
Transforming End-of-Life Care: The British Approach

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End of Life Care Strategy

Promoting high quality care for all adults at the end of life



*‘How people die remains in the
memory of those who live on’*

**Dame Cicely Saunders, founder of the
Modern Hospice Movement**

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Why an End-of-Life Care Strategy?

- ❑ Strong policy thread in 2000s toward increasing patient choice—end-of-life care one example
- ❑ End-of-life care a major source of complaint in NHS surveys; problems confirmed in research literature; underutilization of palliative care services
- ❑ Few people want to die in hospitals (most say they want to die at home) but most deaths (58%) were in hospitals
- ❑ Anticipated increases in numbers of deaths

Ideas in Strategy About a “Good Death”

- ❑ Being treated as an individual, with dignity and respect
- ❑ Being without pain and other symptoms
- ❑ Being in familiar surroundings
- ❑ Being in company of close family/friends

Built on Existing Models

- ❑ Hospice and palliative care
- ❑ Liverpool Care Pathway for hospitalized patients [focus on last days of life]
- ❑ Gold Standards Framework for primary care [focus on last year of life]
- ❑ All focus on identifying appropriate patients and offering them choice and symptom relief

Liverpool Care Pathway

- ❑ Focus on patients who are dying
- ❑ Includes comfort measures and discontinuation of inappropriate interventions
- ❑ Attention to physical, psychological, social, spiritual, and religious needs
- ❑ Attention to information needs of patients & caregivers

Gold Standards Framework

- ❑ Identify patients likely in last year of life (surprise question) and create registry
- ❑ Assess current and future critical needs
- ❑ Plan for meeting those needs [use of the “7 Cs”]

Gold Standards Framework

[7 Cs]

- ❑ Communication & advance care planning
- ❑ Coordination (and lead clinician)
- ❑ Control of Symptoms
- ❑ Continuity across boundaries
- ❑ Care in dying phase (realistic choices re place and act on patient preferences)
- ❑ Caregiver support
- ❑ Continued learning (reflection after deaths)

Theme of the Strategy: Crossing Boundaries

- ❑ Going beyond cancer care to diseases with other trajectories
- ❑ Going beyond hospice & specialist palliative care
- ❑ Going beyond particular settings (e.g. hospitals or home care)
- ❑ Going beyond EOL care

Key Aspects of Strategy— Three Levels

- ❑ Societal—to increase public awareness and change attitudes
- ❑ Infrastructure—emphasis on training professional caregivers
- ❑ Improve quality of care for individual patients (cost savings not rationale)

The End-of-Life Care Pathway (Six Steps for Providers)

1. Identifying patients within year or so of end of life and initiating discussion of their care preferences
2. Developing care plan based on patients' needs & wishes, and modifying as needed over time
3. Addressing the need to coordinate care across multiple organizations that may care for patient

The End of Life Care Pathway (Six Steps for Providers)

4. The delivery of high quality services by all providers
5. Care—particularly “comfort care” and good communication—in last days of life
6. Care after death—re the patient’s body and the needs of family & caregivers

Implementation

Specific activities for each step. Examples:

- ❑ Step 1. Working with clinical groups to tailor pathways to specific patient groups that have different end-of-life trajectories
- ❑ Step 2. Developing guides to assist patients plan for end-of-life care
- ❑ Step 3. Funding local pilots for end-of-life registries
- ❑ Published *Quality Markers and Measures for End of Life Care*

Levers of Change

- ❑ Working group from 10 strategic regional health authorities
- ❑ Funding for workforce development
- ❑ Major role of primary care trusts—the purchasers in the system
- ❑ Use of incentives to get PCPs to create patient registries

Strengths of the Strategy

- ❑ Physician leadership
- ❑ Participatory development process
- ❑ Implementation levers—can use both incentives and oversight
- ❑ Built upon and harmonious with previous policy initiatives
- ❑ Pluralism among primary care trusts and regional health authorities
- ❑ Evidence orientation

Markers of Progress

- ❑ Measurement is a strong component of the strategy—voluntary quality markers & benchmarking
- ❑ Surveys about social attitudes—starting with baseline
- ❑ Percent of deaths at home as a measure
- ❑ Survey of survivors—being piloted

Status of the Strategy

- ❑ High level of acceptance by primary care trusts
 - ❑ Half chose “place of death” as one of 8 indicators (out of 50) by which they are performance managed
- ❑ Positive indicators of physician acceptance (90% got QOF points for physician incentives)
- ❑ Second annual progress report due in July

Challenges

- ❑ To change how end-of-life care is viewed (not just cancer, not just palliative care specialists, death not seen as a failure)
- ❑ Reliably identifying the right patients is difficult
- ❑ To overcome organizational/payment boundaries—e.g. between primary care & hospital care, between hospice and NHS
- ❑ In tough economic times, need to show shift from hospitals to community is cost-effective
- ❑ Potential for controversy (e.g., fear that motivation is to save money)

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