

# The National Policy Agenda and the Opportunities and Challenges

**Eve Richardson**  
**Chief Executive, NCPC**  
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## What is NCPC?

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- **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

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- **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

# Development of the End of Life Care Strategy

# The End of Life Care Strategy: Background

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**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

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- 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

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- **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

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- 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

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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

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- **What are the current problems / concerns?**
- **Emerging themes**
- **Care Pathway approach**
- **Will real change be delivered and a cultural shift achieved?**

# End of Life Care: Problems and Concerns (1)

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- 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)

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- 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

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- 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

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- 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

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- **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?**

## Chronic Respiratory Disease

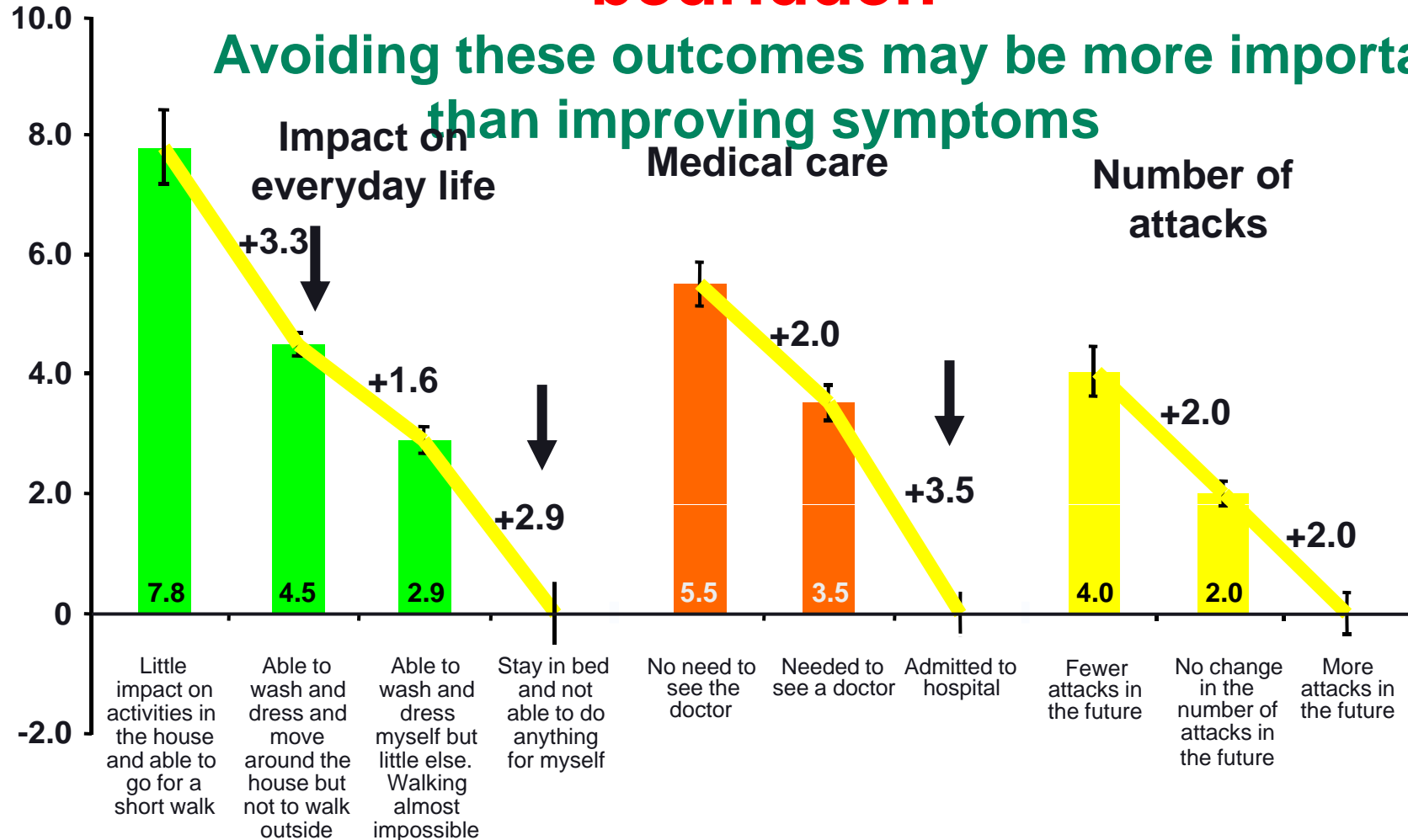
- Influencing the EoLCS/Darzi review and NSF
- Determining current level of service
- Ascertaining user and carer views
- Identifying palliative and end of life care needs
- Triggers for initiating discussions
- Developing good practice in partnership
- NCPC to publish Surveys and Guidance Spring 2008

COPD patients are re most concerned about

being **hospitalised – housebound – bedridden**

Avoiding these outcomes may be more important than improving symptoms

Utility values



## End of Life Discussions

- Most wanted discussion when appear to be deteriorating, rather than at diagnosis or at the point of a “flare up”
- The majority of people wanted to co-ordinate their own services and all wanted a single point of contact
- Most wanted to be at home, majority supported Advance Care Planning
- Need for befriending

# Workforce Development

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- 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 (1)

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- 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

# End of Life Care Measurement (2)

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## What can be done now?

- **Make better use of existing data (MDS,HES,ONS, HCC, CSCI etc.)**
- **Use NCPC's population based needs indices for different conditions**
- **Monitor end of life care planning- all Boards**
- **Extend the National Care of the Dying Audit**
- **Surveys of bereaved relatives**

***Need to do more to measure outcomes and effectiveness***

# What should we try to Measure?

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## *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***

## Commissioning for Outcomes

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- Guidance on outcome measurement has not yet emerged in the course of EOL strategy development
- DH EOL research workshop in April but this is about identifying gaps in the evidence base for EOL care and steps to remedy that
- Probability of a continuing lack of guidance on outcome measurement

# Strengthening Commissioning is key

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- **End of Life Care – A commissioning Perspective: NCPC January 2007**
- **Commissioning Framework for Health & Well-being: DH March 2007**
- **NCPC Response to DH consultation**
- **World Class Commissioning: DH December 2007**
- **Commissioning Framework for Health & Well-being – Making it Happen: DH January 2008**

## Key Messages from 'Making it Happen'

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- **DH Vision as set out in March 2007 paper**
- **Emphasis on partnership**
- **New duty of Joint Strategic Needs Assessment**
- **Commissioning for outcomes**
- **Delivery of services personal and sensitive to need; focus on maintaining independence**
- **Empowering people to take control of decisions about their health & well-being**
- **Promoting health, preventing ill-health**

# Implications for Commissioning Palliative & EOL Care

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**The guidance set out in NCPC's  
publication in January 2007 on  
*End of Life Care: a commissioning  
perspective*  
is largely in line with the new DH policy  
on commissioning**

# End of Life Care Funding

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- 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? - Comprehensive Spending Review awaited**

## Outstanding Questions on Funding

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- **Service specifications, costing and pricing all essential**
- **Will PbR be introduced for palliative care?- If so, when?**
- **What has happened to the 2004 commitment on full cost recovery?**
- **Will the EOL strategy resolve these outstanding issues?**

## Current Situation

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- **Scope of PbR is limited to acute services provided by or for the NHS**
- **Scope excludes NHS community services and independent/voluntary services**
- **DH response to the consultation on ‘The Future of PbR’ recently published**
- **Extension of PbR to community and/or non NHS sectors unlikely before 2010/11**

## Current Situation

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- **Existing HRGs for specialist palliative care services could be introduced in 2009/10 but only for NHS acute sector**
- **Policy on Full Cost Recovery for services dependent on introduction of PbR**
- **Cost for PCTs of over £200 million extra for voluntary hospices -probably unrealistic but what is fair?**
- **EOL strategy unlikely to resolve most issues since dependent on general policy considerations**

## ***DH paper on Future of PbR proposed 3 generic models:***

- **National currencies (HRGs) & associated national tariffs**
- **National currencies (HRGs) & associated local tariffs**
- **Local currencies & associated local tariffs**

# Likely Options

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- 1. Adopt the generic models**
- 2. Define 'local' – probably SHA wide rather than Cancer Network wide or single PCTs**
- 3. Develop local tariffs for the approved HRGs**
- 4. Develop local currencies and tariffs for services not covered by HRGs**

## Likely Options

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**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

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## **This will be a first ever end of life care strategy**

- It covers all conditions and all locations and sectors
- Takes a care pathway approach
- DH aims to publish in summer 2008 and it will be linked to Darzi Report - a new 10 year plan?
- With phased implementation

## **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?