

The End of Life Care Strategy in England Opportunities and Challenges

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What is NCPC?

- **The umbrella body for palliative care**
- **Influences government policy**
- **Supports all sectors involved in providing, commissioning and using hospice and palliative care services**
- **Promotes palliative care for all**
- **Provides guidance on best practice**

Context and Key Themes

- **The End of Life Care Strategy**
- **Darzi Review and SHA Strategies**
- **Challenges to Address:**
 - Terminology
 - Linkages with other National Strategies-
Cancer Reform, Dementia, Long Term
Conditions etc.
 - Public Awareness
 - Workforce
 - Measurement and Funding
 - Commissioning

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- more likely to be implemented?**

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, PPC and now includes 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 are the current problems / concerns?**
- **Emerging themes**
- **Care Pathway approach**
- **For real change to be delivered requires leadership and a cultural shift**

End of Life Care: Problems and Concerns (1)

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

End of Life Care: Problems and Concerns (2)

- 1. Poor care in the last days of life**
- 2. Problems after death (e.g. verification and certification of death; viewing facilities etc.)**
- 3. Inadequate involvement and support of carers**
- 4. Inadequate training and education**
- 5. Lack of robust measures of quality and effectiveness of care**
- 6. Inequalities in care**
- 7. Lack of dignity and respect – often for older people**

End of Life Care Framework: 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 setting up a 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)**

End of Life Pathway

- **How will it address the needs of people with multiple conditions- the norm for many older frail people?**
- **Will it support people with dementia who may be in the last phase of life for many years?**
- **How will it link with all the other emerging pathways?**

Workforce Development

- Needed across all staff groups and at all levels
- Communication skills and end of life care
- Competencies need to be defined
- Targeting different groups across sectors:
 - A: Those working specifically in EOLC*
 - B: Those for whom EOLC is a major part of their work - eg in primary care, some specialists, some care home staff*
 - C: Those for whom EOLC is rarely part of their work- but this will change if more people want to die at home*
- Action will be needed from regulators, commissioners, professional organisations, higher education institutions, employers etc

End of Life Care Measurement

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

What should we try to Measure?

Effectiveness

The measurement of the degree to which the aims of care are achieved (quality)

At three levels:

- At an individual patient or carer level
- In aggregate for a group of patients or carers served by a team, unit or organisation
- At a population level

Essential to achieve this for success

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. Much still difficult to measure but acceptance that current resources are not being best used**
- 3. What will the Government Commitment to double the investment mean? - in Comprehensive Spending Review**

Outstanding Questions on Funding

- **Service specifications, costing and pricing all essential**
- **Will PbR be introduced for palliative care?- If so, when?- Darzi also recommends quality tariffs**
- **What has happened to the 2004 commitment on full cost recovery?- £200m for hospices**
- **Will the EOL strategy resolve these issues and new ones of personal budgets?**

Likely Options

5. Develop service specifications for each core service element

6. Cost the specifications (reference or normative)

7. Identify units of cost measurement (the currencies)

8. Negotiate associated tariffs

Much to do and requires commissioners who understand the services and the issues across sectors

Summary

This will be a first end of life care strategy for England

- It covers all conditions and all locations and sectors
- Takes a care pathway approach
- DH to publish in July 2008 and it will be linked to Darzi Report out end of June

NCPC intends to ensure its implementation, monitor success, progress and challenges in all key areas

- Will it help people with multiple conditions?
- Will workforce, measurement of quality and outcomes and funding be addressed ?
- **Will government and commissioners make it a priority?**