

End of life: a guide

Information for relatives and carers

A decorative graphic featuring a large yellow circle representing a sun, partially obscured by several overlapping green leaves of various shades and orientations.

The Dudley Group
NHS Foundation Trust

www.dgft.nhs.uk

Introduction

Our patients have told us how important it is to know what to expect when someone is near the end of life. This leaflet contains information to help you understand what usually happens and the care we give, when someone is believed to be in the last days and hours of their life.

Nothing can take away the feelings of grief, but having information may help you cope at this anxious time. This leaflet will hopefully answer some of your questions. However, if you have any more questions, please ask the staff caring for your relative.

Discuss your wishes with us

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

The nurses and doctors will give you the opportunity to complete a one page profile which we will keep by your loved one's bed space, to enable us all to care for you all as best we can.

Recognising dying

It can be hard to know when a person is entering their final days and hours. When the team looking after a patient believes they are dying, and only have days or hours to live, they will explain this to you. You will be able to discuss any questions or concerns you have with these staff members.

If it is possible to discuss changes in physical health and decisions about care with the patient, staff will do this. However, the person who is coming to the end of their life may not be well enough to communicate. For this reason, the views of family and friends are very valuable in planning and giving the best care to the patient.



Some people die very quickly with little warning and others gradually become worse over several days. Occasionally, people believed to be dying improve and their condition stabilises.

Every day, senior staff will check to make sure the care being given is correct for your loved one's current condition. If there are any major changes, they will discuss this with you.

Special care

When we believe a person is dying, the team caring for them want to give care that is specifically tailored to their needs. Patients may have already considered what is most important to them. Please discuss this with the team looking after your relative. The following are suggestions about things that are often described as important:

Food and drink

We provide food and drink for as long as needed to help someone feel comfortable. It is normal for someone who is dying not to want much food or drink, and so sips of water may be enough.

Religious, spiritual, emotional and cultural needs

When someone is approaching the end of their life, they may find talking to someone can provide support and be comforting to them. Often this support comes from family and friends but sometimes it helps to talk to someone who is not related.

Your loved one may wish to have any religious and spiritual needs supported by a representative of their faith. Please make this clear to those involved in the care of your loved one.

If your loved one is being cared for in hospital or in a hospice, there are chaplains from different religions available to support you all. If you would like a member of the chaplaincy team to visit, please ask your nurse to arrange this.



Place of care

Some people know where they want to spend their last days. However, these views can change. The care team will talk about what is practical for patients and carers, and will do their best to accommodate individual wishes.

Care in the person's own home or in a care home – some people in hospital would prefer to be cared for in their home or in a care home at the end of their life. If this is the case, doctors and nurses will make arrangements to get your loved one home as quickly as possible, if appropriate care and support can be arranged.

When they are at home, district nurses will visit depending on your loved one's nursing needs. The following services are available at home depending on nursing needs:

- Community specialist palliative care nurses (Macmillan)
- Your loved one's GP
- Palliative care support team

Hospital care – if your loved one is being cared for in hospital, family members can stay with them any time of day or night. The ward staff will tell you about the facilities that are available within the hospital such as showers, food and drink and car parking.

The hospital car park operates a pay on exit system; however, a limited number of value cards are available for visitors who have relatives and friends in hospital. Please ask staff for details.

Hospice care – some people may wish to be cared for in a hospice at the end of their lives. In this case, the health professional involved in your loved one's care can discuss this further and make contact with the hospice.



Medication

When a patient is believed to be dying, doctors will discuss whether the medication they are taking is still helpful. If swallowing medication becomes difficult, it may be given in a way that is easier for the patient, such as by an injection.

A range of drugs will be prescribed that can be used if any troublesome or distressing symptoms occur, such as pain-relieving or anti-sickness medication. Sometimes patients are given a syringe driver which is a small, portable pump (see figure 1). This can be used to deliver continuous medication by injection day and night.



Figure 1 shows a portable medicine pump



Comfort measures

It is very important to make sure all the staff who are providing care meet you and your loved one's needs. You may find it helpful to write down what is important in the 'My notes' section of this booklet.

You may wish to bring in personal belongings for your loved one such as nightwear, a blanket from home or a dressing gown.

Some families and friends may want to be involved in assisting the nurses with comfort and care. If you would like to be involved, please tell the nurses. Families may want to record familiar sounds, such as children, grandchildren or family members 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. Please talk to the nurses to arrange this. If you wish to have a keepsake such as a hand print, lock of hair or a photograph, the nursing staff will be able to help you with this.

Changes in appearance

Every death is different. It is impossible to predict how someone will look in their final hours but there are certain common physical changes that you may notice:

- People often become drowsy, spending much of their time sleeping.
- Their skin may become pale and moist. Their hands and feet may feel cold.
- As they get more unwell, they may have very little interest in their surroundings, even their close family. This is a natural part of the process.



- Eventually they may become unconscious. For some people, this period will be short but for others it may last several days. Though unconscious, they may still be aware that you are there, be able to feel your touch and be able to hear your voice.
- This may be followed by breathing changes, until breathing stops.

At such a sensitive time, relatives and friends may wish to be involved in a practical way. We encourage those who would like to take part in giving care; for example, by giving drinks if your loved one can swallow, or by moistening their mouth. The care team will support you to do what is right for them.

Other changes

Restless moving

A person who is dying may sometimes become restless. This is usually caused by chemical changes in the body that affect the brain. This may be relieved by medications. Restlessness can also be caused by emotional distress. If this is the case, you may find it helpful to talk to a trusted professional, close friend or spiritual or religious leader.

Incontinence

A person who is close to death may lose control of their bladder and bowels. This can be helped by equipment such as incontinence pads or a catheter (a narrow, plastic tube that goes into the bladder).

Pain

Someone who is in the last days of life may not be able to tell us they are in pain. For this reason, the team caring for your loved one will look out for signs such as grimacing (screwing up their face), moving about as if they are in discomfort, and sweating.



If you are worried about pain, talk to the team caring for your loved one and they will help.

Breathing changes

When someone is dying, the pattern of their breathing may change. Their breathing may become fast and shallow or there may be long gaps between breaths. Occasionally, breathing may become noisy due to fluid collecting in the airways.

Although this can be distressing to hear, it does not usually seem to cause distress to the dying person. Staff will monitor things closely and may suggest using a medication or changing their position.

The final moments of life

For many people, the final moments of dying are peaceful. Breathing becomes slower and more irregular with long gaps in between breaths. Eventually, they stop breathing. This might take place over a few minutes but it can be a longer process. Often the person's body will relax completely and they may look very peaceful.

Afterwards

After the death of your loved one, you may feel very shocked, even if you felt well prepared. Usually, you do not need to do anything straight away and if you want to, you can just stay with your loved one for a while. When you are ready, a member of the care team will explain what to do next, whether that is at home or in hospital.

If at any time you are concerned that your loved one seems uncomfortable or distressed, please speak to a member of staff from the care team.



This leaflet can be downloaded or printed from:

<http://dgft.nhs.uk/services-and-wards/end-of-life-care/patient-information-leaflets/>

This leaflet can be made available in large print, audio version and in other languages, please call 0800 073 0510.

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Ulotka dostępna jest również w dużym druku, wersji audio lub w innym języku. W tym celu zadzwoń pod numer 0800 073 0510.

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Aceasta broșura poate fi pusă la dispoziție tipărită cu caractere mari, versiune audio sau în alte limbi, pentru acest lucru vă rugăm sunați la 0800 073 0510.

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Questions for doctors and nurses

Date: _____

My question:



Questions for doctors and nurses

Date: _____

My question:



My notes

