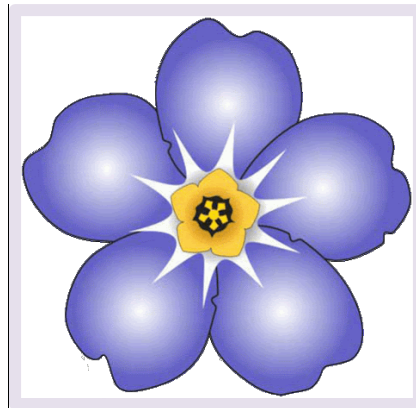


## Care in the Last Days of Life



### Introduction

This booklet contains information to help you to understand what usually happens and the care we give when someone is believed to be in the last days and hours of life. Nothing can take away the feelings of grief, but having information may help you cope at this anxious time.

Everyone will want and need different amounts of information and we are mindful that not all the information will be relevant to your situation or wanted by you at this time.

If you find the information too upsetting or overwhelming at this time or you would prefer then please speak to ward staff regarding any questions you may have instead.

### How do we recognise that someone is entering the last hours or days of life?

It can sometimes be difficult to recognise when someone is entering the final phase of their life. We can use clinical information such as blood tests, observations and scans to guide us but looking at the person themselves and noting any changes in their overall condition is just as important.

Not all deaths are expected. Sometimes a person can deteriorate very quickly and there may be very little time between recognising that someone is dying and their actual death. For others this period can be much longer and a few days may become a week or more.

Occasionally, people believed to be dying improve and their condition stabilises. The team caring for them will review the care they need on a daily basis; if there are any major changes they will discuss this with you.

## What happens next?

When we recognise that a person is likely to die in the next few days, the focus of our care changes to ensure that any symptoms they experience are managed; and to support you all emotionally, socially and spiritually. We will sensitively speak to them to try and ascertain their wishes and ensure they have opportunity to see and speak to those closest to them as they wish. Wherever possible we will try and enable them to die in the place of their choice be that hospital, hospice, nursing home or home. This is however dependant on individual circumstances and staff will be able to discuss this with you.

The image shows a form titled 'Last Days of Life Care Plan' from East Sussex Healthcare NHS Trust. At the top, it says 'East Sussex Healthcare NHS Trust' and 'Check PAB label here'. Below that, there are fields for 'Resident Name', 'Name of person completing', 'Signature', and 'Date'. The main title 'Last Days of Life Care Plan' is in a purple box. Below this, there is a section for 'Personalised Plan for:' with a dropdown menu. The 'Family Contact Details' section is divided into 'GP Contact' and 'Family Contact' with fields for Name, Postcode, Tel No., Mobile No., and 'At any time' checkboxes. The 'Discontinuation of last days of life Care Plan' section has fields for 'Discontinued on', 'Signature', and 'Date'.

Figure 1: Last Days of Life Care Plan

Often when someone is dying they are not as able to express their needs and wishes verbally since they may be too tired or are no longer having periods awake. We would therefore like to offer you the opportunity to tell us what is important, what matters most and how we can best support them. Using this information, we will develop an individualised care plan, the 'Last Days of Life Care Plan' to ensure that the care we provide is tailored to their individual needs.

It is also important that we assess any needs you and your family may have and provide support to you too during this anxious and difficult time. Please discuss any needs or concerns you have with the nursing staff on the ward.

## What medications might be needed and how are they given?

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

A range of medications will be prescribed that can be used if any troublesome or distressing symptoms occur, such as pain relieving medication, anti-sickness, anti-anxiety medications and medications to dry secretions.

Sometimes medications are given via a syringe pump. This is a small battery operated pump that is used to deliver medications continuously beneath the skin day and night.

Some of the medications we use when a person is dying can cause drowsiness and sedation. For some people this is comforting but some people like to remain as aware as possible for as long as possible. It is therefore important for us to understand this as it will influence the medication we prescribe. It is important to also note that medications will only be given to relieve symptoms and will not speed up the dying process. If you have any questions about the medications being used or ones that have been stopped then please ask.

Often a dying person is too unwell to tell us they are uncomfortable, so we have to look for other signs, such as facial expressions or the person becoming restless. If, whilst at the bedside you have any concerns then please alert a member of staff.

### **What other things may continue or be stopped?**

Taking a person's blood pressure, pulse and temperature for example is no longer helpful and can disturb the dying person unnecessarily so will be stopped. The nursing staff will instead focus on regularly observing the person to monitor for signs of pain, distress, nausea and chest secretions so these can be managed quickly if they occur.

Other things will be looked at on an individual basis and will only be continued if they are making the person comfortable. This may include:

- Oxygen – if oxygen is helping then face masks might be changed to tubing that sits in the nose as this can be less uncomfortable.
- Intravenous fluids (drips) – these might continue if a cannula is present and they are not causing any harm. But having a new needle inserted to continue fluids can be uncomfortable, a smaller needle that sits just under the skin may be used instead or fluids might be stopped. If the skin is swollen, or there are oral secretions collecting then fluids will be stopped as they are no longer helping.

We will assess on a daily basis whether giving artificial fluids would aid comfort. For many people focussing on regular mouth care to prevent their mouth from becoming dry will be more helpful to maintain their comfort.

Please ask a member of staff if you have any questions or concerns.

### **When will you be updated to their condition?**

We will keep you updated to any changes in their condition over the coming days when you visit or telephone. If at any time you feel the information has not been clear or you have more questions then please ask.

Please be aware that some questions are very difficult to answer and no clear answers can be given. For example it is not possible to tell you exactly when someone is going to die.

If you wish to be present at the time of death, ward staff will try to call you to allow you to come in, but people can deteriorate very quickly and it may not be possible to do this in time.

Please ensure we have the correct contact details for you and let us know if you would want us to call you during the night or not.

## What may happen in the last hours or days of life?

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

- Sometimes people **talk of dying** or talk of people they know who have died. You may find such conversations difficult and it can be hard to know what to say. Try to be led by them and what they want to talk about. If you find these conversations difficult or need to share your own thoughts and feelings then please speak to a member of staff.
- When someone is dying their body no longer has the same need for food and drink and they often show little interest in **eating or drinking**. This can sometimes be difficult for those around them to accept. We will help them eat and drink things that give them enjoyment and comfort. As they become more unwell, they may be too sleepy to eat or drink. To prevent them feeling thirsty we will give plenty of mouth care and many families find comfort in supporting with this. Please speak with the ward nurses to show you what to do if this is something you would like to do.
- They may **spend less time awake**; they may have very little interest in their surroundings, even their close family. This is a natural part of the dying process. Eventually they may become unconscious. For some people, this period may be short, 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 hear your voice.
- Their **skin** may become pale and moist. Their hands and feet may feel cold.
- They may have times where they seem **muddled or agitated**. Staff will check that there is no reversible cause such as being in pain or needing the toilet for example. Talking to them calmly, holding or massaging their hand or perhaps playing their favourite music may help. If no reversible cause is found and they do not settle then a small dose of medication may be needed to ease their agitation.
- Their **breathing pattern** may change many times sometimes being very fast or very slow. There may be very long gaps between breaths or breathing can be very shallow. Sometimes breathing can be noisy due to a small amount of fluid collecting in the throat. This usually does not distress the person and medications can be used to try and reduce or prevent more fluid collecting. Other things such as turning the person or sitting them in a more upright position can also be helpful.

It is important that if you have any questions or concerns that you discuss these with the nursing or medical team on the ward.

## What may happen at the time of death?

For most people the final moments of life are peaceful.

It can be difficult sometimes to identify the exact moment of death. Their breathing pattern may change. There may be long pauses between their final breaths and their breaths may become very shallow. Alternatively their breathing may become very fast and suddenly stop without warning.

Often the person will look completely relaxed and they may look very peaceful. Their colour may change slightly and they may feel cooler to touch. Occasionally a person's eyes may open slightly at the moment of death.

## Afterwards

After their death, 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 sit quietly with them for a while. When you are ready, a member of the ward team will explain what to do next.

If their death occurs before you get to the hospital, the ward staff will do their best to keep them on the ward until you arrive and will allow you to spend time saying your goodbyes.

If the death happens overnight and you have asked not to be contacted the ward team will contact you the next morning. They will no longer be on the ward, but will have been taken to the hospital mortuary. You can request an appointment to visit them there if you want to. At Rye Hospital they will instead go straight to the undertakers of your choice and you can make an appointment with them directly if you wish.

## How can you look after yourself?

The dying phase may be very short but sometimes it can be a few days. It can be an emotionally and physically exhausting time and it is important to try and look after yourself.

When you remain within the hospital for long periods of time, the days can merge into one and it can be easy to forget to have regular meals or take time for yourself away from the bedside. Try to take advantage of any offers from family and friends of meals, transport to the hospital, shopping etc.

You may have expected the news that they were so unwell or it may have come as a shock to you. Your emotions at this time may be many and can fluctuate. There is no right way to feel. Different family members may all be coping with the news in different ways. Try to find someone in your close family or friends or if not a member of staff to confide in and share how you feel.

Please let us know if there is anything we can do to support you or if there is anything we should know about you to ensure we can care for you in the best way possible.

## What facilities and support are available to you?

**Open visiting** – We have open visiting unless the dying person asks not to have visitors, but at times the ward may need to limit the number of visitors if there are large numbers visiting.

In exceptional circumstances, such as the COVID 19 pandemic, our visiting policy may have to change to follow current guidance and advice. Please be guided by ward staff and be reassured that we will try to ensure you have opportunity to say goodbye and be at the bedside as you wish wherever possible whilst still trying to ensure everyone's safety.

**Car parking** – Staff will issue you with a parking permit to allow you to park for free within the hospital grounds. This is a small blue card, which you take to the hospital parking huts (as you enter the car park), you will then be issued an exit ticket to leave the car park.

**Meal voucher** – If you are remaining at the bedside for prolonged periods and feel unable to leave to have a meal, then a meal voucher can be provided to allow you to have a patient meal at the bedside at the Conquest and Eastbourne Hospitals.

**Shops** – Both main hospital sites have a small shop and a café area located at the main entrance. A trolley service is also run bringing a selection of sandwiches and snacks to the ward areas. This is not available in our community hospitals.

**Relative's accommodation** – There is limited accommodation at both Conquest and Eastbourne Hospitals for relatives to stay. You are welcome to however remain at the bedside overnight and we will do our best to make you comfortable. Please speak to staff if you want to know more about the relative's accommodation.

**Comfort boxes** – These are provided by the hospital with a few small items that may be helpful at this time.

**Chaplaincy/ Pastoral support** – 'Chaplaincy & Pastoral Support – Members of the Chaplaincy & Pastoral Support Team can offer spiritual support to everyone regardless of whether you have a faith or belief or not. It can be helpful to have someone with you to support you during difficult and extremely emotional times and Chaplains are very willing to do this. We believe that compassionate support and sensitive listening is invaluable when someone close to you is dying or has just died.

The Chapels are available 24/7 at Eastbourne & Conquest Hospitals and there is a separate quiet space if you just need time to reflect.

**Supportive and Palliative Care Team** – This is a team of specialist nurses and doctors who specialise in symptom management and end of life care. They may have already been involved in someone's care prior to their deterioration and will continue to do so at this time. If not then a referral to the team will be made if advice is needed with care in the last days of life. The team are available every day from 8-4pm. Outside of these hours should the ward staff need advice for example in how best to manage complex symptoms then they are able to call our local hospices for telephone advice as needed.

**Bereavement Support** – During the initial bereavement period support may come from family, friends, neighbours and faith and community groups. The support you need maybe different to that of other family members since bereavement can affect us all in different ways. If you feel you need a little more structured ongoing support then please speak to your own doctor or contact the bereavement team who can put you in touch with local bereavement services. If you feel you need support right now then please speak to ward staff who can look into arranging this for you.

### **Community Hospitals - Rye Memorial Hospital and Irvine Unit, Bexhill Hospital.**

Both community hospitals are part of East Sussex NHS Trust and they also provide care in the last days of life supporting both patients and those closest to them. The facilities available and the way care is provided may differ slightly at each site so please be guided by ward staff.

### **Sources of information**

- The ward team Tel: 0300 131 4500 hospital switchboard and the ask for the appropriate ward
- Hospital Chaplaincy Team  
Tel: 0300 131 4500 hospital switchboard and ask for the Duty Chaplain
- Supportive and Palliative Care Team:
  - EDGH 07813430421
  - Conquest 07788415014
- Bereavement Office:  
Tel: 0300 131 4500 hospital switchboard and ask for office at the appropriate hospital.

### **Important information**

This patient information is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

### **Your comments**

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team - Tel: Tel: 0300 131 4500 Ext. 734731 or by email at: [esh-tr.patientexperience@nhs.net](mailto:esh-tr.patientexperience@nhs.net)

### **Hand hygiene**

The trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

### **Other formats**

**If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.**

**Tel: 0300 131 4434 Email: [esh-tr.AccessibleInformation@nhs.net](mailto:esh-tr.AccessibleInformation@nhs.net)**

After reading this information are there any questions you would like to ask? Please list below and ask your nurse or doctor.

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## Reference

The following clinicians have been consulted and agreed this patient information:  
Helen McDonald Supportive and Palliative Care Team

The Clinical Specialty/Unit that have agreed this patient information leaflet:  
Palliative Care

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Responsible clinician/author: Helen McDonald Supportive and Palliative Care Team

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