order to verify the death. Once this has been completed, your loved one will be moved to a funeral directors of your choice.

What happens when death is in a Hospice?

After a person has died they will be seen by a doctor or nurse. The nursing staff will ensure that the person is cared for before transfer to the funeral directors of your choice. The nurses will ask if anyone in the family wishes to assist with this care (washing / dressing) Should you have any spiritual, cultural or practical wishes following the death this can be discussed. The hospice has a chaplaincy service who will be happy to provide assistance.

If you have any queries or concerns please speak to a member of the hospice team.

Can organ and tissue donation be considered?

Every year, hundreds of lives are saved with the help of donated organs such as hearts and kidneys, but you may not realise that donated tissue such as skin, bone and heart valves can also save and dramatically improve the quality of life for many.

We rely on, and are very grateful for, the generosity of our donors and their families. Thanks to them we are able to provide skin, tendons, bone and other tissues to help enhance the lives of thousands of people.

Many people can be considered for tissue donation for up to 24 hours after death. In order to ensure donated tissues are as safe as possible, the donor's medical and behavioural history is reviewed in a similar way to blood donors. This reduces the risk of transmitting infection to a patient. A blood sample is taken from the donor and tested for viruses such as HIV and Hepatitis. Family interviews are carried out by specially highly trained Nurses from NHS Blood and Transplant.

All of the major religions of the UK support the principles of donation and transplantation. However, within each religion there are different schools of thought which means that views may differ. All the major religions accept that donation is an individual choice.

The retrieval of tissue usually takes place in a mortuary, occasionally in an operating theatre, and rarely in a funeral home. On occasion the donor would need to be transferred to another location.

Funeral arrangements, the work of the pathologist and HM Coroners are not interrupted or compromised by the donation process.

Further information can be found regarding organ and tissue donation at:

www.organdonation.nhs.uk.

Frequently asked questions:

What happens if my relative gets better?

Occasionally a person's condition can improve. If a person gets better, the care they need will be reassessed by the doctors and nurses caring for them. The care and treatment 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 exactly what you 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. They can also advise you on specialist support to help your children.

What would happen if the person deteriorated and I was not around?

If you are not around when they deteriorate, 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 usually need to be at home with them at all times.

What will happen to my loved one's personal belongings?

The personal belongings may be taken as appropriate by the next of kin.

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 may still be able to communicate a little. As their condition deteriorates further they will be able to communicate less. Sense of hearing is a fairly strong sense and it can be comforting for them to hear familiar voices from friends and family. It may even be appropriate to play music. It is unlikely that they will always be able to continue to communicate with you as their condition deteriorates.

Is it best to let them rest and not to disturb the person?

It is generally best to ensure calm, quiet surroundings for them. Nurses may try to locate a side room for your loved one, however this is not always possible, so as much as possible will be done to ensure a calm ward environment. If they are at home, again as calm an environment as possible is preferable.

Key contacts

GP: _____

Out of hours GP: _____

Out of hours district nursing team: _____

Community palliative care team: _____

Hospital palliative care team: 01902 695212

Chaplaincy team (New Cross): 01902 695098

Bereavement team: 01902 695091



Questions for doctors and nurses

Date: _____

Your Question:



Questions for doctors and nurses

Date: _____

Your Question:



Questions for doctors and nurses

Date: _____

Your Question:



Questions for doctors and nurses

Date: _____

Your Question:



Questions for doctors and nurses

Date: _____

Your Question:



Questions for doctors and nurses

Date: _____

Your Question:

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਬਾਰੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。

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