



National Confidential Enquiry into Patient  
Outcome and Death  
'For better, for worse' and the  
End of Life Care Strategy

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## 21<sup>st</sup> century policies:

- NHS and Cancer Plans 2000
- NICE 2004
- **End of Life Care Initiative 2004**
- The Choice Agenda 2005
- Your Health, Your Care, Your Say 2006
- **Darzi; the Next Steps review 2008**
- **End of Life Care Strategy 2008**



## “For better, for worse?” Treatment decisions:

- 86% patients treated with palliative intent – 51% receiving  $\geq$  2<sup>nd</sup> line
- 21% Perf. Status 3-4 at start of treatment
- 43% patients developed grade 3-4 toxicity
- 19% decisions to treat judged to be inappropriate - <50% discussed in MDT
- 35% last cycles judged inappropriate – 52% deaths after cycle 1



# Factors influencing decision making:

- Patient related –
  - Commitment, age and social circumstances
- Clinician related –
  - Experience, support, training
- Tumour related –
  - Natural history, previous treatment-response

## Decision making; palliative SACT in patients with poor performance status:

- Research evidence to improve understanding of outcomes
- Clarity about intended outcome
- Assessment of benefit : risk for individual
- Clear communication with patient and family

## **“For better, for worse?”-**

### **Recommendations on end of life care:**

- NCEPOD strongly supports the use of an end of life pathway when managing patients in their last days of life
- All healthcare professionals dealing with people who are dying should be able to discuss options and facilitate choices



## End of Life Care Pathways:

- For the care of the patient **in the last days of life**
- For the care of the person **approaching the end of life**



**“For better, for worse?”-**

**Recommendations on end of life care:**

‘A proactive rather than reactive approach should be adopted to ensure that **palliative care treatments or referrals** are initiated early and appropriately. Oncologists should enquire, at an appropriate time, about any **advance decisions** the patient might wish to make should they lose the capacity to make their own decisions in the future.’



# Palliative Care: NCHSPCS 1997

- The active care of patients whose disease is not responsive to curative treatment. Control of physical symptoms and provision of psychological, social and spiritual support are paramount.
- The goal of palliative care is achievement of best quality of care for patients and their families.  
**Many aspects of palliative care are also applicable earlier in the course of the illness *in conjunction with* curative treatment.**



End of Life Care is care that:

Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of physical symptoms and provision of psychological, social, spiritual and practical support.

NCPC 2006



**End of Life Care Strategy**– Promoting high quality care for all adults at the end of life

‘How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.’

2008

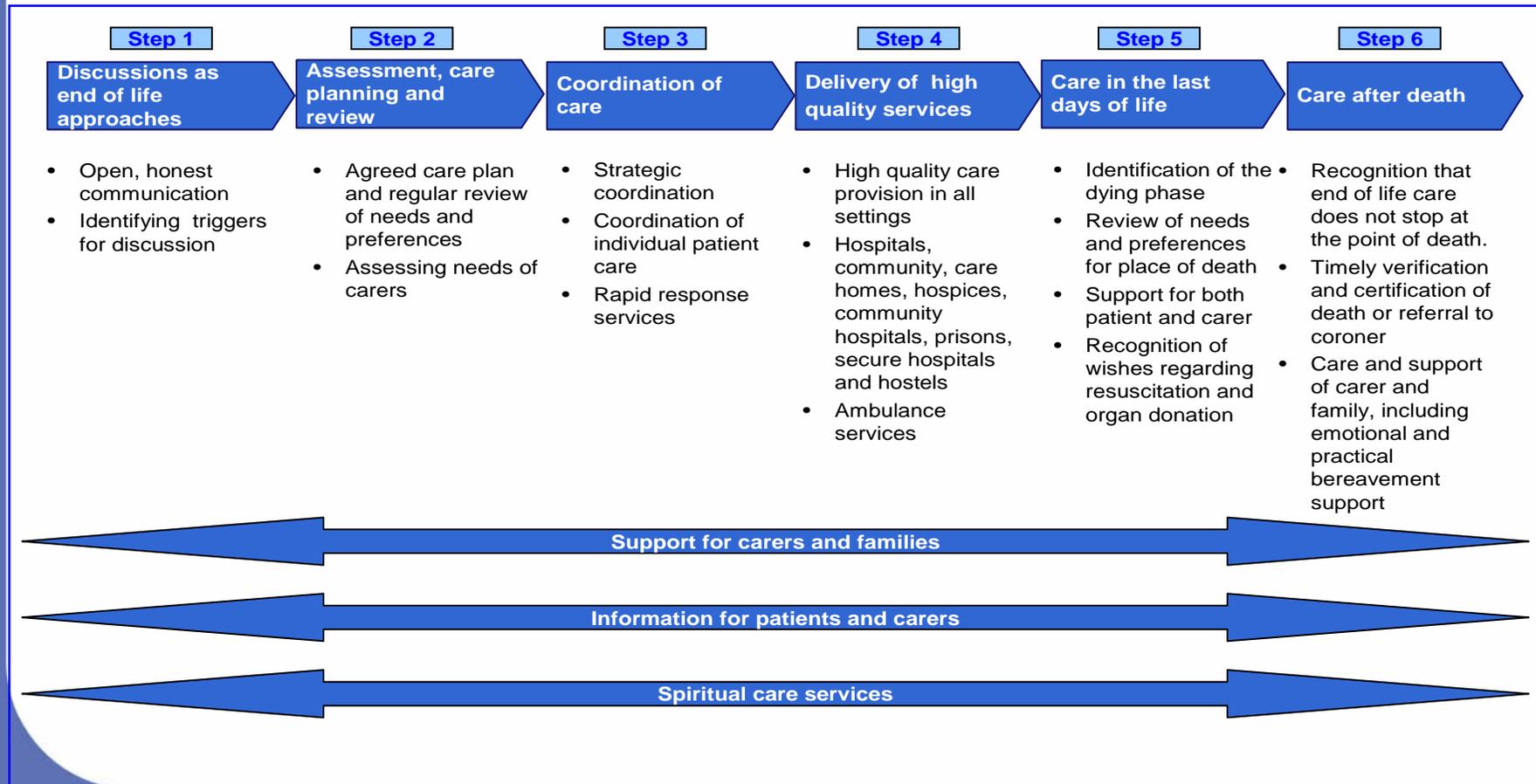


# End of Life Care Strategy:

- For all adults regardless of diagnosis
- For any place of care
- Time period not clearly defined; but “months to a year”
- Within the limits of the current law



# The End of Life Care Pathway



# End of Life Care Pathway

- Identifying people approaching the end of life; initiating discussions
  - Major culture change amongst clinicians needed
  - Prognostication is difficult
  - Communication skills training essential
- Advance Care Planning
- Coordinated, rapidly responsive care in all settings

## **Advance Care Planning:**

An integral part of care. A process of evolving discussion between individuals and their care providers. This may result in creation of an advance statement or decision.

**Advance Statement:** how an individual would wish to be treated if he loses capacity, containing general beliefs and life values.

**Advance Decision:** Clear instructions refusing a specified medical procedure



## “A good death”

- Being treated as an individual, with dignity and respect
- Being free of distressing symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

Palliative care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by early identification, impeccable assessment and treatment of pain and other symptoms, physical, psychological, social and spiritual.

**WHO 2002**

