The End of Life Care Strategy
promoting high quality care for all adults at the end of life

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The End of Life Care Strategy: Rationale (1)

- Around 500,000 people die in England each year. This will rise to around 530,000 by 2030

- 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 at the end of their lives

The End of Life Care Strategy: Rationale (2)

- 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 17% in care homes
  - Acute hospitals accounting for 58% 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: Scope

- The Strategy

  - Covers all conditions
  - Covers all care settings (e.g. home, hospital, hospice, care home, community hospital, prison etc.)
  - Has been developed within the current legal framework

The End of Life Care Strategy: Approach (1)

- The approach to development of the strategy has been as inclusive as possible

  - Advisory Board
  - 6 working groups (including a care pathway working group with over 60 members)
  - Stakeholder consultation
  - Conferences / workshops – including events with leaders of different faith groups
  - SHA clinical pathway chairs for end of life care

- Hundreds of people and organisations have contributed

- Strong support for both a 'whole systems' and a 'care pathway' approach

The End of Life Care Strategy: Approach (2)

The strategy:

- Is based on the best available evidence

- Builds on the experience of hospices and specialist palliative care services

- Builds on recent experience from the Marie Curie Delivering Choice Programme and other innovative service models

- Builds on the existing NHS End of Life Care Programme (e.g. Gold Standards Framework; Liverpool Care Pathway and Preferred Priorities for Care tools)

- We have taken as inclusive an approach as possible

NHS End of Life Care Programme 2004-2007

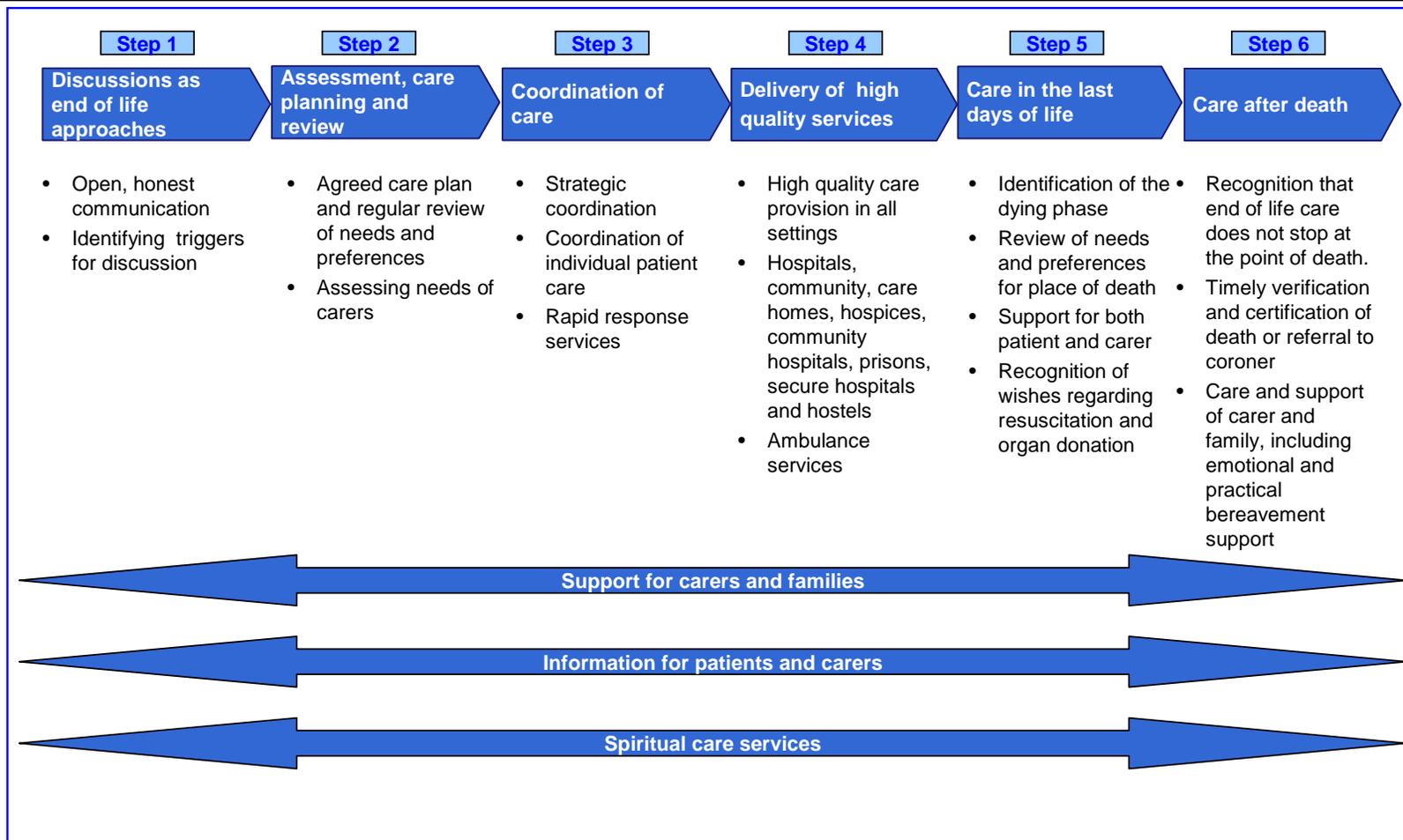|	One or more tools		
	June 2005	Goal	Jan 2008
GP Practices	23%	60%	75%
Acute Trusts			
- 3+ wards	49%	80%	85%
- All appropriate wards	0%	4%	17%
Community Hospitals	9%	20%	47%
Care homes	0.3%	4%	7.6%
Hospices (LCP)	36%	-	75%

The End of Life Care Strategy: Chapters

1. The challenges of end of life care

2. Death, dying and society

3. The end of life care pathway

4. Care in different settings

5. Support for carers and families

6. Workforce

7. Measurement and research

8. Making change happen

Death, Dying and Society (Chapter 2)

- Problems

  - As a society we do not talk about death and dying – this contributes to its low profile in health and social care
  - Most people do not discuss their own preferences for end of life care with their partner / family, hampering individual planning

- Actions

  - A national coalition on end of life care will be established, led by the National Council for Palliative Care with funding from DH
  - A tool to assess change in awareness / attitudes will be developed
  - Local end of life care plans to include actions on awareness / attitudes

The End of Life Care Pathway

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as end of life approaches	**Assessment, care planning and review**	**Coordination of care**	**Delivery of high quality services**	**Care in the last days of life**	**Care after death**

Step 1 — Discussions as end of life approaches
- Open, honest communication
- Identifying triggers for discussion

Step 2 — Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3 — Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 4 — Delivery of high quality services
- High quality care provision in all settings
- Hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 5 — Care in the last days of life
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6 — Care after death
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Support for carers and families

Information for patients and carers

Spiritual care services

The End of Life Care Pathway: Steps 1 + 2

1. Identifying people approaching the end of life and initiating discussions

   - Major culture change needed amongst clinicians
   - Difficulties in prognostication are recognised
   - 'Surprise' question may be helpful
   - Communication skills training required

2. Assessment, care planning (and review)

   - Need for training recognised

The End of Life Care Pathway: Step 3

3. Coordination

- Easy to talk about; difficult to deliver
- Coordination is needed within teams (e.g. GSF) and across organisational boundaries (e.g. coordination centres)
- Locality wide registers may be helpful
- IT links need to be developed – but much can be done already (e.g. NHS mail)
- No single model of coordination is prescribed – but PCTs should demonstrate that they have mechanisms in place.

The End of Life Care Pathway: Steps 4-6

4. Delivery of high quality services

    - See Chapter 4

5. Care in the last days of life

    - Liverpool Care Pathway strongly recommended

6. Care after death

    - The Liverpool Care Pathway has modules for care after death, which can also be used for sudden deaths

Care in different settings (Chapter 4) 1/4

- Community

  - Importance of 24/7 rapid response community nursing services for end of life emphasised
  - GSF or equivalent recommended for use in general practice

- Care homes

  - Major scope for improvement of end of life care in care homes.
  - The NHS End of Life Care Programme (2004-2007) has shown what can be achieved, using GSF, LCP, PPC etc.
  - These approaches now need to be spread
  - Importance of good medical cover is emphasised

- Hospitals

  - 58% of deaths occur in hospitals
  - Hospitals will continue to have a vital role in caring for the dying
  - A major culture change is needed – both amongst clinicians and NHS managers: Death should not be perceived as a failure
  - Board level engagement advocated
  - Importance of specialist palliative care teams emphasised

- Hospices

  - Provide beacons of excellence in the provision of end of life care
  - Should be encouraged to consider what roles they would wish to deliver within an integrated local service

    e.g.   Awareness raising

    Education and research

    Coordination

    Specialist outreach services (e.g. to care homes or community hospitals and for patients with conditions other than cancer)

  - Any new services should be appropriately funded by PCTs

Care in different settings (Chapter 4) 4/4

- Community hospitals

  - Can deliver excellent end of life care
  - Should be included in planning

- Ambulance services

  - Need access to information about people approaching the end of life (e.g. DNAR status)
  - Importance of rapid discharge from hospital for people wishing to die at home is emphasised

- Prisons and hostels for the homeless

  - Examples of good practice identified
  - Should be included in local plans

Support for Carers and Families (Chapter 5)

- Carers provide invaluable support for people approaching the end of life, but may need support themselves

- Carers are central to the team and should be considered as 'co-workers'

- Carers should be offered an assessment of their own needs and to have their own care plan which is reviewed regularly

- Bereavement care should include support for those bereaved through sudden death and also the needs of children

Spiritual care services

- Recognition of the spiritual dimension of each person

    – Each person is unique and should be treated with dignity and respect
    – People approaching the end of life need to discover their own way of making sense out of what is happening and helped to express this

- Action

    – Spiritual needs should be assessed as part of all patient and carer assessments
    – Ritual actions are often helpful for patients and carers as are occasions of remembrance for the bereaved
    – The role of chaplains should be fully integrated into the multidisciplinary team

- Problems

  - The specialist palliative care workforce is relatively small (~5,500). The total number of health and social care professionals who deliver end of life care is huge (several hundreds of thousands)

  - Many staff at all levels have received little or no training or continuing professional development in end of life care

Workforce Development (Chapter 6) 2/2

- Need for education, training and CPD related to

    - Communications skills (e.g. starting the conversation)
    - Assessment and care planning
    - Symptom control
    - Provision of psychological, social and spiritual care
    - Care in the last days of life

- Action will be required by

    - Regulators (e.g. GMC, NMC etc.)
    - Medical schools and higher education institutions
    - Strategic Health Authorities
    - Local commissioners / providers
    - Individual practitioners

- Measurement

  - We need to be able to assess whether individual organisations are providing high quality care and whether progress is being made across the country as a whole following publication of this strategy
  - Currently available measures (e.g. place of death) are useful, but do not provide information on quality of care or on where patients might have chosen to die
  - Better use could be made of existing data sources (e.g. by combining ONS and HES data)
  - The difficulties related to measurement of end of life care need to be recognised
  - Measures of structure, process and outcomes are all useful

Measurement and Research (Chapter 7) 2/3

- Quality standards to assess the structure and process of end of life care are currently being developed, in association with SHA End of Life Care Clinical Chairs

    - For consultation shortly

- Outcome measures

    - Place of death
    - Professional audits (e.g. LCP: National care of the dying audit – hospitals and GSF After Death Analysis)
    - Surveys of bereaved relatives (VOICES)

- Establishment of National End of Life Care Intelligence Network – bringing together 'owners' of data and those with interest / expertise in this area

Research

- The UK makes a considerable contribution to worldwide research on end of life care – but could do better

- There are major research opportunities for further research – especially in relation to conditions other than cancer

- The Department of Health and other research funders are committed to investing in high quality end of life care research – building on the good foundations established through the NCRI Supportive and Palliative Care research collaboratives

Making Change Happen (Chapter 8) 1/5

Key elements

- Funding

- Local strategic planning (PCTs/LAs)

- Actions by all relevant provider organisations

- National support

- Funding

  - Manifesto commitment to double expenditure on palliative care
  - Baseline:
    - NHS expenditure on specialist palliative care (2000)   = £130m

    - Central budget for specialist palliative care (2003/4)   =   £50m

                                                           Total   £180m

  - Commitments in End of Life Care Strategy

    2009/10:   £88m

    2010/11:   £198m

  - Most of this funding will be put into PCT baseline budgets, but they will be expected to monitor investment. Can be used for any of the areas identified in this strategy

  - Some funding for SHAs (workforce development)

  - Small central budget for national initiatives

- Local strategic planning

  - All PCTs will be expected to develop strategic plans for end of life care, building on their baseline reviews and taking account of the national strategy and their SHA vision

  - This is in line with the Next Stage Review commitments for PCTs to set out plans based on each of the 8 clinical pathways

  - Essential that PCTs engage all relevant providers, including the voluntary sector, in this. They may wish to establish a Partnership Board or a Network

- Provider organisations

  - Each provider organisation involved in end of life care should develop a plan which is congruent with local and national strategy

  - The draft quality standards may help providers to identify areas which need action

Making Change Happen (Chapter 8) 5/5

- National support

  - National coalition on end of life care
    - To provide public awareness and to change attitudes

  - National End of Life Care Programme will continue to help spread good practice
  - Survey programme of bereaved relatives to be established
  - National End of Life Care Intelligence Network to be established
  - Research initiatives will be supported
  - Professor Mike Richards will continue to provide leadership within DH. He will report annually on progress to Ministers
  - An external stakeholder group will be established to advise on this

Summary

- The strategy sets out a vision to transform end of life care in this country over the coming years

- Action will now be needed by a very large number of people and organisations who contribute to commissioning, delivery of care, education and research

- Huge thanks to the many people who have contributed to the development of the strategy and who have provided the firm foundations on which we can now build