The Marie Curie
Palliative Care Institute
LIVERPOOL

The Royal Liverpool and NHS
Broadgreen University Hospitals
NHS Trust

DIRECTORATE OF PALLIATIVE CARE
HOSPITAL SPECIALIST PALLIATIVE CARE TEAM (HSPCT)

The Role of the Palliative Care Network Nurse

Nurses can make a difference

Education increases confidence

Time well spent

Working to improve patient care

Opportunity for dissemination

Raising the profile of palliative care

Knowledge leads to empowerment

Reviewed July 2008

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INTRODUCTION

The LCP Central Team UK recommends consideration of forming a local group of clinicians who can support sustainable change within a continuous quality improvement programme for care of the dying underpinned by the Liverpool Care Pathway for the Dying Patient Framework (LCP).

A link nurse programme or key champion group encourages empowerment, knowledge, and ownership to sustain the LCP within the clinical environment.

One example of such a programme is to determine a key champion within each clinical area who links with the Hospital Specialist Palliative Care Team (HSPCT) and takes the responsibility of sustaining the use of the LCP, generic education related to the LCP and compliance with the recommendations within the clinical area.

In 1997 when the LCP was first implemented within the RLBUHT environment, a pilot area was chosen and a link nurse nominated. With dissemination of the LCP across the Trust the number of link nurses increased and the link nurses would meet regularly and formed a group of Palliative Care Network Nurses with a mission statement, philosophy and opportunity for learning and teaching and sharing of best practice.

There are currently 67 Palliative Care Network Nurses across the organisation and their continued programme is coordinated and evaluated by the HSPCT.

This document outlines the current roles and responsibilities of a Palliative Care Network Nurse at the RLBUHT. The Network Nurse at RLBUHT have opportunities to network with colleagues from the community & Hospice setting with integrated learning and shared experiences, challenges and successes.

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Definitions

What is Palliative Care?

Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (NICE 2004)

What is Specialist Palliative Care?

Specialist Palliative Care is the management of unresolved symptoms and complex psychosocial issues, complex end of life issues and complex bereavement issues that is provided by specialist personnel with expert knowledge. (NICE 2004)

What is End of life Care?

End of life care is the active and compassionate approach to care, for all people with progressive, advanced, irreversible, conditions estimated to be in the last months / year/s of life.

Good end of life care enables people to live well and die well in the place of their choosing, and is one of the fundamental rights of every person. End of life care encompasses supportive and palliative and specialist palliative care needs of the patient and family.

The End of Life Care programme 2004 - 2007

The End of Life Care Programme was launched in November 2004 its aim was to increase individuals' choice over where they wish to live and die. To make this a reality the programme has been working alongside a number of different organisations, including social and health care services as well as the voluntary and private sectors. Above all, there is a need to work across organisational boundaries and in partnership with the individual and their family to ensure care is person-centred.

The End of Life Care Strategy July 2008

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

The End of Life Care Strategy launched July 2008, can be viewed at:
www.dh.gov.uk/publications
www.endoflifecareforadults.nhs.uk

The strategy was developed over the period of a year by an advisory board and 6 working groups and over 300 stakeholders were consulted. From this process a consistent message has emerged that a whole systems approach is needed. Within this, a care pathway approach both for commissioning services and for delivery of integrated care for individuals has been strongly recommended.

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The care pathway involves the following steps:

- Identification of people approaching the end of life and initiating discussions about preferences for end of life care
- Care Planning; assessing needs & preferences, agreeing a care plan to reflect these and reviewing these regularly
- Coordination of care
- Delivery of high quality services in all locations
- Management of the last days of life
- Care after death
- Support for carers both during a persons illness and after their death

What is 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 days and hours of their lives. The Specialist Palliative Care Team at RLBUHT 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 of Liverpool (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.

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.

Although the LCP was originally developed for the care of cancer patients in the acute environment it has been adapted and disseminated across all care settings irrespective of diagnosis.

The LCP is fully implemented for all expected deaths across RLBUHT.

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)

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 / reports from this audit can be viewed on the website (www.mcpcil.org.uk)

The second round of this national audit will commence July 2008.

THE ROLE OF THE HOSPITAL SPECIALIST PALLIATIVE CARE TEAM (HSPCT)

The Directorate of Specialist Palliative Care encompasses the Specialist Palliative Care Team, the Complementary Therapy Service and a Satellite Unit of The Marie Curie Palliative Care Institute Liverpool (MCPCIL).

The palliative care agenda aims to ensure that all people who need it have access to rapid high quality palliative care in a setting of their choice. Palliative care promotes the physical, psychological, social and spiritual well being of patients and carers throughout their illness.

The Directorate of Specialist Palliative Care at the Royal Liverpool and Broadgreen University Hospitals continues to develop the existing quality of the service available and to demonstrate this through integrated measurable standards and outcomes. We aim to achieve fair access; timeliness and effective care delivery together with patient and carer empowerment for our client group.

Given the complex nature of service provision we are always striving to sustain and develop our service that clearly achieves continuity of clinical practice and the balance between education, research and evaluation in support of continued progress and the wider governance agenda.

Mission Statement

Within the acute Hospital setting the Directorate of Specialist Palliative Care aims to maximize the quality of life for patients with a life threatening condition and to provide appropriate support to their carers'.

Philosophy

- To provide specialist palliative care for patients and carers, by advising on pain and symptom control, facilitating spiritual and social support and providing psychological and bereavement care
- To empower health professionals to provide evidence based palliative care through education, research and audit.
- To collaborate with health providers across settings to promote national and local policies in pursuit of a seamless palliative care service

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THE ROLE OF THE PALLIATIVE CARE NETWORK NURSE - RLBUHT

The HSPCT will support you to acquire appropriate knowledge and skills in the palliative care.

You will then be able to take a lead role in the support and management of patients with palliative care needs and care of the dying on your ward.

You will have the opportunity to liaise regularly and be supported by the relevant Macmillan Palliative Care Nurse Specialist (MPCNS).

You will be the key champion for the continuous quality improvement framework for care of the dying in your clinical area. You will be the link nurse for Palliative care issues with the support of the HSPCT.

The HSPCT will empower you to share knowledge and skills with other generic workers in the clinical environment.

You will be responsible for the ongoing cascade model of learning and teaching of use of the MS26 Graseby Syringe Driver and the LCP within your clinical environment.

WHAT IS IN IT FOR YOU?

- Empowering the team where you work
- Enhancing the skills of you and others - meeting Personal Development Plans
- Access to continuous learning
- Access to communication skills training
- Access to shadowing programme with colleagues from community and hospice.
- An opportunity to spend time with the Palliative Care Team.
- Network Nurse Certificate
- An opportunity to be part of a wider network of generic nurse with an interest in palliative care across our health economy.

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ROLE OF THE WARD TEAM – KEY DOMAINS OF PALLIATIVE CARE

The following are some key domains of care, related to the referral criteria of the HSPCT at RLBUHT. The key objectives outlined are the generic elements of palliative care, which you will be able to achieve in the care of your patients and their carers with the support and guidance of the HSPCT. For more complex issues or unstable symptoms do not hesitate to contact members of the HSPCT who can give you further advice and support or review your patient as appropriate.

MANAGEMENT OF PAIN

Objectives

- Explore current definitions of pain.
- Distinguish between cognitive and affective components of pain
- Compare and contrast acute and chronic pain
- Develop further skills in assessing the patient in pain
- Initiate treatment according to Hospital Formulary Guidelines and the World Health Organisation pain ladder.
- Develop skills and confidence in patient and family education related to pain management
- To be aware of cultural attitudes to and personal perceptions of pain.
- To be aware of appropriate drug routes of administration.
- To be aware of the nursing care implications of surgery, radiotherapy, chemotherapy and nerve blocks.
- To be aware of nursing strategies and referral to appropriate personnel re other methods of pain relief - e.g. complementary therapies.
- To review / assess patient & document outcome at least 4 hourly
- To document pain assessment and management accordingly.

OTHER SYMPTOMS e.g. Nausea

Objectives

- Further develop knowledge / skills in the assessment and management of the biological and psychosocial aspects of alterations in body function and the resulting symptoms.
- Initiate treatment according to the formulary guidelines
- To review / assess patient & document outcome at least 4 hourly

PSYCHOLOGICAL SUPPORT FOR THE PATIENT AND CARER

Objectives

- Use existing skills and develop knowledge of communication skills related to the care of individuals facing progressive illness and or death.
- To reflect on personal feelings, values and beliefs and philosophy of life, and recognise that they may influence interactions with patient and carers.
- To initiate basic psychological and spiritual support.
- To review and reassess situations as necessary.
- To document outcome.

PATIENT IS DYING / DISTRESSED

Objectives

- To identify that the patient is dying.
- To ensure appropriate symptom control, psychological support and spiritual care is achieved.
- To use the Liverpool Care Pathway for the dying patient (LCP)
- To act as the key champion / educator in the pathway development in the ward area.

INSIGHT OF THE PATIENT / CARER

Objectives

- As with psychological support for the patient/carer.
- To ensure patient and family are aware of diagnosis and current situation and to inform / support decision making in relation to:
- Advocacy
- Mental Capacity act
- informed consent
- truth telling
- treatment decisions
- prolongation of life
- CPR (new policy 2008)
- Confidentiality
- Regularly assess status as the situation changes.
- Document outcome appropriately.

PLACEMENT

Objectives

- Discharge planning process to follow Hospital Policy in liaison with the Community Assessment Team (CAT)

FOR ADVICE OR SUPPORT CONTACT HSPCT
BLEEP = 4191
EXTENSION NO. = 2274

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HOW IS THE PALLIATIVE CARE NETWORK NURSE PROGRAMME GOING TO WORK?

A MPCNS will arrange to visit your ward regularly. It is an opportunity to discuss any palliative care issues with a member of the HSPCT. This process should empower the generic team and prompt early referral to the HSPCT of any patient requiring specialist palliative care support.

Although a referral is required from the MDT for a patient to be seen by the HSPCT; it is important to remember that the HSPCT will be pleased to offer advice and support to the professional team with or without a referral in a consultancy capacity.

The Network Nurse will take the lead in generic palliative care provision within his / her clinical area and all other staff members will recognise the role of the Network Nurse.

Whenever possible the Network Nurse will assess a patient prior to referral to the HSPCT.

A resource folder for supportive information designed by the HSPCT will be available to you and your colleagues on the ward.

A copy of the Merseyside and Cheshire Palliative Care Audit Group Standards and Guidelines Audit will be available from the HSPCT to you and your colleagues within the clinical area.

The Network Nurse will ensure that colleagues know were to access the LCP blue box file and will take responsibility for regularly checking on the stock supply with in them.

The Network Nurse will meet formally with the Palliative Care Nurse Specialist assigned to their ward, on a 2 monthly basis, to discuss any challenges apparent in the clinical area or personal development issues relating to the Network Nurse Programme.

Four Study Days will also be offered throughout the year in conjunction with Primary Care, you will be expected to attend at least 2 of these per year.

The Network Nurse will take a lead role in educating ward colleagues about the LCP and the safe use of the Graseby M26 syringe driver

The Network Nurse will be invited to join an integrated Network Nurse Meeting with Hospice & Community colleagues.

Each year the Network Nurse will have the opportunity to spend 2 days with the HSPCT.

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Key Quotes / Comments

“It is the responsibility of every health care professional to provide palliative care, and to call in specialist colleagues if the need arises, as an integral component of good clinical practice, whatever the illness or its stage”

Directorate Manager RLBUHT
Palliative Care

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”

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APPENDIX 1

HOSPITAL SPECIALIST PALLIATIVE CARE TEAM
REFERRAL CRITERIA

Access to the HSPCT can be gained for both inpatients and those attending as outpatients

REASONS FOR REFERRAL

1. Pain
2. Other Symptoms – e.g. Nausea
3. Psychological support for the patient/family
4. Patient dying with distressing symptoms
5. Problems regarding insight of the patient/family
6. Facilitation and advice regarding complex placement.

METHOD OF REFERRAL

Clinical Team agreement to contact the service - written referral in the patients case notes and The Hospital Information Computer System (PAS) for inpatients or patients attending other out patient clinics or a referral letter for a request to our Specialist Out Patient Clinic**.**

Immediate information / support for any patient:

- Bleep 4191
- Telephone ext. 2274

RESPONSE TIME

- Urgent inpatient referrals will be responded to within one working day - 24hrs
- Routine inpatient referrals will be responded to in two working days - 48hrs
- Outpatients attending other clinics will be seen on request at time of referral. There is no waiting list for the Specialist Palliative Care Outpatient Service. Appointments are allocated on the day of referral and the patient will be seen within 1 – 7 working days.

There is a direct line to the Hospital Specialist Palliative Care Team for external queries:

1st Floor Linda McCartney Centre
The Royal Liverpool & Broadgreen University Hospitals Trust
Prescot Street
Liverpool, L7 8XP

T: +44 (0) 151 706 2274
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APPENDIX 2
Helpful References

CORE TEXT

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4. Spiritual and Religious Care Competencies for Specialist Palliative Care:
   Assessment Tools level 1&2
   Self-assessment tools levels 3&4
   David Mitchell & Tom Gordon
   Marie Curie Cancer Care - www.mariecurie.org.uk/healthcare

Other Useful Websites

Marie Curie Palliative Care Institute Liverpool www.mcpcil.org.uk

End of Life Care Programme – 'Making Change Happen'
www.endoflifecareforadults.nhs.uk

National Council for Palliative Care www.ncpc.org.uk

Mental Capacity Act Code of practice:
http://www.opsi.gov.uk/acts/acts2005/related/ukpgacop_20050009_en.pdf

Decision relating to Cardiopulmonary Resuscitation:
http://www.bma.org.uk/ap.nsf/Content/CPRDecisions07