

Last days of life

Palliative Care Department

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Information for relatives and friends
of adult patients

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Introduction

You have been given this leaflet because your relative or friend is thought to be in the last days of their life. The information is designed to help prepare you for what to expect and to answer some of the questions you may have about what this means.

The doctors and nurses will explain why they think your relative or friend is approaching the last days of their life and will continue to monitor their symptoms.

Some people may know they are dying and will talk openly about this to people who are important to them and to ward staff. Other people may find it difficult to talk about or may choose not to talk.

Please ask a member of staff if you have questions. Writing them down may help you to remember them.

Priorities for care

Dying people have the same right to high quality care as people with curable illness.

When someone is dying and reaches the last days or hours of life, it is important to make a plan of care with the patient and people important to them. This will ensure that the last days and hours are as good as they can be for that person.

This plan will include how symptoms will be managed if they occur. It will be reviewed regularly to ensure the needs of the patient and the people important to them are being met. If there is something you feel is important to your relative or friend, both now and after they die, please tell us.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

Preferred place of care

Some people have a clear idea about where they want to spend the last days of their life and may already have made their wishes known. Let us know if it is important that your relative or friend goes to a care home, home, hospice, community hospital or remains in hospital, so that we can try to organise this.

Sometimes moving a patient out of the hospital is not possible because they have complicated needs or their condition is changing quickly and the doctors are worried about moving them. Sometimes there is a delay in finding a bed in the preferred setting (such as community hospital, care home or hospice) because of high demand. The team will keep you informed about what is happening.

Reduced need for food and drink

In the last days and hours of life, it is normal for patients to eat and drink much less than before. This may be because eating and drinking takes effort when they are feeling weak and tired or because they don't feel the same hunger and thirst as when they were well.

Good mouth care can help relieve a dry mouth and give comfort to the dying person. If your relative or friend is awake and wishes to eat and drink, they can be helped to do this. They may only want to have a few teaspoons for the taste and comfort. If the doctors and nurses have any concerns about the person's ability to swallow they will talk to you and the patient about this.

If you want to help, please talk to the health care team. They can show you how to help the patient. There may be favourite tastes they have. Please talk to staff if you want to bring anything in for the patient to try.

If the patient is still thirsty, despite good mouth care, fluids might be given using a drip. The ward team will keep checking for symptoms or signs of fluid overload or dehydration to make sure the plan is providing comfort and not causing other problems.

Changes in medication

The doctors may suggest stopping some medicines if they are longer helping. Patients often find taking tablets is difficult when they are weak and tired and some medications will become unnecessary.

Your relative or friend may develop new symptoms. To make sure any symptoms are relieved quickly, the doctors will prescribe certain medications "just in case" a problem arises. Medicines are usually given as injections just under the skin, but can be given in other ways if this is preferable.

Medicines to help the symptoms can often be given continuously under the skin via a pump, often called a syringe driver. The team will always try to use the lowest dose of medicine to manage any symptom and will explain what they are giving and why. Please talk to the team about any worries you have.

Changes in breathing

You may notice a change in your relative or friend's pattern of breathing. This is a normal part of dying. Breathing may speed up or it may slow and have long pauses between breaths or become quite shallow. In the last moments of life, breathing may become much slower and quieter before stopping completely.

Some patients develop a noisy rattle to their breathing. This is thought to be because they are not able to get rid of the normal fluids in their throat and chest. It can be upsetting to hear but it does not cause distress to the patient, a bit like snoring.

Patients do not usually need extra oxygen at this stage. Changing the patient's position in bed can sometimes help with noisy breathing. If the patient seems anxious, just sitting and reassuring them that you are there can help. Medicines can sometimes help with changes in breathing if this is causing distress to the patient.

If you are worried, please talk to the team looking after your friend or relative.

Agitation

Agitation can occur for lots of reasons and the doctors and nurses will try to treat the cause if they can.

Your relative or friend may seem muddled at times, which can be upsetting, but this does not mean their feelings for you have changed. You can help by keeping things as normal as possible, speaking clearly, reminding them who you are and that they are safe.

We might use medication to help the patient to feel more relaxed and comfortable.

Pain

Some people experience pain in the last days of life but not all. In most cases, pain can be controlled. If the patient has been on regular painkillers by mouth and this becomes difficult, these will need to be given in a different way, usually using a pump.

Your relative or friend will be checked regularly for signs of pain and other symptoms. You can help by letting staff know if you notice any signs of distress. If your relative or friend has had particular ways of showing they were in pain in the past, it would be helpful to share this with staff.

Weakness and sleeping more

Patients who are dying often spend more time sleeping and they may seem more drowsy when they are awake. They may drift in and out of sleep or may become unrousable for a short time or for a few days before they die.

People who are dying may shut their eyes often. When they seem asleep or unconscious, the person may still be able to hear you. This might be a time to say things that are important to you both. Don't feel you need to stop communicating. You could sit and hold their hand, read to them or play prayers or some favourite music.

Skin changes

Changes in the way the blood moves around the body can mean that hands, feet, ears or nose feel cold to touch. Skin may change colour becoming mottled, pale or blue. Sometimes parts of the body can swell a little. It does not seem to cause pain for patients and is a normal part of dying. If you want to put on gloves or socks for your relative or friend, it may be comforting or gentle massage might help.

Spiritual support

Patients and their families and friends may experience lots of different emotions at this time, such as sadness, anger, fear, guilt and confusion. Talking to someone can help.

The healthcare team in Leicester's hospitals includes chaplains of various faiths as well as a non-religious "chaplain". They can provide spiritual support, someone to listen to and help you to make some sense of your situation or find some peace and comfort.

The chaplains can also provide religious support but you do not need to be religious to ask for their help.

There are also chapels and prayer rooms at the hospitals, which are a place for quiet reflection or prayer. They are clearly signposted.

Continuing to care and respecting wishes

As a continuation of care we would like to ask you to consider your loved one's wishes. UHL offers all families the choice to help others by the act of tissue donation after death. Tissue donation can save and enhance the life of up to fifty people from one donor. The act of giving and honouring someone's wishes can bring comfort in an otherwise tragic situation. With your consent a specialist nurse will contact you to explore the possibility of your loved one becoming a donor.

Looking after yourself

It is important that you are supported too. Please talk to staff about how you are feeling and what you feel you need.

Further information and support

The Macmillan Cancer Support booklet "A guide for the end of life" gives more information that you might find helpful.

You can order a copy from the Macmillan Support Line, Freephone: **0808 808 00 00**.

Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary, Leicester LE1 5WW

Telephone: 0116 258 6189

Email: cancerinfo@uhl-tr.nhs.uk

Website: www.leicestershospitals.nhs.uk/cancerinfo

Chaplaincy Teams

Leicester General Hospital Chaplaincy 0116 258 4243

Leicester Royal Infirmary Chaplaincy 0116 258 5487

Glenfield Hospital Chaplaincy 0116 258 3413

UHL Specialist Palliative Care Teams

Leicester General Hospital 0116 258 4680

Leicester Royal Infirmary 0116 258 5414

Glenfield Hospital 0116 256 3540

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਸ਼ਿ ਹੋਰ ਭਾਸ਼ਾ ਵਲਿ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk