NHS

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Home support for last days of life (Rapid Support Service)

Information for Patients & Carers

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Name:

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

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To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

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1. Introduction

The rapid discharge process supports the needs and wishes of patients in their last days/hours of life who wish to die at home.
A person important to you has expressed this preference.

This leaflet aims to help you learn about the process. If you have any concerns please talk to the doctors and nurses looking after the person important to you.

The doctors and nurses will have explained to you that there has been a change in your relative/ friend's condition. They believe that the person you care about is now dying and in the last days or hours of their life. Your relative/friend has said that they wish to die at home. We want to do our very best to achieve this wish for you all. This leaflet is to support you and answer any questions you may have about what will happen.

End of life patients have the same right to high quality care as people with curable illness. It is important to have a care plan so that that the last days and hours are as good as they can be for your relative/ friend. We will review this plan to make sure the needs of your relative/ friend and the people important to them are being met. This plan will include how we will manage symptoms if they happen. If there is something you feel is important to your relative/ friend, either now or after they die, please tell us.

It is important to note that people are all different. Not all things that we talk about will happen to everybody or happen in the same order. Although what happens when someone is dying is unique to each person, there are changes we most often see before someone dies. These changes can help us know that somebody is likely to be in the last few days of life. Knowing what to expect may help to ease anxiety.

If you have any questions please ask one of the doctors or nurses who are looking after your relative/ friend. Writing down questions may help you to remember them.

2. Preferred place of care in the last days of life.

Some people have a clear idea about where they wish to spend their last days. They may have already told you about their wishes.

It is important that these wishes are shared. The earlier we know about them, the sooner we can meet these. Please talk to your doctor or nursing staff about this. For other people, who they are with is more important than where they are when they die.

People who choose to die at home will be supported by the Integrated community palliative care team and /or district nursing team. An assessment will be carried out to learn about the physical, social and emotional support needed.

There may be some situations where symptoms are difficult to control. The team looking after you or your relative/friend may seek advice from the specialist palliative care nurses or LOROS the local hospice.

The doctors and nurses looking after your relative/friend believe that if we are to help your relative/friend go home, we need to arrange things quickly. Knowing that someone is going to die can be difficult. Everyone is different. There are times when a person who is dying will live longer than expected. There are other times when a person will get worse and die sooner than expected. There is a risk that your relative/friend’s condition may change and they may die in the ambulance on the way home.

If your relative/friend becomes less well before they go home, the Discharge Specialist Sister (DSS) will talk with the medical team. They will assess if it is still advisable for them to make the journey.

The team may speak to the Hospital Specialist Palliative Care team if they are not sure.

If there is a concern that your relative/friend may not survive the journey, you will be offered a choice of:

- Going ahead with the journey despite the risks. If this is the choice we will talk about this with you and what we will need to do.
- Staying in hospital to be cared for instead.

In this case a final decision will be made on the day of discharge.

3. What happens when your relative/friend is ready to go home?

The role of the Discharge Specialist Sister (DSS)

When it has been decided to arrange for your relative/friend to go home for their last days of life, the Discharge Specialist Sister (DSS) will attend the ward. They will talk with you, the family/ friend. They will tell you about:

- the level of care that you and your relative will get,
- how this care will be given by the Integrated Community Specialist Palliative Care Team (ICSPCT),
- the role of the ICSPCT team.

They will talk with you about the availability of this team and the plans that can be put in place should the ICSPCT not have capacity to support.

- The DSS will also talk with you about any equipment that can be put in place and your availability in supporting this.
- Your relative/friend may also need oxygen for comfort. They will coordinate this alongside the ward.
- The use of anticipatory (also known as just in case) medicine will also be discussed with you. They will make sure that this is available to you and your relative/friend to make sure they are kept as comfortable as possible.

The role of the Discharge Specialist Sister is to support you and your relative/friend. They will support the discharge plan alongside the discharge support team on the ward.

Their aim is to make this difficult time as easy as possible for you and the person close to you. They will give you contact details should you need any more information or have any concerns at home after discharge.

4. Transport home

We will asses the patient’s ability to travel before discharge to their preferred place of care. Most, though not all, will need an ambulance to transfer. The ambulance team will be given all the information they need for example, infusions, infections, positioning of patient to maintain comfort.

Discharge can take place at any time of day and any day of the week in agreement with patient, carers and primary care services. We will think about the risks of discharging patients at the most suitable time when discharging out of hours.

Giving end of life care in the community is a complex and challenging process. It needs support from a number of health care professionals. It is important to make sure that these support networks are available and accessible when discharging a patient out of hours. If a healthcare professional responsible for the care of your relative/friend is not confident that it is safe to discharge out of hours then they will advise the patient and carers of this.

There will be some important paperwork that you will be given to take home. You need to keep these in a safe place as you will need to show them to the community nurses and doctors.

This paperwork includes:

- A ReSPECT form with details of your relative/friend’s wishes about medical care.
- An authorisation form to let the community nurses to give medications by injection if needed.
- A discharge letter that details the important information about the recent hospital admission.

It may be possible for you to travel in the ambulance to the preferred place of care with your relative/friend. Please make this wish known to nursing staff. We will do our best to make this happen on the journey.

Should a patient die whilst being transported by ambulance, they will be returned to the hospital. They will not continue the journey to the preferred place of care.

5. Changes in medication

Anticipatory (just in case) medicines: medicines to manage symptoms

People often find swallowing tablets becomes difficult when they are weak and tired. Stopping medicines that are no longer needed can help.

Sometimes new symptoms such as pain or sickness happen as people become less well and new medicines can help. To make sure that any symptoms are helped quickly, the hospital doctor will prescribe certain medicines to take home ‘just in case’ a problem arises.

Having injectable medications available is good practice. Some people may not need them, but, having them available is important and prevents delays in managing symptoms. These medicines are given under the skin (subcutaneous) by the District nurse. These will be explained to you before your relative/friend comes home.

Syringe drivers

Your relative/friend may need a regular dose of medicines to control their symptoms. When a person finds it difficult to swallow medicines or if they are too sleepy to do so, it is important that they still have their symptoms controlled. It is usual to give medicines as a continuous infusion under the skin using a pump (syringe driver). The doctors and nurses will always use the lowest dose or medicine to manage any symptom. They will explain to you what they are giving and why. If a syringe driver is already being used before you leave hospital the ICSPCT will give this medicine.

6. How you can help?

You will have a vital role to play in getting your relative/friend home. This may involve working with other family and/or friends. For example, you may need to clear a suitable space in a downstairs room so a hospital bed can be set up or to arrange for someone to be available at the house for delivery of equipment.

It is also helpful for the doctors and nurses in the hospital to talk to the same person about the plan of care, so choosing who this will be is very helpful.

Disagreements between family members or between patient and family can sometimes happen when making decisions about the place of care at the end of life. It should be remembered that making choices at the end of life is often stressful and circumstances often change. As a result patients and their families may sometimes change their mind about taking part in the rapid discharge process. This should be respected.

7. What happens when your relative/friend gets home?

The Integrated Community Palliative Care Team (ICSPC) and District Nursing Team support people who go home from hospital for their last days of life.

It is not possible to offer 24 hour constant care at home but the ICSPC work together with other professionals. These include: community nurses, GP's Specialist Palliative care medical teams and care agencies.

The ICSPC team is available between 8am and 10pm, 7 days a week.

8. The role of the Integrated Community Specialist Palliative Care Team (ICSPC)

The ICSPC are a team of nurses who will visit your relative/friend at home.

After your relative/friend arrives at home, one of these nurses will visit within 2 hours. They will carry out a full assessment. They will assess both the physical and emotional needs of your relative/friend.

The ICSPC nurse may offer you advice such as practical nursing care concerns or management of any symptoms.

Your relative/friend will stay under the care of the ICSPC team unless, after an assessment or review, it is felt their needs could be better met by another service such as the district nursing team.

9. Questions you may want to ask

Write your questions here:

10. Useful telephone numbers/websites

Organisation	Contact Number
Integrated Community Specialist Palliative Care Team (ICSPC)	0300 300 7777 8.00am to 10.00pm
LOROS www.loros.co.uk	0116 231 3771
District nursing Team contacted through Single Point of Access (SPA)	0300 300 7777 24 hours a day
Coping with cancer A local voluntary organization that offers support, counselling, befrienders and complimentary therapies	0116 223 0055
www.dying matters.org	
www.mariecurie.org.uk/help/support	
Adult Social Care (Leicester City)	0116 454 1004 9.00am to 5.30pm
Adult Social Care (Leicestershire County)	0116 305 0004 9.00am to 5.30pm
www.england.nhs.uk/eolc	

11. Raising any concerns

All our staff work hard to offer the best possible care and service. Sometimes though things can go wrong. You might feel unhappy or concerned about the care or treatment you or your relative/friend has received.

The first thing you should do is talk to a member of staff at the place the care or service was provided to try to resolve things. If this does not resolve your concerns, you can contact the relevant patient liaison service and they can help you to decide what steps to take next.

- For concerns about the care received at Leicester Royal Infirmary, Glenfield Hospital or Leicester General Hospital, please contact the Patient Advice and Liaison Service (PALS) at University Hospitals of Leicester NHS Trust (UHL):

Free phone:	**0808 178 8337**
Email:	uhl-tr.pals@nhs.net

Online contact form: www.uhleicester.nhs.uk/patients-visitors/support/feedback-complaints/pals/

- For concerns about the care received in any other NHS community hospital in Leicester, Leicestershire or Rutland, please contact the Patient Advice and Liaison Service (PALS) at Leicestershire Partnership NHS Trust (LPT):

Telephone:	**0116 295 0830**
Email:	lpt.pals@nhs.net

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ 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 ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
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LEICESTER'S RESEARCH

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