

What's happening next?
**The End of Life Care Strategy -
Anticipating Ways in which this will
Improve Care**

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What is NCPC?

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

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, Mental Capacity Act
 - Public Awareness
 - Workforce
 - Outcomes, Commissioning, Funding

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 are the current problems / concerns?**
- **Will a care pathway approach help?**
- **What cultural change is needed?**
- **Who so we increase public awareness?**

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?**

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

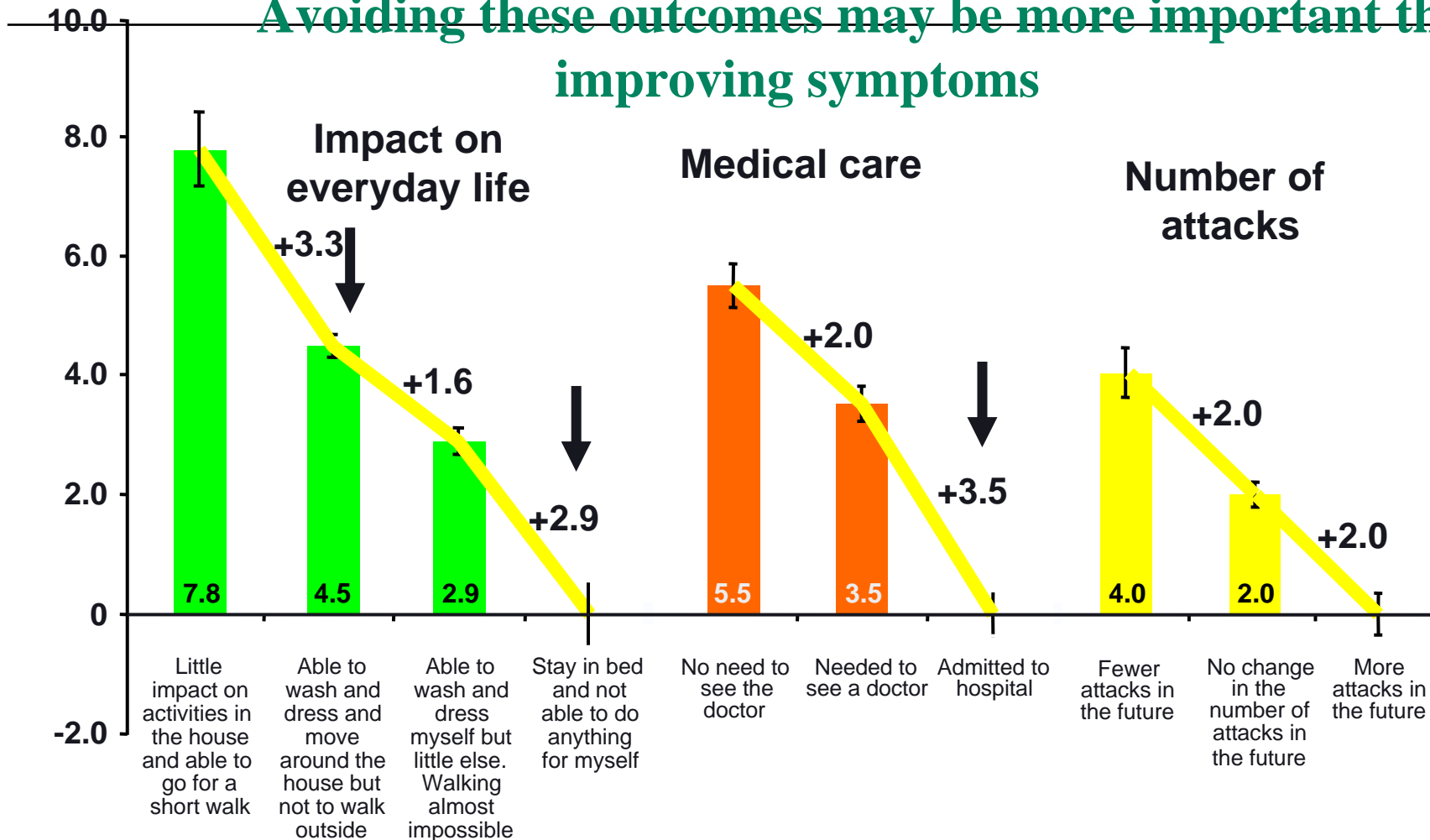
Discrete choice modelling: Utility shifts

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

- 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*
 - C: Those for whom EOLC is rarely a part of their work*
- Action will be needed from regulators, professional organisations, higher education institutions, employers etc. 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

Summary

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?

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

- Will it help people with dementia/complex conditions?
- Will workforce and training, measurement of quality and outcomes and future funding be addressed ?
- Will government and commissioners make it a priority?