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# Progress on Implementing the End of Life Strategy

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## Progress: Overview

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- A brief update on the End of Life Care Strategy
- Coalition government and end of life care
- A forward look

## Brief update on the End of Life Care Strategy

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- Strategy published July 2008
- Second annual report published August 2010:
  - “Much good work across England” (T. H-H)
  - “Challenge of finding ways to do more for less” (T. H-H)
  - “Some areas of the NHS are investing and some aren’t.” (T. H-H)
  - “Real sense that momentum is building” (MR)

## End of Life Care Strategy: Aims

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1. Quality: To bring about a step change in the quality of care for people approaching the end of life
2. To enhance choice at the end of life
3. To reduce inequalities (e.g. Geographical and cancer vs. Non-cancer)
4. To prepare for the demographic challenge: increasing numbers of deaths, particularly amongst people over 85 years
5. To raise the profile of end of life care
6. [To deliver the previous government's manifesto commitment to double investment in palliative care: £286m over 2 years]

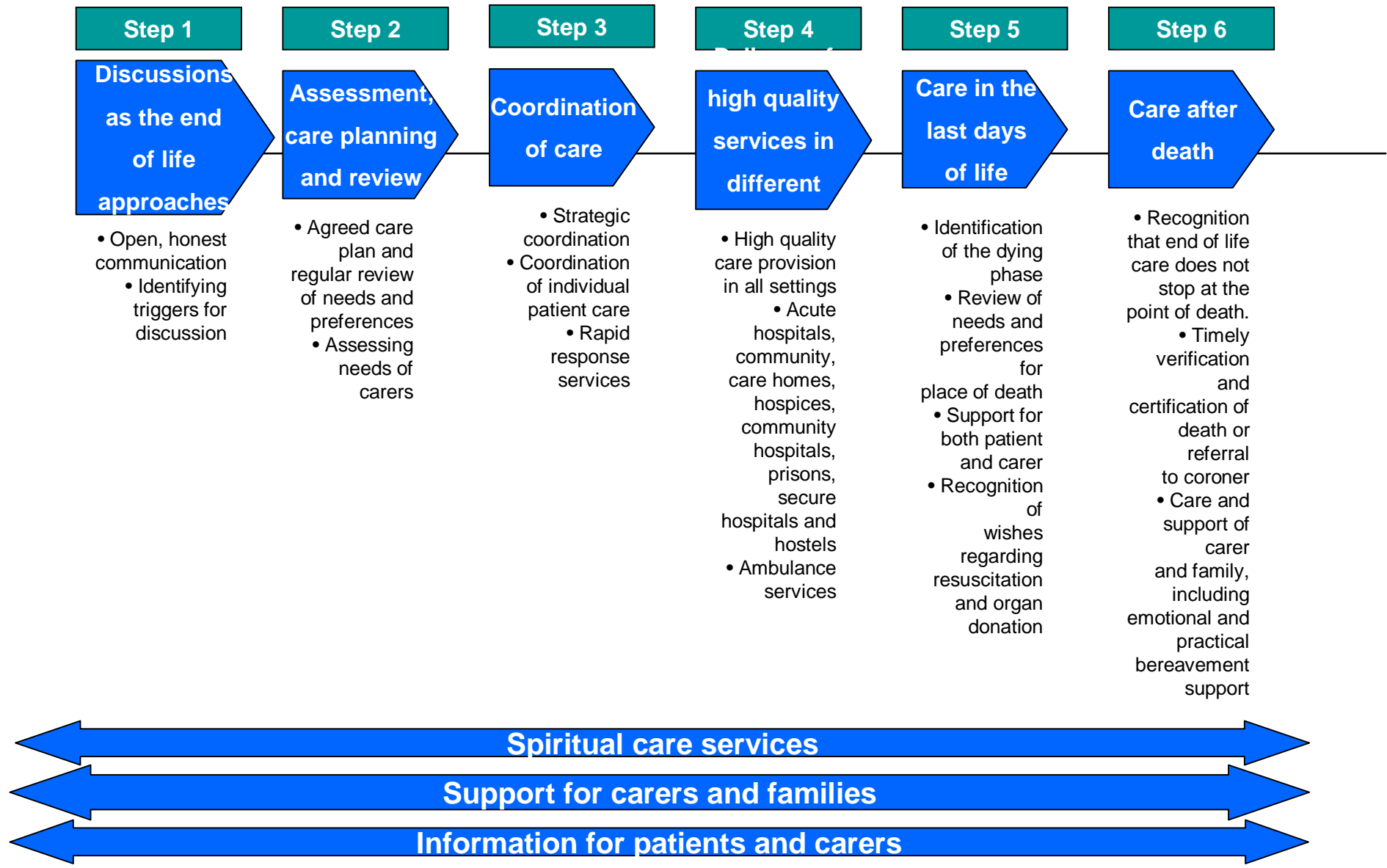
# End of Life Care Strategy

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Key elements:

- Societal level: Actions to raise awareness of death and dying and to change attitudes
- Individual level: Integrated service delivery based around a care pathway
- Infrastructure: Workforce development, measurement, research, funding, national support etc.

# The End of Life Care Pathway



# Progress on Implementation (1)

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- National
  - DH Policy Team and National End of Life Care Programme
  - Dying Matters Coalition (led by NCPC)
  - Pilots of Locality registers (coordination of care)
  - Quality Markers published – and being used
  - E-Learning programme launched
  - National End of Life Care Intelligence Network established
  - Measuring quality: VOICES survey of bereaved relatives in development
  - Routes to success guides
  - Tracking investment exercise

## Progress on implementation (2)

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- SHA level

- Good clinical and managerial engagement, building on the Darzi end of life care workstreams
- Differing priorities, but with potential for cross-fertilisation (e.g. On social marketing; DNAR policies; EOLC registers; Quality Marker implementation by commissioners and providers)

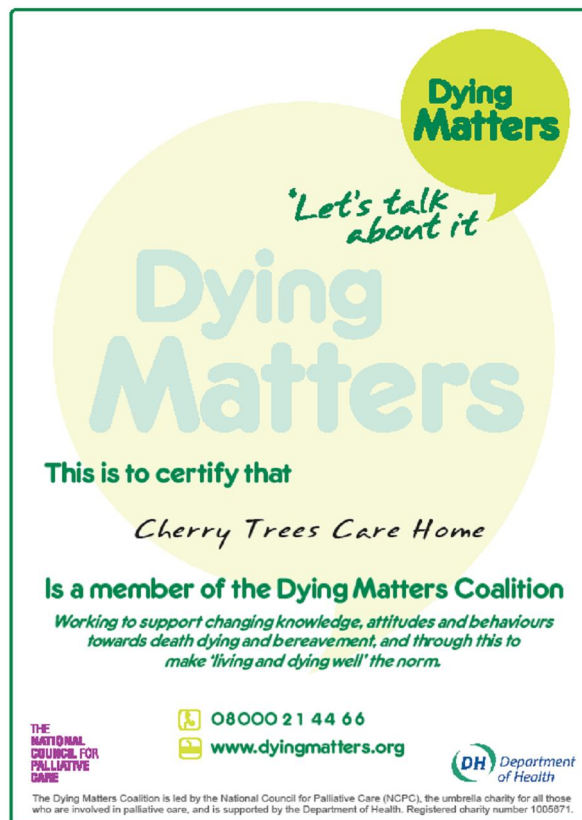
- PCT level

- Around half of PCTs have identified place of death as one of their 8 key indicators (out of a possible 50)



# Death, dying and society

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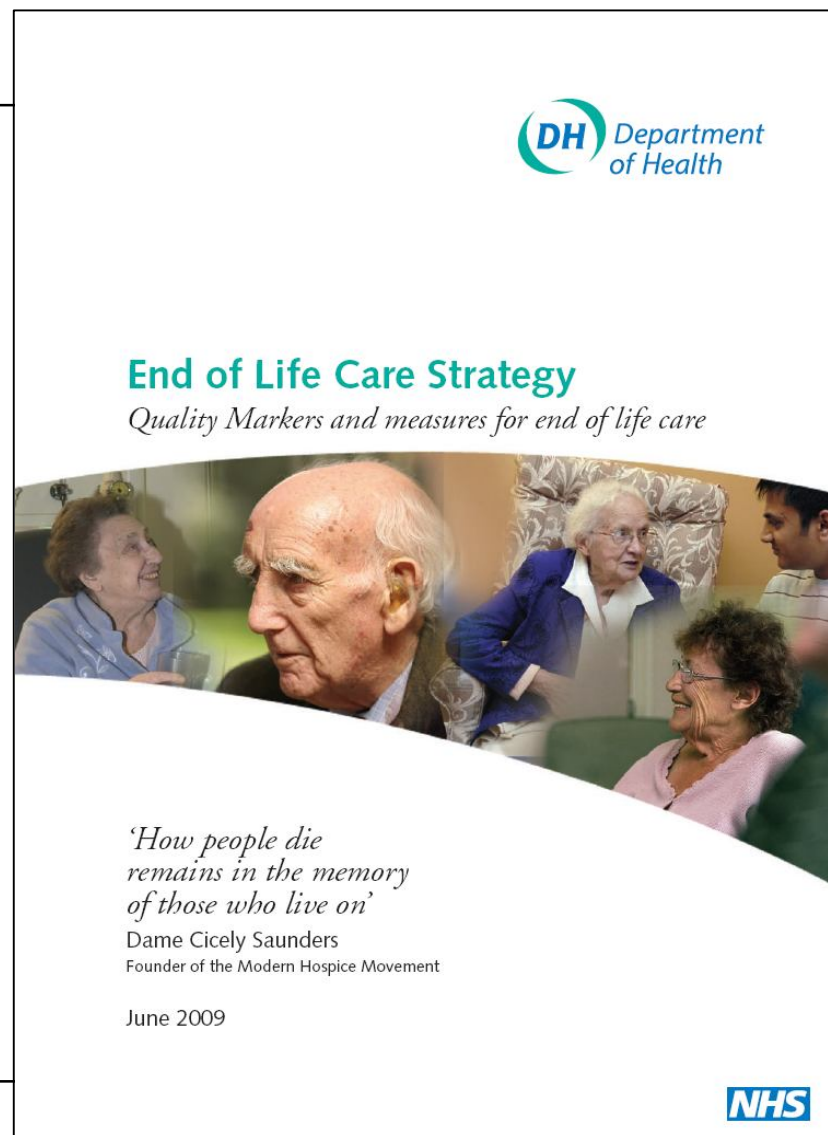
- National Council for Palliative Care is running the national coalition ***Dying Matters***
- Around 7000 members – hospices, schools, solicitors, the GMC
- NatCen Survey, has set a baseline for current awareness and attitudes
- Literature review (Professor Jane Seymour)
- Awareness week: March 2010

## **Step 1: Identifying people who are approaching the end of life and initiating discussions**

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- Arguably the most difficult step
- Clinical culture focused on cure: death can be seen as a failure
- Prognostication is very inexact
- Using the ‘surprise question’ – or variants
- Clinical triggers or indicators relevant to individual conditions
- Routes to success

## Step 4: Delivering high quality services



# Progress on Measurement of End of Life Care

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- Aim: from 'data poor' to 'data rich' to drive improvements in quality and productivity
- Two key components
  1. Surveys of bereaved relatives (VOICES)
  2. National End of Life Care Intelligence Network
- These align close with the Coalition Government's emphasis on information, choice and outcome measures

# National End of Life Care Intelligence Network

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- Brings together people/organisations
- Brings together datasets (e.g. ONS, HES, social care, primary care, specialist palliative care)
- Established 2010, but is already producing important new reports e.g.
  - Place of death
  - Neurodegenerative diseases
  - Renal diseases
  - Deaths in older adults
  - Analyses of transfers from care homes to hospitals in the last week of life (ongoing)
  - Analyses of health and social care activity and expenditure at the end of life (ongoing)

## The Coalition Government

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- Strong commitment to improving end of life care, building on the End of Life Care Strategy
- Integration between health and social care is a high priority
- Ongoing commitment to Quality, Innovation, Productivity and Prevention (QIPP)
- ‘Equity and Excellence: Liberating the NHS’ – sets the direction
- Specific consultations on (for example): outcomes, information and choice
- Dedicated palliative care funding review

## QIPP and End of Life Care

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- End of Life Care is a recognised work stream within QIPP
- This is being led by Sophia Christie, Chief Executive of Birmingham East and North PCT
- Particular emphasis is being given to implementing Steps 1 and 2 of the End of Life Care Strategy
  - Identifying people approaching the end of life and initiating discussions
  - Assessment and Care Planning

## Per Patient-Funding Review

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- Coalition Commitment (May 2010)
- “We will provide £10m a year beyond 2011 from within the budget of the Department of Health to support children’s hospices in their vital work. And so that proper support for the most sick children and adults can continue in the setting of their choice we will introduce a new per-patient funding system for all hospices and providers of palliative care.”
- Review is being led by Thomas Hughes-Hallet and Professor Sir Alan Craft



# Alignment with the White Paper

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- Information Revolution and choice
  - No decision about me without me
  - NEOLCIN is well placed to make information on end of life care services available
- Outcome measures not process targets
  - The VOICES surveys will produce new evidence on patients' experience of care at the end of life (mapping to Domain 4 of the Outcomes Framework)

## Summary

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- Early progress on implementation of the End of Life Care Strategy is promising – but there is still a huge amount to do
- Early signs from the new government are very encouraging in terms of commitment to end of life care
- With better metrics we should be able to set ourselves milestones against which further progress can be monitored.