



EllenorLions Hospices

'without them we would have been lost'

The National End of Life Strategy and local services.

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6th April 2009

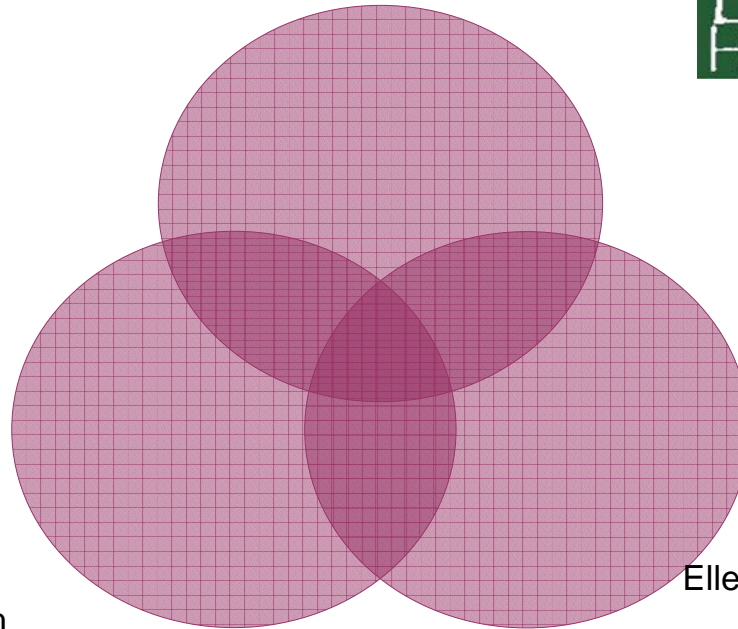


EllenorLions Hospices

'without them we would have been lost'

Merged 2007

Lions Hospice



Shining Lights
Children's team

Ellenor Hospice at Home
SPCT



End of Life Care

'How people die remains in the memory of those who live on'

Dame Cicely Saunders

Founder of the Modern Hospice Movement



‘good death’ ?

- Being treated as an individual – Dignity, Respect
 - Being without pain and other symptoms
 - Being in familiar surroundings
 - Being in the company of close family and/or friends.
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End of Life Care Definition

“End of life care 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 into bereavement”

Healthier people, excellent care

NHS SE Coast

Why are patients and carers needs not met?

- Professionals not eliciting problems & concerns
 - Service not available
 - Patients & carers unaware of the services available
 - Professionals unaware of benefits of existing services, not offering access or referral
 - Poor communication & co-ordination amongst professionals
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Social Changes

- Life expectancy increasing
 - More older people living alone
 - More people living with multiple chronic conditions
 - Families
 - Less experience death & dying
 - 'Social taboo'
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The End of Life Care Strategy

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



Department of Health
July 2008

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
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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
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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
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Background

- Of the 500,000 who die each year
 - 2/3 aged over 75
 - 25% Cancer
 - 19% Heart Disease
 - 14% Respiratory Disease
 - 11% Strokes & related disorders
 - 31% other
 - 15% of the total population-over 65, increasing to 20% of population by 2020 (ONS 2003) 1:3 Dementia in last yr
 - Estimated that 1:4 over 85 will move into a Care Home
 - 29% over 85 diagnosed with Ca, HF, COPD + Dementia
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End of Life Care Strategy

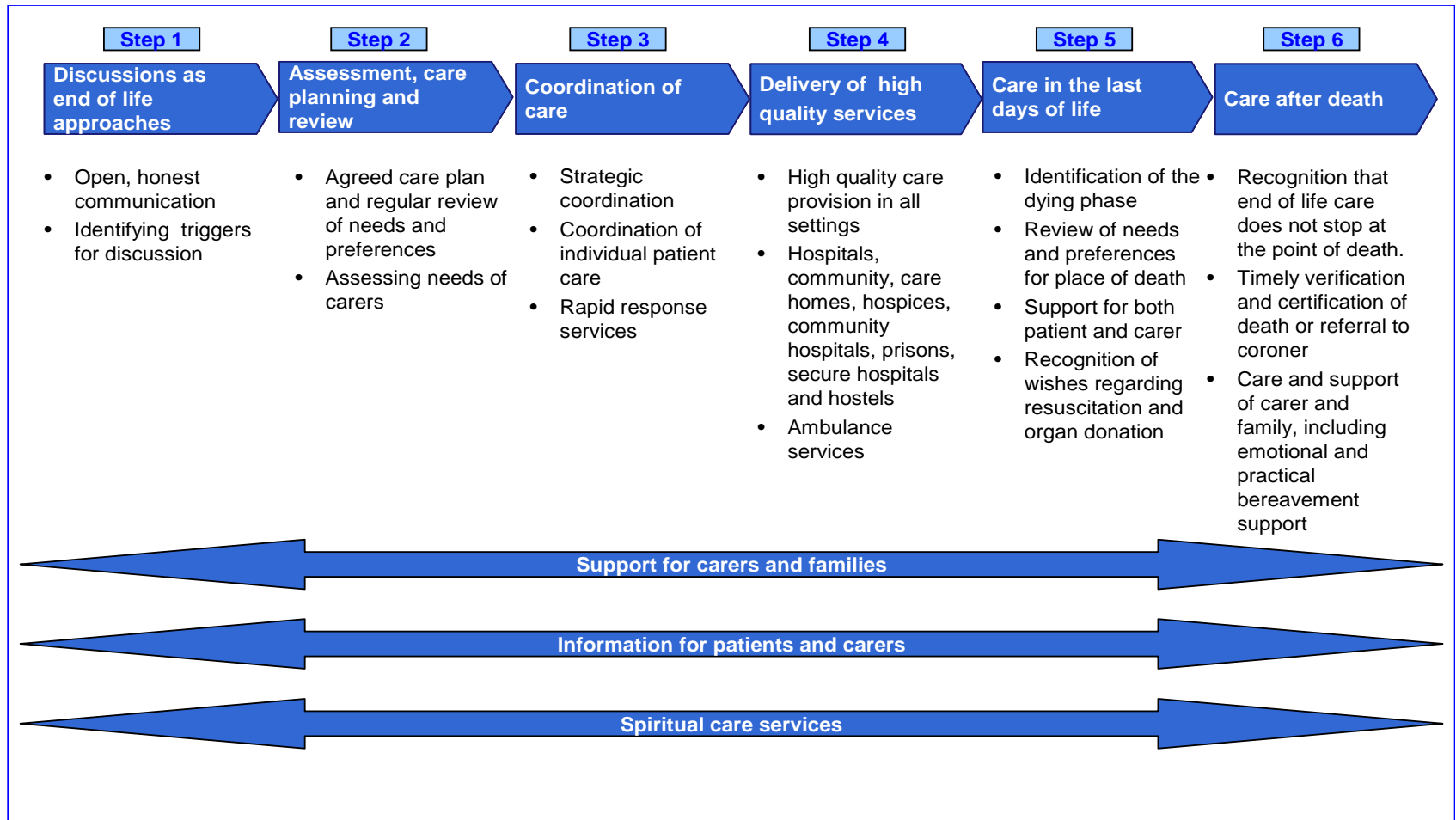
- Raising the Profile
- Strategic commissioning
- Identifying people approaching EoL
- Care Planning
- Coordination of care
- Rapid access to care
- Delivery of high quality services all locations
- Last days of life & care after death
- Involving & supporting carers
- Education & Training CPD
- Measurement & Research
- Funding (£88m 2009/10 £198m 2010/11)



Whole Systems and Care Pathway Approach

- Identification of People. Discussion, Choice
 - Assessment, Care Planning, Review
 - Coordination of care
 - Delivery of high quality services all locations
 - Management of last days of life
 - Care after death
 - Support for carers into bereavement
 - Information, spiritual care services
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The End of Life Care Pathway



Recommendations

- End of Life Care Networks
 - Rapid Response Teams
 - Hospice at Home Services
 - Improving skills of generalists
 - Increased use of recommended tools - GSF, LCP, PPC
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Gold Standards Framework

- Developed in 2001 by Dr. Keri Thomas
 - GP practice and community based framework
 - 7 Key Tasks/Standards
 - Step by step approach
 - Improves organisation and quality of care of patients in last year of life
 - GP, care homes, hospitals
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7Cs/Standards

- 1. Communication
 - 2. Co-ordination
 - 3. Control of symptoms
 - 4. Continuity
 - 5. Continued Learning
 - 6. Carer Support
 - 7. Care of the Dying
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Liverpool Care Pathway

- Provides a framework for care in the last days of life
 - Non-essential interventions are stopped
 - Consideration given to comfort measures
 - Psychological & religious/spiritual support
 - Information for families/carers
 - Bereavement planning
 - Community, care homes, hospital, hospice
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Preferred Priorities of Care (PPC)

- Tool to determine and record patient and carers' wishes in relation to their care and ultimate place of death
- Originated from Palliative Care Education Programme (Cancer Plan 2000)

Lancashire & S. Cumbria Network

SE Coast Review NHS

Recognised Barriers

- 'Dying' Taboo - public & professionals
 - Traditionally low priority NHS v Social Services
 - Poor coordination of care across sectors
 - Poor ICT systems
 - Inequality in access. Lack of dignity/respect
 - Poor support for carers
 - Problems with verification of death/certification
 - Viewing of a body at mortuary, return of property
 - Lack of robust measures to assess quality/effect
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Vision EoL Care SE Coast

- By 2012 all providers will use best practice tools eg. GSF, LCP, PPC
 - By 2015 a visiting service to help people with pain (?symptom management) available everywhere
 - NHS in Kent, Surrey & Sussex will work with staff, public & partners to raise awareness of EoL issues.
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Workforce Development

- Development should be across health and social care. Partnership Working
 - Prepare the future workforce. (Pre Reg)
 - Important to develop skills wider workforce
 - Include Social Services, NVQ's, Nursing Homes and Independent Sector
 - Need for multi-professional advanced communications skills training
 - Involvement of Higher Education Institutions to embed EOL into programmes
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Locally

- End of Life Care Facilitators
 - GP Facilitators
 - Formation of EoL care Network groups
 - Locality & PCT wide EoL Steering Groups
 - Pbc groups – QOF, LES
 - Reorganisation of Community Nursing
 - Increased engagement with Care Homes
 - Local Authority training opportunities
 - OOH Services
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- In-patient Hospice
- Day Hospice/Therapy
- Community Hospice Services
- Hospital Palliative Care Teams
- Care Homes Support
- Children's Palliative Care
- Transition Nurse
- Education



- Multi-professional teams providing specialist medical, nursing and psychological care



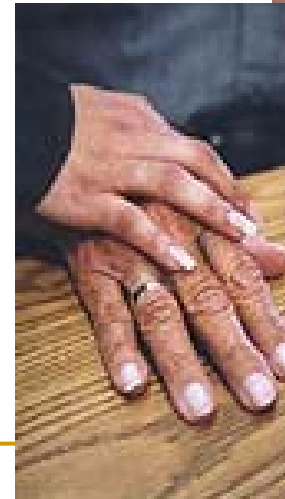
- Doctors
 - Specialist Nurses
 - Social Worker
 - Counsellors
 - Chaplain
 - Music Therapist
 - Play Therapist
 - Respite Team
 - Nursery Nurse
 - Volunteers
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- 24 hour contact provided to referred patients.
- 24 hour advise to professionals
- Respite and practical care at home
- Patient activity groups

Other Services provided to patients and families

- Social support
- Emotional support
- Spiritual care
- Play and music therapy
- Complementary therapy
- Carers support
- Bereavement support



ELH Care Homes Project

‘Dying at Home’

- a model for enhancing end of life care in care homes

- Grant funded by Help the Hospices 1 year
 - Burdett Trust 3 years
 - Support and education local care homes
 - Practical support within the homes
 - Develop support to residents and families
 - Reflection and evaluation
 - Partnership working
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ELH Care Homes Project - Outcomes

- Greater choice for patients
 - Decrease in number of emergency admissions to hospital last days of life
 - Decrease number of transfers from care homes in last weeks of life.
 - Increase in the use of EoL tools – GSF, LCP, PPC/ACP
 - Staff to feel more supported, enabled and satisfied with care delivery
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Support for Carers and Families

(Chapter 5 EoL Strategy)

- 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
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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
 - DVH and ELH have chaplaincy services

Core Principles

- All dying people, not just cancer patients
 - Continue to build local capacity, capability & clinical leadership
 - Change Management – measurement & evaluation
 - Knowledge Management
 - Development of integrated approach
 - Focus on local needs & priorities
 - Not a quick fix
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Summary

- The national 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
 - We need to work across the whole locality to find solutions that suit our patients and families
 - We need to ensure the new End of Life money is spent on good end of life care that will make a difference.
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How should we respond
locally to the EoL Strategy?

What would you like to see
provided for you or your patients?
Think creatively!