



# HEFT Care of the dying pathway for use in adults in the last days of life

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Disclaimer: These guidelines are only valid for use in Birmingham Heartlands and Solihull NHS Trust until the specified review date.

### Meta Data

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### Revision History

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## Table of Contents

1	Flow Chart	4
2	Overview/Introduction	4
2.1	Reason for Development of the Guideline	4
2.2	Methodology	4
2.3	Implementation	5
2.4	Monitoring	5
3	Application of the Guideline	6
4	Objectives of the Guideline	7
5	Guideline Steps	7
6	Drug administration.	10
7	References	10

## 1 Flow Chart

The following flow charts are attached:

- Heft end of life pathway based on Liverpool care pathway. The pathway includes an algorithm to support the clinical decision making process regarding recognition and diagnosis of dying and use of the pathway to support care in the last hours or days of life.
- Guidelines for Managing Breathlessness in the Last Days of Life
- Guidelines for the Management of Respiratory Tract Secretions in the Last Days of Life
- Guidelines for Management of Pain in the Last Days of Life
- Guidelines for the Management of Nausea and Vomiting in the Last Days of Life
- Guidelines for the Management of Agitation in the Last Days of Life

## 2 Overview/Introduction

- 4,000 people died in HEFT hospitals in 2009/2010.
- Half of all complaints are related to end of life care (EOLC)<sup>2</sup>.
- Half of all deaths in the UK are anticipated, but not recognised<sup>3-5</sup>.
- Variations in quality of care.
- Most people do not die of cancer
- Many patients will require hospital care during their final illness
- The End of Life Care Strategy in 2008<sup>2</sup> has raised the profile and the importance of improving EOLC across all settings, including the acute sector.
- Despite the growth of Hospital specialist Palliative care teams it is unrealistic to expect them to care for all dying patients within the organisation

### 2.1 Reason for Development of the Guideline

The Liverpool Care Pathway (LCP), is an integrated care Pathway, empowers doctors and nurses to deliver high quality care to dying patients and their relatives. It facilitates multi professional communication and documentation, integrating national guidelines into clinical practice. It provides demonstrable outcomes to support clinical governance and should reduce and inform complaints commonly associated with this area of care. The LCP has been identified as best practice within the NICE Guidance for supportive and Palliative care (2004) and is currently being disseminated nationally as part of the End of life care Initiative.

### 2.2 Methodology

The specialist Palliative care team at the royal Liverpool University hospital together with staff from Marie Curie Centre in Liverpool developed an integrated care pathway as a potential tool to improve care of the dying. They were awarded beacon status in 2000, and the support of the Cancer Action team and the end of life programme has provided funding and strategic guidance. MCPCIL was launched in 2004. The imperative for the project was to translate hospice care into the acute sector and develop outcome measures at the end of life. The pathway has continually been revised and up dated. Version 12 of LCP was launched in November 2009. The use of LCP has been approved by Mark Goldman, Ian Cunliffe, and Mandie Sunderland. HEFT has adopted the LCP but it has been adapted it to suit the needs of our organisation. The Pathway has been

taken to the Nursing and midwifery quality standards board. The accompanying algorithms have been approved at the drugs and therapeutic committee. It has been sent out to all members of the specialist Palliative care team and the End of life strategy committee for consultation.

### **2.3 Implementation**

- Current practice and best models of practice for end of life care, have been identified
- Executive endorsement has been gained
- Pathway has been mapped
- Draft document formulated and circulated for comments
- End of life prescribing guidelines developed and approved by drugs and therapeutic committee.
- Base review undertaken. After death analysis undertaken to look at last 20 deaths on each site i.e. GHH, BHH, SOH.
- Training and education programme developed, to include 5 day end of life course run by the Faculty of Education and accredited to degree level by Stafford University. Ward based training on LCP, grand round, medical training forums, and foundation training programme for nurses, simulation training etc.
- Develop SharePoint on the intranet
- Develop relative's information
- Pilot the pathway.
- Develop a database of patients on the pathway
- End of Life Metrics to audit progress.

Coordinate the Implementation of HEFT End of life care pathway - based on LCP, and train staff in its use, which includes:

- Encouraging acceptance that dying is a part of hospital care.
- Recognition that for some people hospital is their preferred place of death.
- Increasing confidence in symptom control, and cessation of unnecessary interventions.
- Provide explicit standards, and greater consistency in practice
- Improved clinical documentation
- Introduction of research and evidence based practice
- Improve multidisciplinary communication and collaboration.

Implementation will taking place through the groups, starting group 2 respiratory medicine.

### **2.4 Monitoring**

Pre-implementation and post-implementation audits have been undertaken as part of the implementation of the pathway to each site. The findings of the post-implementation audit, and feedback from staff has lead to some changes to the pathway document, to make it more user friendly. The revised document has been sent to the Liverpool team for ratification, it has been piloted on 2 wards, and sent out for consultation to lead Consultants, Matrons, Link nurses, and Palliative care. There will ongoing regular audit of the pathway, which will include the use of the symptom management guideline at annual intervals.

There will be participation in the National care of the dying audit.

### 3 Application of the Guideline

LCP is applicable to all adult patients in the last days of life, regardless of diagnosis.

The pathway includes an algorithm to support the clinical decision making process regarding recognition and diagnosis of dying and use of the pathway to support care in the last hours or days of life. Once the MDT has made the decision, the pathway can be commenced. (MDT refers to medical and nursing team) The pathway must be initiated by a Doctor. The decision to start LCP should be discussed and endorsed by the Consultant or Registrar, responsible for the patient's care at the earliest opportunity (or if not available the Registrar or consultant acting on their behalf).

A multidisciplinary team approach to the diagnosis of dying avoids giving conflicting messages to the family/carer.

The MDT assessment will include the following

- Is there a potentially reversible cause for the patient's condition e.g. exclude Opioid toxicity, renal failure, Hypercalcaemia, infection.
- Could the patient be in the last hours/days of life?
- Is Specialist referral needed? e.g. Referral to specialist Palliative care or a second opinion?
- Escalate to seniors if unsure

If the team agrees that the patient appears to be dying, then this should be communicated appropriately.

Decisions leading to a change in care delivery should be communicated to the patient where appropriate and the relative/carer

- All decisions should be documented on the LCP.
- All **goals** are in **heavy** typeface. Interventions, which act as prompts to support the goals, are in normal type face.
- Practitioners are free to exercise their own professional judgement, however, any alteration to the practice identified within the LCP must be noted as a variance on the sheet at the back of the pathway
- Once commenced **ALL personnel** should document in the **Pathway** and **NOT** in the medical notes
- The patient will be **assessed regularly** and a **formal full MDT review must be undertaken every 3 days**.

A Full MDT reassessment & review of the current plan of care should be triggered when one or more of the following apply:-

- Improved conscious level; oral intake; mobility; ability to perform self care
- Concerns expressed regarding management plan from either patient or family or member of the team
- It is 3 days since the last full MDT assessment. This reassessment is documented in the box on the MDT pages.

A small number of patients may improve and the LCP may then need to be discontinued. This documented on page 1

## 4 Objectives of the Guideline

- To improve the quality of care in the last hours /days of life
- To improve knowledge and skills related to the process of dying

## 5 Guideline Steps

The LCP provides an evidence-based framework as a multi-professional document.

It is accepted as the legal document that replaces all other documentation in this phase of care.

If applicable, this document should be photocopied and the copy should follow the patient between care settings.

The LCP outlines goals, which are signed off as they are achieved. An alternative approach can be considered by the MDT if appropriate or if it is preferred by the patient. The rationale for this decision & the action planned/taken are then recorded as a variance. If a “NO” is recorded against a goal, the action taken are recorded on the variance chart.

The LCP provides guidance on the different aspects of care required for the last days of life. This includes comfort measures, anticipatory prescribing of medicines & discontinuation of any inappropriate interventions or medications that are, at this stage, inappropriate in supporting ‘quality’ care for the individual patient

The front page provides instructions on how to use the LCP. The signature log is a useful reference when following up a case, long after the event. You only need to record this once. Clinical guidelines can be found on page 16.

There are 3 sections to the LCP

- Initial Assessment made on diagnosing dying
- Ongoing Assessment
- Care after Death

### ***Section 1 - Initial Assessment Goals 1-17 – Joint assessment undertaken by Dr and nurse***

This requires documentation of the Diagnosis and physical condition on commencement of the LCP. It also requires the date, time and signature of Dr commencing the pathway, and the consultant/ registrar endorsing the decision.

The assessment in Section 1 has specific goals:

#### **Goal 1, 2, & 3 – Medication**

Decisions need to be taken in recognition of the patient’s condition: Examples include:

- Stopping inappropriate interventions/medications.
- Anticipatory prescribing of PRN medication.
- syringe Driver guidance

#### **Goal 4, 5 & 6 – Current interventions**

Decisions need to be taken regarding:-

- The need for current interventions i.e. Blood tests, Intravenous antibiotics, MEWS recording etc.
- Discussing/recording resuscitation status.
- ICD is deactivated if appropriate

#### **Goal 7 & 8 – Nutrition and hydration**

- The patient should be supported to take food and fluid by mouth wherever possible
- A reduced need for food and fluid is part of the normal dying process
- If clinically assisted nutrition and hydration is in place this should be documented and reviewed and communicated with patient where possible and relatives

#### **Goal 9 - Communication with patient and relatives**

- The patient and relatives are able to take a full and active part in communication

#### **Goal 10 – Insight into condition assessed**

- The patient (where appropriate) and relative understand the diagnosis and that the patient appears to be dying
- It also identifies patient's preferences re: preferred priorities of care; wishes for donation etc

#### **Goal 11 – Communication with the Family**

- The team has up to date contact details and knows; who, when, and how to inform family of any conditional change, or impending or actual death.

#### **Goal 12 – Communication with GP**

- The patient's GP is notified that the patient appears to be dying

#### **Goal 13 - Spiritual needs**

- A clear component of the LCP is to determine what is important to the patient & family/carer at this stage of life. This Includes support/coping mechanisms of both the patient (as able) & those of family/carer in relation to spiritual needs.

Completion of this goal must involve a conversation with the patient (where able) & the family/carer as these can change with time/situation. Assumptions of belief, wishes or desires at this point cannot be

#### **Goal 14 – skin care**

- The patient's skin integrity is assessed, and measures put in place to prevent pressure ulcers or further damage if one is already present.

#### **Goal 15 & 16- Summary of 'agreed' plan of care**

- This should be summarised with the patient (where able) &/or family/carer.
- It is important that the family & others are aware that the LCP has been commenced & their concerns are identified & documented & they have understood the plan of care.
- Completion of this goal must involve a conversation with the patient if appropriate & the family/carer.

#### **Goal 17 - Written information is given to relatives**



## ***Section 2 - Ongoing assessment goals 18-34***

These are specific goals that should be assessed 4 hourly/or more frequently if there is a need. Family/Carers may wish to add to the assessments.

These assessments relate to the management of:-

### **Symptom and Comfort Measures such as:-**

- Pain
- Agitation
- Nausea and vomiting
- Respiratory tract secretions
- Dyspnoea

### **Treatment Procedures such as:-**

- Mouth care
- Micturition
- Bowel care
- Medication delivery

### **Other assessments such as:-**

- Mobility/Pressure area care.
- Psychological/Insight support
- Care of the family

## ***Guides***

There are prompts to support each goal/clarify aims. For symptom control, guidelines are available on the SharePoint.

## ***Variance Reporting***

The variance sheet enables documentation/communication of the rationale of variances of actions/decisions contrary to care delivery outlined in the LCP.

Variance is an important part of the LCP. It is a positive process providing information of the 'individual' patient journey.

Variance analysis can have a direct effect on educational initiatives & resource utilisation in order to achieve maximum impact in the provision of clinical care.

Each variance is recorded on the variance Sheet to include:

- Date and time
- What occurred and why
- Action taken

## **Multidisciplinary progress notes**

This multidisciplinary progress sheet can be used to record any significant event/conversation that has not already been recorded on the LCP .i.e.:-

- a specific conversation with a named carer
- Information following a doctor's round

## **Section 3 - Care after death – goals 35-38**

This section is Intended to guide the multi-disciplinary team (MDT) to support family/carers after death & ensure the relevant information/documentation has been provided. This can be a distressing time & so it is important to document & avoid repetition. Goals relate to:

- Verification after death
- Contact with GP practice/relevant others.
- Relevant Procedures/Policies
- Information given (both verbal and written) including 'what happens next' & provision of the DHSS's booklet 'what to do after a death'.

## **6 Drug administration.**

The LCP contains a prescribing flow-chart guide for 'typical' symptoms that may arise during the dying process. A copy is available on each of the wards and on the End of life SharePoint -

<http://sharepoint/endoflifecare/default.aspx>

All Medications including anticipatory drugs will be prescribed on Electronic prescribing( EP). By entering "End of Life" into EP a bundle of drugs to manage anticipatory symptoms of Pain; agitation; respiratory tract secretions; dyspnoea; and nausea and vomiting can be obtained  
Syringe drivers will be prescribed on Trust syringe driver prescription chart

## **7 References**

1. End of life care strategy group 2008
2. DOH end of life care strategy 2008
3. Higgs R. The diagnosis of dying. J R Coll Physicians London 2000; 33: 110/12.
4. Jack et al 2003
5. Knight M, Field D. A silent conspiracy: coping with dying cancer patients on an acute surgical ward. J Adv Nurs 1982; 6: 221/29.
6. James V, Field D. Who has the power? Some problems and issues affecting the nursing care of dying patients. Eur J Cancer Care 1996; 5: 73/80
7. NICE 2004 Supportive and palliative care
8. MCPCIL 2000 Liverpool care Pathway