Welcome everyone
Resource –Link Nurse Palliative Care Study Day
13th August 2013

Palliative Care
is the care for people of all ages with a life-limiting illness, which aims to:

➢ optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs

➢ support the individual’s family, whānau, and other caregivers where needed, through the illness and after death.

The Principles of palliative care service provision are that it should be

➢ provided according to an individual’s need, and may be suitable when death is days, weeks, months or occasionally even years away

➢ available wherever the person may be

➢ provided by all health care professionals, supported by specialist palliative care services

➢ Provided in such a way as to meet the unique needs of individuals from particular communities or groups

Challenges for Palliative Care in NZ

➢ Ageing population
➢ Increasing number of people with chronic conditions
➢ People living with longer period of decline
➢ Access to appropriate palliative care services important
➢ Primary providers have an increasing role in providing palliative care

Place of death for all deaths over a five year period in NZ (2003-2007)

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>Percent of all deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>34%</td>
</tr>
<tr>
<td>Residential Care</td>
<td>31%</td>
</tr>
<tr>
<td>Private Residence</td>
<td>22%</td>
</tr>
<tr>
<td>Hospice</td>
<td>6%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
</tr>
</tbody>
</table>

Source: Palliative Care Council of New Zealand, 2011
Primary Palliative Care Providers

- General practice
- Aged residential care
- Public hospitals
- Community hospitals
- District nursing services
- Home health care agencies

Primary palliative care (generalist)

- Is provided by any health care professional who is not part of a specialist team
- It incorporates a palliative approach to the care of those affected by a life-limiting illness regardless of setting
- Is a integral part of standard practice by any healthcare professional

Specialist Palliative Care

- Provided by health professionals who have undergone specific training and/or accreditation in palliative care and work in the context of an expert interdisciplinary team
- Provide palliative care services to patients and their family/whanau who needs exceed the capability of the primary palliative care providers
- Provides consultation services and support to primary providers 24/7 telephone advice and support
- Specialist service provided by Arohanui Hospice and MidCentral Hospital Palliative Care Team

Quality care at end of life is achieved when both primary and specialist palliative care providers have strong networks and relationships to meet the needs of all people

The Role of the Resource Nurse

- Maintain and update palliative care knowledge using evidence and best practice guidelines
- Role model for colleagues – sharing knowledge
- Patient/Resident advocate
- Appropriate referral to specialist palliative care
- Support audits and quality initiatives

Resource Nurse Meetings

- Supports collaboration between Primary & Specialist Palliative Care Providers
- Education component key part of meeting
- Networking with specialist palliative care
- Empower each other to be reflective practitioners by sharing knowledge, narratives and support
- Debriefing opportunity, able to reflect on practice
**Todays Study Day**

- Includes nurses and caregivers from primary and specialist palliative care providers
- Cutting edge for primary/specialist collaboration
- Evaluations important
- Presentation to PCNNZ conference Nov 2013

**An Update on the Liverpool Care Pathway**

How will you feedback information from this study day to your colleagues?

**UK-Independent National Review of LCP**

Conducted in 2013 following alarming stories in the press and media

- LCP is a way of hastening the death of the terminally ill (Daily Mail)
- Cash incentive for NHS trusts that meet targets on Liverpool Care Pathway
- Reports that patients wrongly being denied nutrition and hydration while on LCP
- Stories of poor standards of care

**Reviews findings**

- Plenty of evidence received by the Review shows that, when the LCP is used properly, patients die a peaceful and dignified death
- BUT the review is also convinced, from what it heard and read, that when the LCP is used it is not infrequently associated with poor care
- LCP to be phased out in UK within next 6-12 months and replaced by end of life care plan for each patient backed up by condition-specific good practice guideline
- 44 recommendations made not all relating to LCP

**Review Findings related to LCP**

- Terminology and definitions problematic
- Examples of falsification and incomplete documentation
- Diagnosis of dying: LCP can engender considerable distress when the patient does not die within days or recovers
- Good and bad stories of the involvement of the patient, relatives and carers in decision making
- LCP deficient in making it distinct and clear where the need for consent and explanations exist
Review Findings related to LCP

- *Involvement in care plan:* Significant number of relatives and carers did not feel they were involved in the discussions about the care plan.

- *Hydration and nutrition:* Refusing food and fluids is a decision for the patient, not clinical staff to make.

- *Sedation and pain management:* Opioids and tranquillisers used inappropriately as soon as LCP started.

- *CPR:* Review heard of good and bad approaches to CPR discussions.

- *Ethical Issues:* Some people believe that starting the LCP is a way of deliberately hastening someone's death.

Key components of good quality end of life care

- Communication (with patient, families, health providers within the MDT)

- Patient/family involvement in decisions and agreements about the plan of care

- Education in end of life care

- Care and compassion

- Access to specialist palliative care for support and advice should be available 24/7

- Involvement of the MDT and patient/family in care

- A care plan for each patient at the end of life

What does this mean for NZ?

- LCP has been implemented differently in NZ.

- MOH supports the LCP as part of an integrated and collaborative approach involving the lead clinician, MDT, patient and family in care planning & decisions around care.

- MOH reiterated the LCP is not intended to replace clinical judgement and practice.

- MOH advised DHB’s to assign appropriate person to reflect on the review.

Opportunity for NZ

- National Issue

- Media articles – Manawatu Standard, Sunday Star Times

- Important to have clear direction

- Learn from UK experience

- Major palliative care groups interested in national coordination

- Watch this space

Quotes: Frank Brennan Standing on the platform. Stories and reflections from palliative care

- Too often, as doctors, we speak practically and are heard emotionally (pg 17)

- That death, that unique loss, will be remembered by that family and the story told over and over. What we do, how we do it and what we say will enter the narrative of that family forever. We now know that families have extraordinary recall of those last days – where they were, what they wore, what the doctor or nurse said when they entered the room. All of it shall be remembered (pg 59)

References


