

The Marie Curie  
Palliative Care Institute

LIVERPOOL

## Liverpool Care Pathway for the Dying Patient (LCP) Briefing Paper

“Can the LCP be used for all patients in the  
last hours / days of life irrespective of their  
diagnosis?”

LCP Central Team UK  
MCPCIL

T: +44 (0) 151 706 2274  
Email: [lcp.enquiries@rlbuht.nhs.uk](mailto:lcp.enquiries@rlbuht.nhs.uk)  
Web: [www.mcpcil.org.uk](http://www.mcpcil.org.uk)

May 2009  
Review Date Nov 09

# Contents

	<b>Page (s)</b>
<b>Introduction</b>	<b>3 - 4</b>
<b>4 key phase approach to demonstrate transferability of the LCP to a specific diagnostic group</b>	<b>5 - 6</b>
<b>LCP – In Paediatrics (phase 1)</b>	<b>7 - 8</b>
<b>LCP – Neurological Conditions (phase 2)</b>	<b>8</b>
<b>LCP – In Heart Failure (phase 3)</b>	<b>9 -10</b>
<b>LCP – Advanced Chronic Kidney disease (phase 3)</b>	<b>11 -12</b>
<b>LCP – In Intensive Care Unit – ICU (phase 3)</b>	<b>13 -14</b>
<b>LCP – BUPA Care Homes (phase 3)</b>	<b>15 -16</b>
<b>Metric &amp; Measurement</b>	<b>17 -18</b>

---

## **Contact Details**

LCP Central Team UK  
Marie Curie Palliative Care Institute Liverpool (MCPCIL)  
Satellite Unit  
c/o Directorate of Specialist Palliative Care  
1<sup>st</sup> Floor, Linda McCartney Centre  
Royal Liverpool University Hospital  
Prescot Street  
Liverpool  
L7 8XP

Tel: +44 (0) 151 706 2274

Email: [lcp.enquiries@rlbuht.nhs.uk](mailto:lcp.enquiries@rlbuht.nhs.uk)

Website: [www.mcpcil.org.uk](http://www.mcpcil.org.uk)

# Introduction

## **The Liverpool Care Pathway for the Dying Patient (LCP)**

Over the past few years a major drive has been underway to ensure that all dying patients, and their relatives and carers receive a high standard of care in the last hours and days of their life. The Specialist Palliative Care Team at the Royal Liverpool and Broadgreen University Hospitals NHS Trust and the Marie Curie Hospice, Liverpool developed the Liverpool Care Pathway for the Dying patient (LCP). This is an integrated care pathway for the dying. The Framework is one of the key programmes within the Marie Curie Palliative Care Institute Liverpool University (MCPCIL).

The LCP was recognised as a model of best practice in the NHS Beacon Programme (2001). It was subsequently incorporated into the Cancer Services Collaborative project and the National End of Life Care Programme (2004-7). It was recommended in the NICE guidance on supportive and palliative care for patients with cancer (2004) as a mechanism for identifying and addressing the needs of dying patients. It was recommended in the Our Health, Our Care, Our Say white paper 2006 as a tool that should be rolled out across the country. It is recommended in the End of Life Care Strategy DH 2008.

Best practice in care of the dying should be seen as the norm not the exception in our society driven by patient and carer expectations with generalists and specialists working together to inform and respond to the national agenda.

### **The LCP Framework incorporates:**

#### **1 Aim**

To improve care of the dying in the last hours / days of life

#### **2 Key Themes**

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

#### **3 Key Sections**

Initial Assessment  
Ongoing Assessment  
Care after death

#### **4 Key Domains of Care**

Physical  
Psychological  
Social  
Spiritual

The LCP therefore provides a useful template to guide the delivery of care for the dying to complement the skill and expertise of the practitioner using it. Once commenced the goals of care prompt staff to consider the continued need for invasive procedures and whether current medications really are conferring benefit. The clinician has the opportunity to follow the LCP guidance or to record the reason for decisions to determine a plan of care that deviates from this pathway. Using the LCP in any environment requires regular assessment and involves continuous reflection, challenge, critical decision-making and clinical skill.

We continue to believe the LCP is a means to empower health professionals by winning time in the climate of "busyness" to enable best practice in the last hours / days of life. The LCP is a vehicle through which best quality of care for the dying is made measurable, explicit and visible. It is valued because of the positive impact on the patient, carer and staff and it can therefore bring about a change in the culture of an organisation.

*Professor Mike Richards, Chair, End of Life Care Strategy Advisory Board commented in the Forward of the final Report of the National Audit that:*

**“How we care for the dying must surely be an indicator of how we care for all our sick and vulnerable patients. Care of the dying is urgent care; with only one opportunity to get it right to create a potential lasting memory for relatives and carers.”**

End of Life Care Strategy July 2008

**“Good PCT’s will want to ensure that the particular needs and wishes of all people who are dying should be identified and addressed. The LCP provides a well-established mechanism for achieving this. PCT’s are therefore strongly recommended to ensure that the LCP is adopted and its use audited in all locations where people are likely to die”**

The LCP provides guidance on key aspects of care including:

- Symptom Control
- Comfort measures
- Anticipatory prescribing of medication
- Discontinuation of inappropriate interventions
- Psychological and spiritual care
- Care of the family (both before and after the death of the patient)

Implementation of the Liverpool Care Pathway in a new setting involves a number of key steps:

- Training of health and social care professionals
- Baseline reviews and analysis
- Implementation and reflective practice
- Benchmarking of care provision within a National Audit Process

This document serves to demonstrate how the LCP can be utilised for all expected deaths in the generic environment. Use of the LCP Continuous Improvement Programme requires a change management programme across the health economy which can drive up the quality of care of the dying for the patient, relative and carer and health care professionals.

## 4 Phased Approach into a specific Diagnostic Group

**There is a 4 phased approach to demonstrate transferability into a specific diagnostic group, sub speciality area / non cancer patient cohort as outlined below;**

### **Key Requirements for all projects:**

- A specialist palliative care team who have implemented the LCP within the generic environment
- A specialist palliative care team with the resource to implement the LCP in the sub-speciality areas
- Sub-speciality areas with the capacity to engage in the LCP programme

### **Key Phases:**

#### **PHASE 1 (Local)**

**Induction Model - Local Pilot / Single site specific diagnostic group / sub speciality area / non cancer patient cohort**

- A local project is led by the LCP Central Team UK at the MCPCIL
- Utilise Action Research Model
- Determine Local Project Group
- Review current status & undertake a retrospective audit of documentation / Base Review
- Review Current Version of the generic LCP
- Discuss potential for transferability & or modification if required
- Review information / supportive documentation
- Agree design of LCP and associated information leaflets
- Pilot LCP within local clinical area
- Project update on the website
- Consider publications / presentations
- Agree way forward - Potential Dissemination / sustainability plan – Consider potential for a Phase 2 Project

#### **PHASE 2 (Local or National)**

**Dissemination Model to 4 – 6 sites (This may be a local dissemination or a national dissemination depending on the clinical arena and potential for national support)**

- Outcomes & lessons learned from phase 1 local pilot project leads to wider interest and site participation
- Project is registered with the LCP Central Team UK within the MCPCIL Portfolio and the MCPCIL will coordinate future programme
- Interested sites invited to attend an initial meeting and then determine Project Group (representation across all participating areas)
- Agree lead nurse and lead doctor within each participating area
- Utilise Action Research Model – agree regular action learning meeting timetable with potential for focus groups
- Review current status & undertake a retrospective audit of documentation / Base Review within each participating site
- Key personnel to attend an LCP Foundation Day if required
- Consensus regarding agreed version of the LCP (as agreed by Phase 1 group)
- Review information / supportive documentation
- Pilot of LCP agreed within each local participating clinical site
- Key personnel to attend an LCP Advanced Day
- Project update on the website
- Consider publications / presentations
- Agree way forward - Potential Dissemination / sustainability plan - Consider potential for a Phase 3 Project

### **PHASE 3**

#### **National Dissemination Model**

##### **Advertise a National Meeting**

- Building on outcomes & lessons learned from Phase 2 – the LCP Central Team UK at the MCPCIL coordinates a National meeting to share findings
- Discuss potential for either of the following options:
  - National consensus and endorsement of agreed outcomes and the LCP design as outlined in Phase 2. Then look at potential for Phase 4 development
  - Determine need for future pilot project in more specific sites
- Project update on the website
- Consider publications / presentations
- Agree way forward - Potential Dissemination / sustainability plan - Consider potential for a Phase 4 Project

### **PHASE 4**

#### **NATIONAL EVALUATION MODEL**

The National Meeting agreed consensus and proposes a National Benchmarking programme in line with National Audit Programme.

## LCP in Paediatrics (Phase1)

In most industrialized countries today, the death of a child is a rare phenomenon (Papadatou, 1997). However, when it does occur, it is often after the child has received long and complex medical interventions aimed at curing their illness or prolonging their life. But as uncommon as childhood death may be, for those families who have to confront the problems of caring for a terminally ill child, the burden is great. For the healthcare workers too, dealing with the particular problems of the dying child and their family, as well as acknowledging and coming to terms with their own sadness, can provoke considerable stress and anxiety (Goldman, 1994).

The limited experience of health professionals in caring for the dying child and their families may result in discomfort in dealing with the intense emotional response associated with the death of a child. Health professionals may react by becoming distant, both emotionally and physically, from the dying child and their parents at a time when, it may be argued, they need support most (Sahler et al, 2000). Sahler et al (2000) suggest that training all health care students (doctors and nurses) to manage the shock and distress associated with a child's death, (through teaching them to prepare a family for a potentially negative outcome while also maintaining hope, and by encouraging them to incorporate palliative care into their care delivery strategies) should result in health professionals who are competent and able to deal with the relative burdens of living and dying in paediatrics. In light of the fact that the death of a child is a relatively rare phenomenon and that the provision of appropriate care for dying children and their families pose particular challenges for health professionals, Brook, *et al* (2003) have proposed the potential value of introducing an integrated care pathway to support the provision of appropriate end of life care for paediatric patients and their families.

A local Action Research Programme has been running for a number of years in Liverpool within the paediatric service to the community teams from Alder Hey Hospital and Claire House Children's Hospice.

The LCP Paediatric project commenced with the formation of a Steering Group. Membership of the Steering Group consisted of expert representation from

- ♦ LCP Central Team UK
- ♦ Adult Hospital Specialist Palliative Care Team
- ♦ Paediatric Palliative Care Team / Oncologist
- ♦ Paediatric medical and nursing personnel

The Steering Group developed a detailed work plan and all pieces of work were co-ordinated by a project manager.

Based on the understanding gained from the analysis of the base review and current best practice, the adult LCP document was modified to reflect more closely those areas pertinent to the care of a child in the last hours / days of life. The steering group discussed and determined the initial changes required to the generic LCP for use in paediatrics. Several cycles of reflection and discussion were required before a draft document was agreed and specific supporting documentation developed.

### ☆ Current Status ☆

- This local action-learning programme continues.
- A database has been collated listing all interested parties across the UK from paediatrics who had declared interest in the local Liverpool Action Research Project.
- We are currently considering a project to pilot the current paediatric LCP across other local areas.

### **Key References – (Paediatrics)**

Brook L. et al (2003) Paediatric deaths in hospital: Scope for paediatric palliative care? *Archives of Disease in Childhood*. 88 (Supp I), A61

Goldman A. (Ed) (1994) *Care of the Dying Child*. Oxford, Oxford University Press

Matthews K, Gambles M, Ellershaw J, Brook L, Williams M, Hodgson A, Barber M (2006) Developing the Liverpool Care Pathway for the Dying Child. *Paediatric Nursing* **18**(1): 18-21

Papadatou D. (1997) Training health professionals in caring for dying children and grieving families. *Death Studies*. 21, 6, 575-600

Sahler O. J. Z. et al (2000) Medical education about end-of-life care in the paediatric setting: Principles, challenges and opportunities. *Paediatrics*, 105, 575-584

## **LCP in Neurological Conditions (Phase2)**

On the 20<sup>th</sup> May the National LCP Workshop for Neurological Conditions was held in Liverpool, coordinated by the LCP Central Team UK at the Institute supported by the Department of Health in collaboration with the National Council for Palliative care (NCPC).

The Workshop was extremely successful and associated work streams will be reported on in the very near future culminating in a final meeting in spring 2010.

### **★ Current Status ★**

#### **Key Issues discussed as follows;**

- Need for a Consensus meeting regarding End of Life Care & Care of the Dying medication prescribing for Parkinson Disease (PD) patients.
- Collate key comments regarding criteria to start the LCP to be considered for inclusion in Version 12 LCP
- Current Coping with Dying Leaflet needs more information included re nutrition and hydration
- Consider the need for Healthcare Professionals Fact Sheet
- Include information / outputs with 6 monthly LCP Briefing Paper for the Web site

## LCP in Heart Failure (Phase 3)

Heart failure has become a major cause of morbidity and mortality in the UK. Estimates of prevalence range from 2 to 10 per 1000 population (Davis 2000) and the incidence is rising as more people survive acute coronary events (Hanratty et al 2002). Mortality figures are suggested to be 31-48% at one year from diagnosis of heart failure and to be 76% at three years (Gibbs 2002). This survival for heart failure is worse than for many of the common cancers (Hanratty et al 2002; Horne and Payne, 2004; Ellershaw and Ward, 2003).

Palliative care for patients with heart failure has gained interest from government, statutory bodies, as well as physicians over the last few years (Hanratty et al 2002; Ellershaw and Ward, 2003; Horne and Payne, 2004). The national service framework for coronary heart disease (DoH 2000) endorsed this view but failed to address the question of how it should be provided or to identify new sources of funding (Hanratty et al 2002).

With the prevalence of heart failure increasing (2 to 10 per 1000 population, Davis 2000) planning for the needs of people dying with heart failure must be addressed and one approach that has been suggested is the introduction of the LCP (Ellershaw and Ward 2003).

An Action Research approach has been used to facilitate the use of the generic LCP and associated documentation for patients with heart failure in the last hours and days of life.

### **The specific aims of the LCP Heart Failure project were:**

- To determine transferability of the generic Version 11 LCP for the management of patients in heart failure within a specialist heart unit / ward in the last hours and days of life.
- To undertake an implementation pilot in up to 10 hospital settings delivering care via the LCP to patients dying from heart failure within a specialist heart unit / ward in the last hours and days of life.
- To determine the need for supportive documentation / information for healthcare professionals.
- To determine the need for supportive documentation / information for patients / carers
- To determine specific guidance for health care professionals and patients and carers re the Management of Implantable Cardioverter Defibrillators (ICD's)
- To collate a final report in support of a dissemination model for the use of the LCP in patients with heart failure in the last hours / days of life.

The LCP Heart Failure project commenced early 2005 with the formation of a Steering Group. Membership of the Steering Group consisted of expert representation from

- ♦ LCP Central Team UK
- ♦ Cardiology
- ♦ Specialist Palliative Care
- ♦ Patients / carers.
- ♦ Secondary and tertiary care
- ♦ Statutory and voluntary sector
  - i. British Heart foundation
  - ii. National Council for Palliative Care

The Steering Group developed a detailed work plan and all pieces of work were co-ordinated by a project manager. Many acute units showed interest in taking part in the LCP Heart Failure pilot, however only a total number of three acute units out of a potential ten units were able to undertake the pilot project through to the final stage, due to small numbers of deaths during the data collection period. Each unit has carried out the full process to implement the LCP for patients with Heart Failure.

The data collection period for the LCP Heart Failure project ended 31<sup>st</sup> December 2006. Data from a cohort of up to 20 pathways used for patients with heart failure within each of the participating sites has been collated and analysed descriptively to provide a snapshot of care in the last hours and days of life. Each participating site received a report on their own performance on each of the goals against the aggregate performance of all sites for comparative purposes. This provided a detailed picture of the effectiveness of the implementation process particularly with regard to the accompanying education programme. The report also helped as a starting point in identifying the gaps in the education programme. A full research protocol that details the research/audit elements of the project has been compiled. A final meeting to end the project took place in March 2007. As well as providing feedback regarding the data submitted to the LCP Central Team UK, the meeting also provided a forum for the LCP Central Team UK and participating units to share 'Lessons Learned' from the project and identify the barriers to and benefits from conducting the overall project.

## ✳ Current Status ✳

### **Project Outcomes:**

- 2 additional goals added to the generic document:
  - Management of Dyspnoea
  - Management of Implantable Cardioverter Defibrillators (ICD's)
- Determined the need for supportive information
- Patient / Carer information – designed by Arrhythmia Alliance – ICD Patient Information [www.arrhythmiaalliance.org.uk](http://www.arrhythmiaalliance.org.uk) to locate this booklet you will need to click on About Arrhythmias, then click on booklets and the ICD Patient Information booklet is available to print off.
- Healthcare Professional information for '**Implantable cardioverter defibrillators in patients who are reaching the end of life**' is available from the British Heart Foundation [www.bhf.org.uk](http://www.bhf.org.uk)  
BHF by calling the BHF Orderline on 0870 600 6566 or email [orderline@bhf.org.uk](mailto:orderline@bhf.org.uk) **Product code M105**
- Implemented the LCP into 10 pilot Hospital settings

### **Key References – (Heart Failure)**

Davis, R.C., Hobbs, F.D.R., and Lip, G.Y.H. (2000) ABC of heart failure: history and epidemiology. *British Medical Journal*, Vol. **320**, p.39-42

Department of Health (2000a). *National Service Framework for coronary heart disease: modern standards and service models*. London: Stationary Office.

Ellershaw, J., and Ward, C. (2003) Care of the dying patient: the last hours or days of life *British Medical Journal*, Vol. **326**, p.30-34

Gibbs, J.S.R., McCoy, A.S.M, Gibbs, L.M.E., Rogers, A.E., and Addington-Hall, J.M. (2002) Living with and dying from heart failure: the role of palliative care. *Heart*, Vol. **88** (Suppl II), p. ii36-ii39

Hanratty, B., Hibbert, D., Mair, F., May, C., Ward, C., Capewell, S., Litva, A., and Corcoran, G. (2002) Doctors' perceptions of palliative care for heart failure: focus group study *British Medical Journal*, Vol. **325**, p.581 - 585.

Horne G, Payne S (2004). Removing the boundaries: palliative care for patients with heart failure, *Palliative Medicine*, Vol. **18** (4), p.291-296

## LCP in Advanced Chronic Kidney disease (Phase3)

Recent advances in the treatment of advanced chronic kidney disease have meant that many patients are now surviving for longer, and with increased quality of life, due to renal replacement therapies and kidney transplants. Over 50% of the best-matched kidney transplants are still functioning after twenty-five years and some patients can survive for over twenty years on dialysis (Medical Outcomes Trust, 1999). But for those patients in whom such interventions are not appropriate or no longer effective, the shift to palliative care should be encouraged to maintain a good quality of life in dying patients.

In the United Kingdom alone, it is estimated that more than 13,000 patients die each year of illnesses and conditions affecting the kidneys, and the National Service Framework for Renal Services: part 2 (DoH 2005) states that approximately 50% of patients will die within three months of developing end-stage renal failure. However, despite such statistics, palliative care for patients with end-stage renal failure is often a neglected aspect of nephrology (Gunda et al, 2005), irrespective of the fact that due to the high mortality rate of end stage renal failure, nephrologists care for many dying patients (Holley et al, 2003).

Taking into account that the number of cases of renal cancer has risen by 68% in the last 20 years, and with the increasing level of factors such as obesity and diabetes in the population, it is likely that the prevalence and mortality rates of patients with end-stage renal failure is set to increase (Kidney Research UK, 2005), and as such the palliative care needs of this patient population need to be addressed (Poppel et al, 2003). An action research approach has been used to facilitate the transferability of the LCP for use in these more specialist renal areas.

### **The specific aims of the LCP project for advanced chronic kidney disease were:**

- To determine transferability of the generic Version 11 LCP for the management of patients in renal failure within a specialist renal unit / ward in the last hours and days of life.
- To undertake an implementation pilot in up to 8 hospital settings delivering care via the LCP to patients dying from renal failure within a specialist renal unit / ward in the last hours and days of life.
- To determine the need for supportive documentation / information for healthcare professionals.
- To determine the need for supportive documentation / information for patients / carers
- To develop drug guidance for patients with renal failure in the last hours / days of life.
- To collate a final report in support of a dissemination model for the use of the LCP in patients with renal failure in the last hours / days of life.

The LCP project for advanced chronic kidney disease commenced late 2005 with the formation of a Steering Group. Membership of the Steering Group consisted of expert representation from

- ♦ LCP Central Team UK
- ♦ Nephrology
- ♦ Specialist Palliative Care
- ♦ Patients / carers.
- ♦ Secondary and tertiary care
- ♦ Statutory and voluntary sector
  - i. National Kidney Federation
  - ii. National Council for Palliative Care

The data collection period for the LCP advanced chronic kidney disease project ended 28<sup>th</sup> February 2007. Data from a cohort of up to 20 pathways used for patients with renal failure within each of the participating sites was collated and analysed descriptively to provide a snapshot of care in the last days of life. Each participating site received a report on their own performance on each of the goals against the aggregate performance of all sites for comparative purposes.

This provided a detailed picture of the effectiveness of the implementation process particularly with regard to the accompanying education programme.

A full research protocol that details the research / audit elements of the project has been compiled. A final meeting to end the project was held June 14<sup>th</sup> 2007. As well as providing feedback regarding the data submitted to the LCP Central Team UK, the meeting also served to finally sign off the symptom management guidance for renal failure patients in the last hours / days of life and provided a forum for the LCP Central Team UK to share 'Lessons Learned' from the project and identify the barriers to and benefits from conducting the overall project. The project goals of developing an information leaflet for healthcare professionals and the development of symptom management guidelines have been met. It is anticipated that there will be a lot of demand for each of these publications in the future and to this end the LCP Central Team UK is currently working closely with the Department of Health and Lead Renal Groups to secure appropriate supportive endorsement.

The Institute has now secured a Renal LCP Lead.

## ★ Current Status ★

### Renal Documents

- Guidelines for LCP Drug Prescribing in Advanced Chronic Kidney Disease was launched in June 08 and is now available to view, print and order on our website [www.mcpcil.org.uk](http://www.mcpcil.org.uk)  
This document will be up for review later this year.
- Patient / Carer and Healthcare Professional leaflets are awaiting a publication date – please monitor the 'NEWS' pages on our website [www.mcpcil.org.uk](http://www.mcpcil.org.uk) for further information.

### Key References - (Renal Failure)

Department of Health (2005) National Service Framework for Renal Services: part 2: Chronic Kidney Disease, Acute Renal Failure and End of Life Care. London: Stationary Office.

Gambles, M., Jack, B, and Ellershaw, J. (2005) Author's Reply to: The Liverpool Care Pathway: its impact on improving the care of the dying. *Age and Ageing*, Vol **34** (2) p198 - 9

Gunda, S., Thomas, M., and Smith, S. (2005) National survey of palliative care in end-stage renal disease in the UK. *Nephrology Dialysis Transplantation*, Vol. **20** (2), p.392-395

Holley, J.L., Carmody, S.S., Moss, A.H., Sullivan, A.M., Cohen, L.M., Block, S.D., and Arnold, R.M. (2003) The need for end of life care training in nephrology: national survey results of nephrology fellows. *American Journal of Kidney Diseases*, Vol. **42** (4), p.813-820

Kidney Research UK (2005) Kidney Health Information: Kidney Disease in the UK Today. [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org): Accessed 01-11-2005

Medical Outcomes Trust (1999) Functional status and well-being in end stage renal disease. *Monitor*, Summer Edition. Available from: [www.outcomes-trust.org/monitor/sum99mon.htm](http://www.outcomes-trust.org/monitor/sum99mon.htm)  
Accessed 22-12-2005

Poppel, D.M., Cohen, L.M., and Germain, M.J. (2003) The Renal Palliative Care Initiative. *Journal of Palliative Medicine*, Vol. **6** (2), p.321-326

National LCP Renal Symptom Control Guidelines (June 2008)  
[www.mcpcil.org.uk/about\\_the\\_institute/July\\_news/June\\_2008/06\\_June\\_2008](http://www.mcpcil.org.uk/about_the_institute/July_news/June_2008/06_June_2008) (last accessed 9th July 2008)

## LCP in the Intensive Care Unit – ICU (Phase 3)

An Action Research project has been carried out at the Royal Liverpool & Broadgreen University Hospital Trust (RLBUHT) to adapt the LCP for use on the Intensive Care Unit (ICU). Many patients with advanced illnesses spend some time on the Intensive Care Unit during their final hospital admission (SUPPORT 1995). The RLBUHT has approximately 2000 deaths per year, of which 7-10% occur on the ICU

The literature suggests that 70% of deaths occur on ICU after withdrawal of treatment, i.e. a trial of aggressive intensive care has not led to improvement, and after review the treatment is withdrawn as it has become futile (Winter and Cohen 1999). Further deaths will occur after withholding treatments that are unlikely to offer benefit, and so can also be predicted (Hall and Rocker 2000).

It may be true that in the ICU more than in any other part of the hospital, the culture is such that even a comfortable and inevitable death is a professional failure, and so a peaceful death is not recognised as a legitimate goal of medical care (Nelson and Meier 1999). There is, therefore, little motivation to complete a care pathway and so demonstrate a “good death”.

ICU deaths differ from other deaths within the hospital. The first component of the LCP is a series of criteria, designed to facilitate the diagnosis of dying (Ellershaw and Wilkinson 2003). These are not all applicable on the ICU, where a more technical definition of dying is required, taking into account the results of investigations and monitoring equipment (Seymour 2000).

The ongoing assessment of patients on an LCP consists of a series of symptom control goals. This assessment is completed every four hours and the goals marked as ‘achieved’ or ‘variance’ (Ellershaw and Wilkinson 2003). This is suitable for a deteriorating patient who is likely to be on the pathway for 24 – 48 hours, but patients on ICU whose treatment is withdrawn are likely to have a much shorter dying phase, with a mean of around 4 hours (Hall and Rocker 2000). A shorter and more intensive programme of assessment may therefore be more appropriate.

The literature points to the fact that collaboration between palliative care and critical care physicians could lead to the provision of optimal end-of-life care on the ICU, but also points out barriers to achieving this (Levy and Carlet 2001, Nelson and Danis 2001).

A local Action Research Programme has been running for 4 years within the ICU at The Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT)

The LCP ICU project commenced in 2003 with the formation of a Steering Group. Membership of the Steering Group consisted of expert representation from

- ♦ LCP Central Team UK
- ♦ Hospital Specialist Palliative Care Team
- ♦ ICU medical and nursing personnel

The Steering Group developed a detailed work plan and all pieces of work were co-ordinated by a project manager.

- The Steering group has ratified LCP ICU Version 11. (This document looks very different to the generic version 11 LCP and has been specifically designed for use in a level 3 ICU)
- Data continues to be collated on use of the LCP in the ICU environment in Liverpool at RLBUHT.
- A National LCP ICU Foundation Study Day was held in April 2007.
- Interested ICU and palliative care partnerships can register with the national LCP ICU Project.
-

## **ICU Documents**

On the Institute website – [www.mcpcil.org.uk](http://www.mcpcil.org.uk) (LCP and specialist areas) you will be able to view and print the following documents:

- The current LCP ICU Version 11
- LCP ICU Algorithm
- Registration / Information documents on how to register with the LCP ICU project

## **The LCP Central Team UK is hopeful that we can secure funding for a National Action Research ICU Programme**

We would propose this project would run over a 3-year period to:

- evaluate the effectiveness of the customised LCP for use in a cohort Intensive Care environments (potentially 10 units)
- enable an in-depth exploration of the culture of death and dying in a cohort of intensive care environments particularly regarding the use of the LCP and protocols for withdrawal of treatment.

## **☆ Current Status ☆**

The collaboration across ICU & Specialist Palliative Care has been crucial to the success of the project

A National LCP ICU Foundation Study Day was held in April 2007 to share some of the challenges and successes to date of this innovative exciting action research programme.

We have more than 65 ICU's across the UK currently linked with this project we are planning to run a further Study Day to share learning and develop this project further.

The LCP ICU study day will be held on the 26<sup>th</sup> of June 2009 at the Royal Society of Medicine in London. To register for the study day see the Institute web site [www.mcpcil.org.uk](http://www.mcpcil.org.uk)

## **Key References – (ICU)**

Ellershaw JE and Wilkinson S (ed.) (2003). *Care of the Dying*. Oxford University Press, Oxford.

Hall RI, Rocker GM. (2000) End-of-life care in the ICU: treatment provided when life support was withdrawn. *Chest* 2000;118:1424-1430.

Levy MM, Carlet J. (2001) Compassionate end-of-life care in the intensive care unit. *Critical Care Medicine* 2001;29,2(Suppl): N1.

Nelson JE, Danis M. (2001) End-of life care in the intensive care unit: Where are we now? 2001;29,2(Suppl):N2-N9.

Nelson JE, Meier DE. (1999) Palliative care in the intensive care unit: part I. *J Intensive Care Med* 1999;14:130-139.

Principal Investigators for the SUPPORT Project. (1995) A controlled trial to improve care for seriously ill hospitalised patients: the study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). *Journal of the American Medical Association* 1995;174:1591-1598.

Seymour JE. (2000) Negotiating natural death in intensive care. *Social Science and Medicine* 2000;51:1241-1252.

Winter B, Cohen S. (1999) ABC of intensive care: withdrawal of treatment. *British Medical Journal* 1999;31:306-308.

# LCP in BUPA Care Homes (Phase 3)

## Background

In 2006 BUPA Giving pledged £1.8m to the MCPCIL and the NCPC to fund three different projects in the field of palliative and dementia care over three years. BUPA Giving commissioned the MCPCIL to work on a major service improvement programme to develop practice in palliative care and care for dying residents.

## The BUPA research projects

The chosen projects seek to extend the use of the acclaimed LCP in care homes:

1. Implementing the LCP as part of a continuous Quality Improvement Programme for care of the Dying in BUPA care Homes
2. A National Pilot for implementing the LCP into Dementia Care
3. Building the capacity of the workforce through palliative care education.

## Project 1

The first project involves introducing the LCP to 125 care homes across the UK. The pilot phase involves 20 BUPA care homes with Regional project leads working closely with care home managers and nominated Key Champions in each care home.

Together they are undertaking a standardised process of education and training to underpin implementation of the LCP into each care home. Further cohorts will join on a 5 monthly basis throughout the project. Evaluation (ongoing and summative) is a major element of this work.

It is exciting for the Institute to work alongside the care home environment to fully understand the challenges faced by this care sector and develop the learning related to care of the dying to meet the needs of the residents, relatives / carers, staff, in support of best practice in this field.

We continue to build, share and consolidate knowledge skills and attitude in support of best practice and performance management that is firmly rooted within a governance framework for care of the dying within BUPA.

“It has truly been a privilege to work alongside the BUPA Key Champions for this project, implementing the LCP for the dying resident. Without question, the motivation, passion and determination of the Key Champions has been a major influence in ensuring the initial success of this project. We are confident that this level of commitment will help to ensure that the LCP becomes fully integrated into clinical practice, standardising high quality care for residents within their last hours and days of life.”

**Janet Howard & Sharon Phillips,**  
BUPA Regional Project leads

## Projects 2 and 3

The second and third projects will focus on improvements in care delivery through building the knowledge and confidence of the care home workforce by providing enhanced education and training for both qualified and non-qualified staff. This will support the delivery of high quality care to patients residing in BUPA care homes.

Find out more about BUPA at: [www.bupa.co.uk](http://www.bupa.co.uk)

### About the BUPA project

“I always knew the care that we gave was good but now with the LCP we can evidence this – and even do better!”

**Nurse, BUPA Care Home**

“The BUPA Foundation day was inspirational – building confidence, competence and a huge desire to make a difference for my residents.”

**Delegate, BUPA LCP Foundation day.**

## Metric & Measurement

The LCP Central Team UK at MCPCIL views success as a journey and not a destination.

The success of the LCP programme within specific diagnostic groups has demonstrated that the LCP is clearly beneficial to all those death is expected. The LCP document itself is only as good as the clinical teams using it and the learning and teaching programmes that support its implementation and development.

In each of the local and national models of dissemination supportive information has been required in relation to;

- Patient / carer information
- Health professional guidance
- Prescribing information

One of the key measures of success is the ability to benchmark practice across other organisations. The Institute has coordinated 2 national Care of the dying audits across hospitals in collaboration with the Royal College of Physicians (RCP) supported by Marie Curie Cancer Care and the Department of Health.

### **National Care of the Dying Audit – Hospitals (NCDAH)**

The first National Care of the Dying Audit – Hospitals (NCDAH) was undertaken by the MCPCIL and the Royal College of Physicians supported by Marie Curie Cancer Care & the Department of Health UK. This assessed the quality of care given to 2672 patients who died across 94 hospital trusts in 118 hospitals in 2006 / 07. The quality of care for each patient had been documented through the use of the LCP. Each hospital provided information on up to 30 patients. Over half of the patients reported did not have cancer.

The audit enabled trusts to benchmark their performance against national findings on a range of domains, including:

- Physical comfort of the patient
- Psychosocial & spiritual aspects of care
- Communication
- Information giving & receiving
- Following appropriate procedures

The results from this audit can be viewed on the web site ([www.mcpcil.org.uk](http://www.mcpcil.org.uk))

The recently published End of Life Care Strategy UK recommends the LCP or equivalent tool to be used in all expected deaths wherever people die.

Department of Health (2008) End of Life Care Strategy – promoting high quality care for all adults at the end of life. DH. London

The LCP Continuous Quality Improvement Programme should reflect the organizations goals, performance management and governance framework in support of best practice in care of the dying

Over the past decade teams working with the LCP have used the document to guide care for patients dying of conditions other than cancer. Importantly the audit was not confined to cancer patients, 55% of cases had a non-cancer diagnosis. However, there are other specialist areas that have shown an interest in implementing the LCP.

### Round 2 of the audit - 2008/2009

The second round of the National Care of the Dying Audit Hospitals, co-ordinated by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Royal College of Physicians (RCP) supported by Marie Curie Cancer Care and the Department of Health, is currently underway.

One hundred and fifty-five hospitals from within 115 acute hospital trusts in England provided a total of 3893 individual datasets for patients who were cared for in the final days and hours of life using the Liverpool Care Pathway for the Dying Patient (LCP). This represents a 32% increase on the number of hospitals that took part in round 1 and 104 hospitals participated in both rounds. Round 2 also includes a pilot cohort of 13 hospitals from 5 Trusts in Northern Ireland.

New this round, alongside data from the goals of care on the LCP, information on the prescription and administration of medications for agitation and restlessness in the last 24 hours of life will be reported, as well as data recorded on the variance sheets for a selection of goals. Data analysis is now nearing completion and the reports are currently under construction. We plan to make individual hospital reports available to participating hospitals in the summer of 2009.

These reports will allow hospitals to benchmark their relative performance on key domains of care (physical, psychosocial and spiritual, communication, information and adherence to policies and procedures) and to make comparisons with their performance in the previous rounds where appropriate. Once again, we plan to undertake regional workshops in Liverpool, London and this time in Belfast in September and October of 2009 to allow participants to debate the findings and action plan for improvements in future care.

Regional workshops will be undertaken in the autumn of 2009 to allow participants to debate the findings and action plan for improvements in future care. Importantly, the results from this round of the audit will also be used to inform the development of Version 12 of the LCP which will be launched 25<sup>th</sup> November 2009 at the 6<sup>th</sup> National LCP Conference at the Royal Society of Medicine, London. For further information on the audit and the national conference see [www.mcpcil.org.uk](http://www.mcpcil.org.uk)



