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CARE**

# **Influencing the End of Life Care Strategy**

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# The End of Life Care Strategy

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## 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 20% do so with a further 20% in care homes
  - Acute hospitals accounting for >50% of all deaths
  - Around 4% in hospices
- ❖ Only around one third of general public have discussed death and dying with anyone

## The End of Life Care Strategy: Context (1)

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- ❖ 2005 election manifesto – ‘in order to increase choice for patients with cancer we will double the investment going into palliative care services, giving more people the choice to be treated at home’
- ❖ Our health, our Care, Our Say (Jan 2006)
  - Strategic planning for EOLC (networks)
  - Rapid response services
  - Skilling up generalist workforce
  - Health Reform Agenda
  - Stronger commissioning, choice, plurality, tariffs, regulation
- ❖ Ministerial announcement of strategy (June 2006)

## The End of Life Care Strategy: Context (2)

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

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- ❖ Advisory Board (charities, NHS, Health and social care professionals, regulators, DH)
- ❖ 6 working groups
- ❖ Engagement with as many stakeholders as possible:
  - Patients/carers, charities, hospices, clinicians, NHS, social care, faith groups, care home providers, ambulance services, funeral directors
- ❖ Equality Impact Assessment
- ❖ Engaging with carers and users
- ❖ Spiritual issues

# 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

## Care Pathways/Service Models

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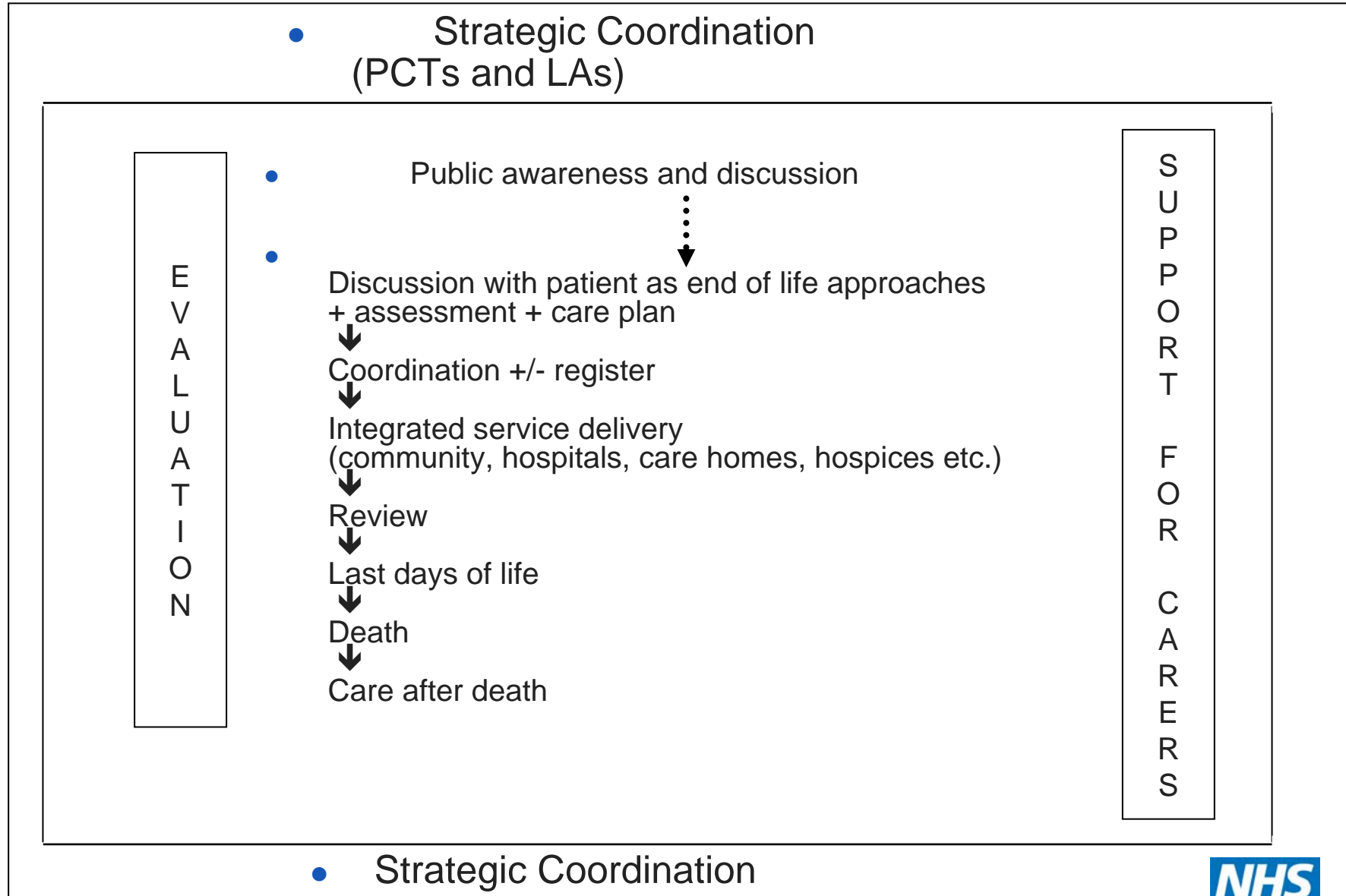
- ❖ Social perspective e.g Home → sheltered accommodation → care home → hospital → death
- ❖ Medical perspective e.g. Health → diagnosis of chronic illness → reasonable health/active life → deterioration (+/- exacerbations/improvements) → death
- ❖ Key question: when does the end of life care pathway commence?

## **Care Pathways/Service Models: Issues**

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- ❖ **Initiating discussions about preferences for EOLC**
  - ❖ **Patient and carer assessment of needs and preferences**
  - ❖ **Planning care (and reviewing at intervals)**
  - ❖ **Communication and co-ordination**
  - ❖ **Service provision in different locations**
  - ❖ **Physical environments**
  - ❖ **Care in the dying phase of illness**
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- ❖ **Support for carers and families and bereavement**

# End of Life Care Pathway: Key steps



# Workforce Development

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- Three categories
- 1 Staff devoting all of their time working time to end of life care (eg. Palliative care physicians/nurse specialists and hospice staff)
- 2 Staff for whom end of life care is a major part of their role (eg. oncologists, cardiologists, care of the elderly, acute medicine, GPs, DNs, Community Matrons, some care homes staff)
- 3 Staff for whom end of life care is a small part of their role (eg. pathologists, radiologists, some care homes staff, domiciliary care, ambulance services)

# Core Minimum Requirements

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- Define in terms levels of competence required to demonstrate levels of competence and ‘fit for practice’ for the 3 groups of staff
- Recognition of diversity of the workforce.
- Required to support the care pathway and service models emerging.
  - initiating discussion, care planning and care delivery
  - competencies include assessment, communication skills, advanced care planning
- Leadership and performance management for cultural change
- Levers for change- professional and regulatory bodies, commissioners of services

## Care Homes

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- ❖ Around 19,000 care homes in England and just under 20% of all deaths occur in care homes
- ❖ There are some concerns about the quality of EoL care
- ❖ Two key tasks for this Working Group:
  1. To continue overseeing the care homes element of the current (2004-2007) End of Life Care Programme and expand to include extra care housing and home care
  2. To make recommendations on future improvements in end of life care in care homes in relation to person centred care, commissioning and regulation and provider development

## Analysis and Funding

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- ❖ What is currently being spent on end of life care (NHS, social care, voluntary sector)?
- ❖ What is currently being spend on continuing care?
- ❖ What is expenditure at different points of the pathway?
- ❖ What are the costs and benefits of alternative models of life care?

## Commissioning and Levers for Change

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- ❖ How can we use the new levers for change to promote, quality, equity and value for money?
- ❖ Potential levers:
  - Stronger commissioning
  - New providers (e.g. independent/third sector)
  - Payment by Results
  - Regulation (HCC and CSCI)
- ❖ What would 'good commissioning' look like?

# Measurement of Quality and Outcomes

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- ❖ How will we know if quality of end of life care has improved in 5 years' time?
- ❖ How can we measure choice, quality and equity?
  - What information is currently available? (structure, process and outcomes)
  - What measures should we develop/implement for future use?
- ❖ Measurement framework
  - structure, process and outcome measures at each step in the care pathway

# Summary

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- ❖ 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
  - ❖ Take a care pathway approach
  - ❖ Phased implementation
- ❖ DH aims to publish later in 2007
- ❖ Note the EoLC baseline review required by all PCTs and LAs this year- NCPC guidance key to delivery

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**NCPC'S further influencing  
of  
End of Life Care Strategy**

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# **Chronic Respiratory Disease Policy Group**

- **First meeting new group June 2007**
- **Survey to palliative care and respiratory teams June 2007**
- **Influencing and Informing the NSF and EoLCS**

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# Understanding Co-morbidity

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“Decline remains our fate; death will come. But, until that last backup system inside each of us fails, decline can occur in two ways. One is early and precipitately, with an old age of enfeeblement and dependence, sustained primarily by nursing homes and hospitals. The other way is more gradual, preserving, for as long as possible, your ability to control your own life.

Good medical care can influence which direction a person’s old age will take. Most of us in medicine, however, don’t know how to think about decline. We’re good at addressing specific, individual problems: colon cancer, high blood pressure, arthritic knees. Give us a disease, and we can do something about it. But give us an elderly woman with colon cancer, high blood pressure, arthritic knees, and various other ailments besides—an elderly woman at risk of losing the life she enjoys—and we are not sure what to do”

(Gawande, 2007).

- **In one study in primary care older people were found to have on average 2.4 chronic conditions and be on an average of 5.1 medications. For example approximately 29% of people aged 85 and over with cancer, circulatory or respiratory disease will also have dementia. stay twice as long in hospital.**
- **NEXT STEPS**
  - Paper to influence EoLCS
  - Practical Guidance later in year

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# **Supporting People with Dementia**

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# Key issues

- **Difficult disease trajectory**
- **Comorbidities**
- **Symptom control can be challenging**
- **How it fits with the proposed end of life care pathway**
- **NCPC project group developing guidance**

## **Cancer Reform Strategy**

- **NCPC's cancer policy group working to influence this parallel strategy**
- **Ensure palliative and Eolc does not fall between the gaps**
- **Key to influence both strategies**

# **Strategy Implementation**

- **Ensure Palliative and Eolc is in Health and Social Care Accountability Framework to give teeth nationally and locally**
- **Ensure there are some ‘must dos’ around minimum core training requirements**
  - **Ensure on all Board agendas**
  - **Produce influence guidance on Commissioning, Workforce, MCA**
    - **etc- as levers for change**