THE NATIONAL COUNCIL FOR PALLIATIVE CARE

Dying Matters 'Let's talk about it'

INFLUENCING PUBLIC POLICY TO DRIVE CHANGE IN END OF LIFE CARE

Societal Impact of Pain

May 2012

SIMON CHAPMAN

DIRECTOR OF POLICY

& PARLIAMENTARY AFFAIRS

NCPC & The Dying Matters Coalition

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Dying Matters 'Let's talk about it'

DM set up by the National Council for Palliative Care, the umbrella charity for all those involved in palliative care, to support the 2008 End of Life Care Strategy

We are a broad based, inclusive national Coalition, working in partnership, with over **16,000** members from across the NHS and voluntary and independent health and care sectors, social care and housing, faith, community and retirement organisations, schools, legal, insurance & funeral sectors, & wider corporate partners.

Our Mission:

- *"Support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make 'living and dying well' the norm*."

Overview

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- Pain relief as a human right
- It's not all about pain: setting pain in the overall context of end of life care policy
- England's End of Life Care Strategy (2008)
- Role of NICE (The National Institute for Health & Clinical Excellence)

Human Rights & pain relief

- 2003, Council of Europe recommended legislation should make opioids available
- 2005, World Health Assembly :
  - Palliative care an urgent humanitarian responsibility
  - Stressed need to improve opioid availability
- 2008, UN Special Rapporteur:
  - “Many other human rights issues need urgent attention such as palliative care”

Kathleen M. Foley, Cicely Saunders Lecture, 2012

Our Greatest Fear

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How scared are you of the following happening to you?

- **Dying in pain 83%**
- Dying alone 67%
- Being told you are dying 62%
- Dying in hospital 59%

Compare with:

- Going bankrupt 41%
- Divorce/end of a long-term relationship 39%
- Losing your job 38%

ComRes 2011

Taboos have consequences

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Deciding not to talk is just that – a decision....

- Our families & carers may not know what we want
- If we don't discuss, anticipate and plan, it makes unplanned "crisis care" and hospital admission more likely
- Bad care impacts bereavement
- Harder to challenge bad care – tough to change something we won't talk about
- No Dress Rehearsals – we only get one chance to get it right
- If we expect it to be bad, we're not surprised when it is

End of life care policy in England

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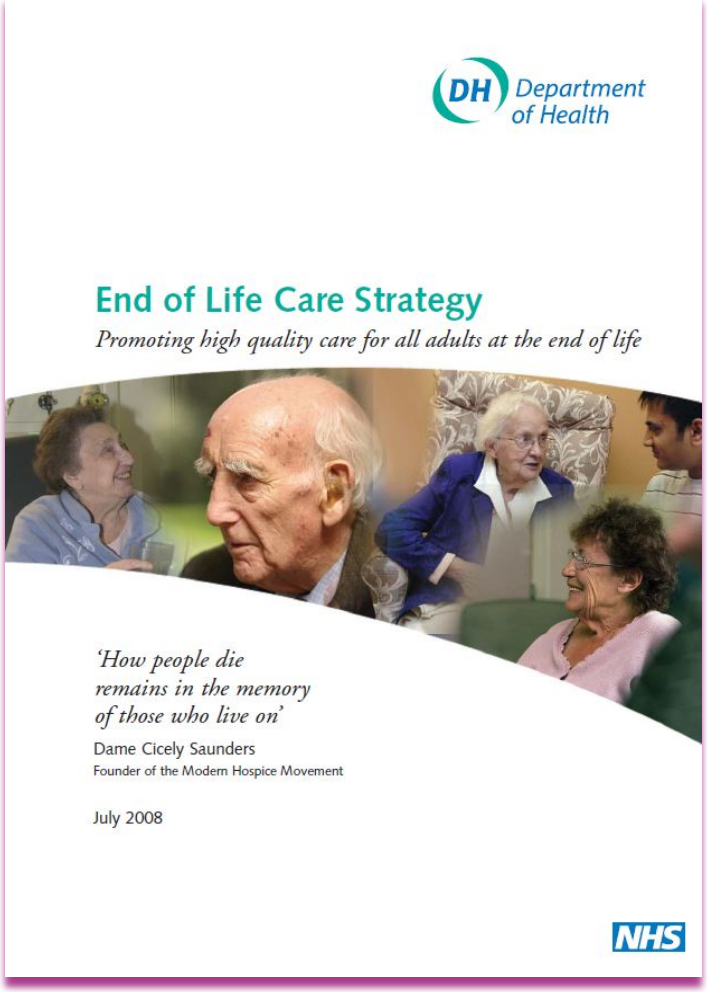

- 1st ever national strategy
- Comprehensive across all settings
- Key insight: 70% want to die at home; 58% were dying in hospital
- Whole systems approach to change
- Cross-party support

www.ncpc.org.uk

www.dyingmatters.org

Trends

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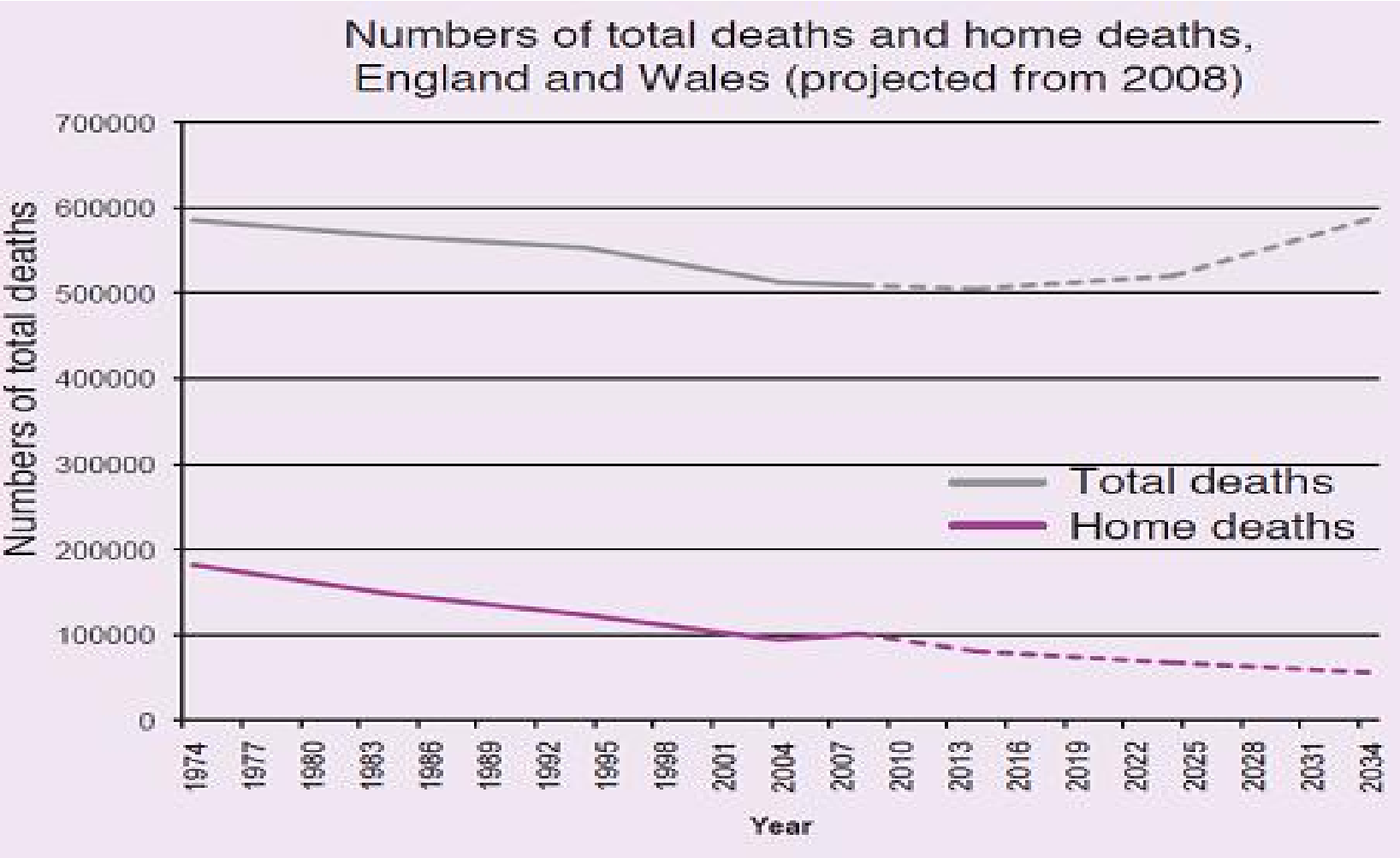

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Deaths in Usual Place of Residence increasing

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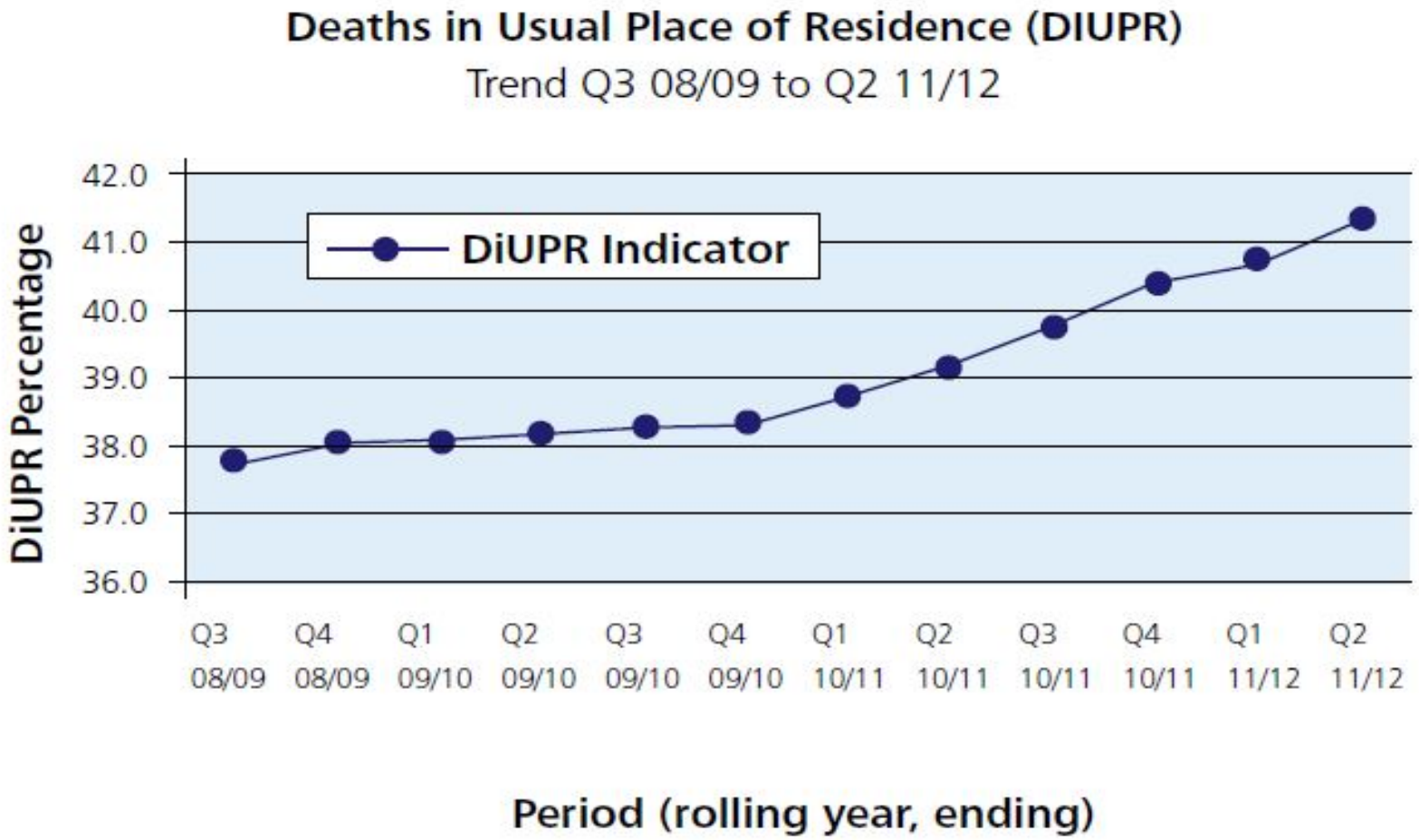

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Care “at any time of day and night”

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- Helping people to be cared for where they are
- **Not “out of hours”**
- QIPP: prevents unplanned crisis hospital admission
- **Access to nursing, specialist advice & symptom control**
- Care co-ordination
- **Anticipatory prescribing**

NICE Quality Standard

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- 16 statements on end of life care
- No1: identification – all else flows from that
- **4 to be accessed "at any time of day and night":**
  - Physical needs including access to medicine
  - Consistent co-ordinated care across all services
  - Urgent care, if crisis
  - Specialist palliative care

www.ncpc.org.uk

Professional trepidation

- Many GPs still lack confidence with opioids & pain relief (NCPC 2011)
- 2008: 29% Doctors, 18% nurses received training in end of life care
- 2012 RCP survey: 1/3 of (2000) doctors had received Eolc training in last 5 years
- Key to include:
  - Communication
  - Symptom control

NICE Clinical Guideline on Opioids in Palliative Care

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"Many people with chronic or advanced conditions will experience a high level of pain which can only be treated by opioids such as morphine as weaker forms of pain relief will no longer be effective. **However, we understand that patients can be anxious about using these medicines for a number of reasons. Likewise, healthcare professionals may not always be sure about when to prescribe certain types of opioids**.

The new guideline aims to address all those fears and provide clear advice to the NHS to ensure a consistent approach to treatment and ultimately help to drive up standards of care."

Professor Mark Baker, Director of NICE Centre for Clinical Practice

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NICE Clinical Guideline on Opioids in Palliative Care

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- Published May 2012. Recommendations include:
  - Communication
  - Starting treatment & titration
  - First-line maintenance therapy
  - Management of constipation, nausea, drowsiness

Coming soon

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- Results from Office for National Statistics survey of 49,000 bereaved people about quality of care
- To inform a new outcomes framework for the NHS, which explicitly includes experience of people approaching end of life care
- Seeking data including on pain & dignity

Some levers

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- Implementing NICE (guidelines are not mandatory)
- Training & education for public as well as professionals
- Commissioning & performance management based on people's experience

Contacts

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