

**THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**

Development of the End of Life Care Strategy

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The End of Life Care Strategy: Background

- ❖ Around 500,000 people die in England each year
 - **DH has never had a comprehensive strategy on end of life care**
- ❖ Some patients receive excellent care, others do not
 - **54% of complaints in acute hospitals relate to care of the dying/bereavement care (Healthcare Commission 2007)**
- ❖ Hospices have set a gold standard for care, but only deal with a minority of all patients

The End of Life Care Strategy: Background

- ❖ There is a major mismatch between people's preferences for where they should die and their actual place of death
 - Most would probably like to die at home
 - Only around 18% do so with a further 16% in care homes
 - Acute hospitals accounting for >58% of all deaths
 - Around 5% in hospices
- ❖ Only around one third of general public have discussed death and dying with anyone

End of Life Care Strategy: Development

- Election manifesto commitment: May 2005
- Our Health, Our Care, Our Say: January 2006
- Ministerial announcement of strategy: June 2006
- Broad consultation with stakeholders
- Advisory Board + 6 Working Groups (Care Pathway; Commissioning; Measurement; Workforce; Care Homes; Analysis/Funding)
- Original intention had been to publish by December 2007
- Linkage to Next Stage (Darzi) Review and SHA Groups

The End of Life Care Strategy: Context

- ❖ Covers all conditions and settings
- ❖ Builds on the experience of hospices and specialist palliative care services
- ❖ Builds on the existing End of Life Care Programme (e.g. GSF, LCP and advance care planning)
- ❖ Builds on recent experience from the Marie Curie Delivering Choice Programme and other innovative service models

End of Life Care: Working Groups

1. Care Pathways/Service Models
2. Workforce Development
3. Care Homes
4. Analysis/Funding
5. Commissioning and levers for Change
6. Measurement of Quality and Outcomes

End of Life Care: Approach

- What is a good death?
- What are the current problems / concerns?
- Emerging themes
- Care pathway

What is a good death?

Each individual will have a different idea, but for many this will involve

- Being treated as an individual with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

End of Life Care: Problems and Concerns (1)

- Lack of familiarity with death and lack of public discussion
- Low priority given to EOLC by the NHS and social care
- Clinicians' difficulty in identifying people who are approaching the end of life
- Clinicians difficulty in initiating discussions
- Inadequate assessment and care planning
- Poor coordination of care
- Suboptimal services in hospitals, care homes and the community

End of Life Care: Problems and Concerns (2)

- Poor care in the last days of life
- Problems after death (e.g. verification and certification of death; viewing facilities etc.)
- Inadequate involvement and support of carers
- Inadequate training and education
- Lack of robust measures of quality and effectiveness of care
- Inequalities in care
- Lack of dignity and respect provided to some people

End of Life Care: Emerging themes

1. Raising the public profile of end of life care
2. Strategic commissioning (PCTs and LAs) to give a whole systems approach
3. An end of life care pathway
4. Workforce development
5. Measurement
6. Funding

The End of Life Care Pathway

1. Identifying people approaching the end of life and initiating discussions
2. Assessment and care planning
3. Coordination (and register)
4. Integrated service delivery
5. Review of people's needs and preferences
6. Care in the last days of life
7. Care after death
8. Support for carers (throughout illness and into bereavement)

Workforce development

- Needed across staff groups and at all levels
- Communication skills and end of life care
- Competencies need to be defined
- Targeting different groups:
 - A: Those working specifically in EOLC
 - B: Those for whom EOLC is a major part of their work
 - C: Those for whom EOLC is rarely part of their work
- Action will be needed from regulators, professional organisations, higher education institutions, employers etc. etc.

End of Life Care Measurement (1)

- How will we know if quality of end of life care has improved in 5 years' time?
- How can we identify localities / institutions which are doing relatively better or worse?
- Ideally we would be able to measure choice, quality , equity and value for money

End of Life Care Measurement (2)

What can be done relatively quickly?

- Make better use of existing data (HES, ONS, hospices, HCC, CSCI etc.)
- Monitor end of life care planning
- Extend the National Care of the Dying Audit
- Surveys of bereaved relatives

End of Life Care Funding

1. Work is in progress to estimate expenditure in
 - Hospitals
 - Hospices and specialist palliative care services
 - Community nursing
 - Care home sector
2. General acceptance that current resources are not being best used
3. Comprehensive Spending Review awaited

End of Life Care Framework

- Public Profile
- Strategic Commissioning (PCTs and LAs)
- End of Life Care Pathway
 - Starting the conversation
 - Assessment and care planning
 - Coordination and register
 - Integrated service delivery
 - Review
 - Last days of life
 - Care after death
 - Support for carers
- Workforce development
- Measurement
- Funding

Summary

- ❖ This will be a first ever end of life care strategy
- ❖ It will:
 - ❖ Cover all conditions and all locations
 - ❖ Use the new levers available in the NHS and LAs
 - ❖ Take a care pathway approach
 - ❖ Phased implementation
- ❖ DH aims to publish in summer 2008 and it will be linked to Darzi Report
- ❖ Note the EoLC baseline review required by all PCTs and LAs by March 2008 is key – NCPC's guidance in key areas will help with delivery of this