Scoping Education and Training for End of Life Care in the North West of England

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On behalf of the team......

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Why do we need such a study?

• End of life care has attracted attention from both policy and practice

• Increasing prominence of end of life care through Department of Health End of Life Care Strategy (2008) and in Lord Darzi’s review of the National Health Service (2008) and in the strategic health authority (SHA) plans
Contextual factors

• A marked reluctance in our society to talk about death and dying
• The End of Life Care Strategy (UK) is being implemented just as the number of deaths is predicted to rise, putting additional pressure on those who deliver services
• By 2030 fewer than 1 in 10 people will die at home
• Health spending is likely to be tight over the next few years while at the same time the demands of the population for care at the end of life are likely to change
Education is crucial

• To accommodate a large increase in demand for end-of-life care in the next 10-20 years – for generalist and specialist staff across the professions

• To manage the expected increase in either hospital or community services without considerable additional investment
Workforce development

• EoLC strategy recommends that significant workforce developments will be required to enable and support professionals in delivering improvements particularly in identifying and discussing with patients their needs and preferences in relation to end-of-life care
Changing hearts and minds

- Need for education, training and CPD related to
  - Communications skills (e.g. starting the conversation)
  - Assessment and care planning
  - Symptom control
  - Provision of psychological, social and spiritual care
  - Care in the last days of life
- Perception that change isn’t happening fast enough....how do we educate the workforce and facilitate real change in our staff?
Department of Health
End of Life Care Strategy (2008)

• Aims to bring about a step change in access to high-quality care for everyone approaching the end of life, wherever they are being cared for.
• It seeks to ensure that patients can exercise meaningful choice about where they are cared for and where they die.
• Describes an end-of-life care pathway, including services and mechanisms that are required to be in place to support people at each stage of the pathway.
The End of Life Care Pathway

**Step 1**
Discussions as end of life approaches
- Open, honest communication
- Identifying triggers for discussion

**Step 2**
Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

**Step 3**
Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

**Step 4**
Delivery of high quality services
- High quality care provision in all settings
- Hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

**Step 5**
Care in the last days of life
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

**Step 6**
Care after death

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**Support for carers and families**
- Information for patients and carers
- Spiritual care services
Tools within EoLC Strategy

Gold Standards Framework (GSF)
• Standards to ensure care needs assessed and a plan of care put into place

Preferred Priorities of Care
• an advance care planning, patient-held document used to facilitate patient choice in relation to end of life issues

The Liverpool Care Pathway
• an evidence-based framework related to care of the dying patient and their relatives in the last days and hours of life, in a variety of settings
Regional focus

- 1 year study commissioned by NHS Wirral, Merseyside and Cheshire Cancer Network and supported by NHS North West (April 2010-2011)
- NHS North West EOLC Model in place since 2007 with links to Liverpool Care Pathway
- NHS North West Education Governance Framework
Project aim

• to understand to what extent education and training in the field of end of life care, contributes to the well being of people approaching the end of life
Project methodology

1. Education and training surveys to establish North West profile
   - Surveys x 4 Web based - HEIs pre and post registration programmes / Organisations training and education departments / Staff
   - Preliminary and follow-up telephone contact with HEI and training/education leads in organisations
   - Documentary analysis (curriculum, literature)
   - Establishing a template for data collection and organisation
Methodology: **Gap analysis**

2. **Mapping and staff focus groups**
   • Gap analysis determines the steps to be taken in moving from current education and training provision to a desired future state
   • mapping of met and unmet needs
   • focus groups to ascertain the views of staff who have received training
   +
   • telephone Delphi Survey with strategic and educational leads in end of life care
Methodology: patient and carer views

3. accessing patients views on education and training of staff through exploring their experiences of care

- exploration of the narratives of patients and carers: Conversations for Life + literature

- Optional access:
  - Focus groups
  - Telephone survey
  - Web survey
Scoping and dissemination workshop

• the impact of education /training programmes on practice across the workforce and the quality of end of life care provision

• to consider approaches to curriculum and programme design

• to reflect on the demands of education governance in developing the workforce to provide quality end of life care

• live feedback, brainstorming and table syndicate working sessions using text tablet laptop
Current challenges

• Death and dying remain taboo subjects in society

• Designing information fliers and participation leaflets – language use

• Increased range of participants to include health and social care teams, nursing home staff and further education colleges – leading to redesign of initial surveys

• Managing sample size

• Managing data as it comes in - template design

• Applying for a research passport and access to individual organisations
Project overview

• Challenging and demanding
• Working with stakeholders and ensuring inclusivity
• Evolving design
• Managing risk: achieving outcomes
• Research governance and ethical issues
• Managing the dissemination strategy (awareness, understanding and involvement)
A Working Definition of End of Life Care

End of life care is care that:
Helps all those with advanced, progressive incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

National Council for Palliative Care 2006