End of Life Care in the New World of Commissioning and Service Delivery
A daughter’s story
Step 1: Discussions as the end of life approaches
Step 2: Assessment, care planning and review
Step 3: Co-ordination of care
Step 4: Delivery of high quality care in all care settings
Step 5: Care in the last days of life
Step 6: Care after death
End of Life Care Strategy 2008

- To bring about improvements in the quality of end of life care in all sectors – hospital, community and primary care.
- To understand end of life of life care in its broadest sense covering palliative, nursing, personal care, psychological and spiritual support, last twelve months of life.
- To allow people to make early and informed choices about their end of life care support needs and where they want to die - better planning and coordination.
- To promote collaborative models of commissioning and support
- Major programme of workforce development to improve outcomes
- Equity of access in all sectors, conditions and communities
- To respond to the needs of increasing numbers of people with long term conditions
- To promote wider awareness of our attitudes to death and dying
Social care at the end of life

- Domiciliary care
- Direct payments
- Essential and unique role of social care in supporting people with end of life care needs
- Care homes
- Extra care
- Supported living

National End of Life Care Programme
Improving end of life care
Supporting People to Live and Die Well: progress and opportunities
DH End of life Care Strategy July 2008
NEoLCP established to support implementation
Social Care Leads appointed 2009/10
Social Care Framework published July 2010
Implementing the Social Care Framework

Phase 1: Regional Roadshows

Roadshow in each of the 9 ADASS regions held between October 2010 and March 2011 – to roll out the SCF

Attended by nearly 1400 people in total, many more delegates interested
Roadshows - Key Messages

- Streamline processes, single systems
- Improve and simplify access to training
- Improve information-sharing
- Publicise strategies better
Commissioning messages

- GPs must promote holistic commissioning
- Commissioning processes may be watertight but can providers always provide?
- Commissioners must pay attention to skills and resources
- We need joint commissioning with health and social care
- Do not commission in silos – escape silos and boundaries
- Commissioning should be practice-based
- Commissioning should require measurement against National Quality Markers for Care
- Facilitate commissioning of person-centred integrated care
Test sites commissioned September 2010

- Hospice at Home Personal Budgets pilot - Lancashire County Council/ Rossendale Hospice
- Developing Key Worker competencies for domiciliary care workers to support an integrated EOLC pathway Hull and Wakefield PCTs + partners
- Mentoring workshops for adult care SW and field work support assessors Sue Ryder, Leckhampton Court Hospice, Gloucester
- Implementing integrated palliative care and EOL service in N Norfolk Norfolk CC/ Norfolk NHS
- Integrated health & social care discharge planning at end of life W Essex Community Health Services/ Essex CC + partners
- Delivery of integrated health & social care pathway for End of Life across Essex Essex CC/ Essex Community Health Services + partners
- Exploring role of EOLC lead in SW teams in Lambeth & Southwark Guy’s & St Thomas’s Modernisation Initiative/ Lambeth/ Southwark
- End of Life intervention skills consultation & education St Christopher’s Hospice, London

National End of Life Care Programme
Improving end of life care
Test-sites recurrent themes

Support from senior/front-line managers is crucial

A cultural shift is one of the most important factors in improving EOLC in social care

Mainstream social workers (and their managers) have low knowledge/confidence in end of life issues/ skills but benefit significantly from dedicated training and mentoring

Domiciliary care workers/front-line support services require endorsement of their role in EOLC and lack recognition but are exercising relevant skills and can play a crucial role in supporting people to die at home
Support the effective contribution of domiciliary care workers to EoLC MDT meetings – Wakefield workstream

Support the effective contribution of home care staff in EoLC pathways of care delivery – York workstream

Supporting Integrated Working Between Social Care & Primary Health Care Y & H Social Care EOLC Strategic Leads Group

Raising Primary Care professionals’ awareness of the role of social care in EoLC - Hull workstream

A Joint Social & Health Care Training Needs Analysis & Scoping Exercise for the Delivery of Integrated EoLC Norfolk CC/Norfolk Community Health & Care NHS Trust/NHS Great Yarmouth & Waveney/Anglia CN

A Community Response to End of Life Care - Creative Commissioning
Delivering Integrated EOLC Training through joint Social and Health Care Professional Education
Merseyside & West Cheshire Palliative & EoLC Network

End-of-life intervention skills: consultation and education for Bromley social care staff
St Christopher’s Hospice/London Borough of Bromley

Using Action Learning to Embed End of Life Training in Social Work Teams
East Lancashire Palliative Care Partnership/Cumbria and Lancashire End of life Network/Lancashire County Council

Developing Training from the Prisons Route to Success
Prisons RTS Project Working Group/Merseyside & Cheshire Palliative & EoLC Network

Using Action Learning to Embed End of Life Training in Social Work Teams
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Developing a Good Death Charter for People with Dementia and their Carers
NE Good Death Charter Group/ NE Dementia Alliance

End of Life within Dementia Care Homes
Derby City Council/Derbyshire CCG/Making Space

An approach to localised involvement and development in support of people at End of Life - including family carers and people living and dying with dementia
South of England Health and Social Care Partnership

RESPONDING TO THE DEMENTIA CHALLENGE
The Dementia Challenge
Purpose

1. To support development of a **virtual network**
   - across South of England (SoE)
   - multi agency,
   - social care led

2. To **raise awareness and share best practice**
   - relating to End of Life Care, specific to the needs and issues of people with dementia and their carers
Project Outcomes

→ Build on momentum established from NEoLCP in DH

• Develop managed virtual network to support:
  - local engagement;
  - knowledge and information sharing;
  - action planning;
  - and joint working initiatives.

• Identification of established multi-agency EoLC groups, specific to the support of carers and people living with dementia

• Facilitation of information sharing via virtual platform and e-products

• Development of an e-bulletin

• Provision of an e-based compendium of good practice EoLC-Dementia
Progress to date

- Established **multi-agency Board**
  (SE + SW) reporting to national team
- Identified a local **academic partner**
  (School for Policy Studies, Bristol University)
- Begun **recruiting network members** across SoE and building database
- Designed and circulated first **bulletin**
- Initiated development of **compendium of good practice**

➔ **Accelerate learning and Joint action**
➔ **Enabling local initiatives on EoL and dementia to thrive**
Building partnerships on the front-line
Supporting the effective contribution of domiciliary care workers to EOLC multidisciplinary team meetings
EXPECTED OUTCOMES

- Primary Care in Wakefield are aware of the role and purpose of social care in supporting service users during end of life pathway.
- Social care staff are core members of appropriate community multi-disciplinary meetings related to end of life. (Gold Standard Framework)
- Individuals’ Advance Care Plans are on the Social Care system.
- People get quick social care help when required as part of their Advance Care Plan.
NEoLCP SCF OBJECTIVES

(1) Identify and raise awareness of the role of social care in supporting people at the end of life, among public, social and health care workforce and management.

(5) Promote understanding and best practice in holistic assessment of individuals, their carers and families at end of life.

(6) Promote early engagement with end of life care planning that builds on an holistic understanding of wellbeing.

(8) Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care.
5 GP Practices Engaged in the Project.

Advance Care Planning pathway into Social Care in development.

5 Social Workers attending the Practice Gold Standard Framework meetings.

Domiciliary Care Service linked to Gold Standard Framework meeting.
Hospices: a community resource in a new commissioning environment

Robert Melnitschuk
Policy and Advocacy Officer
UK leads in end of life care

The quality of death
Ranking end-of-life care across the world

A report from the Economist Intelligence Unit
Commissioned by LIEN foundation
What is hospice care?

• Modern hospice care was born in the UK in 1960s
• Joined-up health and social care for dying people, their carers and families
• Provided by:
  – Nearly 200 local independent charity hospices;
  – Nearly 20 national charity hospices and;
  – A handful of NHS hospices
What is the impact of hospice care?

• 86% hospice care provided in people’s own homes or the community

• More likely to be cared for and die in preferred place if receiving hospice care
Hospices: setting the gold standard

Quality of care as rated by bereaved relatives

- care at home
- care in hospitals
- care in hospices
- care in care homes

- very poor
- poor
- fair
- good
- very good
- excellent

81%
Hospices and social care today

- Hospice care includes many social care components
  - Palliative day care
  - Respite care
  - Personal care
  - Hospice at Home care
  - Welfare advice and support
  - Bereavement care
Joining-up care

• **Help the Hospices**
  - Keen to learn what commissioners need and want
  - Get in touch with us

• **Hospices**
  - Keen to engage and share expertise – HWBBs
  - Meeting care needs of the dying – J SNAs & J HWBSs
  - Get in touch with your local hospice
Systems resilience

- **The Rowan’s Hospice, Waterlooville**
  - Working with 5 other hospices
  - Provide education and training to care home, domiciliary and other care workers

- **Douglas Macmillan, Stoke-on-Trent**
  - Provide an emergency advice line for health and social care workforce
  - Working to deliver choice for dying people
Care and nursing homes

- St Francis Hospice, Berkhamstead
  - Developed a service model to improve end of life care for care/nursing home residents
  - Regular input and continuing assessment by the specialist doctor and nursing team from the hospice
  - Provide training in end of life care for care/nursing home staff – sensitive communication
Social care

- **Martlet's Hospice, Hove**
  - Launched a social care agency in 2007
  - Market research; sustained demand
  - Delivering care at a competitive prices
  - Now on local authorities list of general providers
Dementia care

- **St Luke’s Cheshire Hospice, Cheshire**
  - Partnership with Dementia UK
  - 12 month project to assess care and services needed to provide quality end of life care
  - Focus on people dying with dementia
  - Involves families, care homes and hospitals
  - Supported by the University of Liverpool
Engaging communities

• **Severn Hospice, Shrewsbury and Telford**
  - Compassionate Communities – increasing community capacity to support through training volunteers
  - Volunteers care for dying people and their carers to maintain links with the wider community to reduce social isolation

• **St Joseph’s Hospice, Hackney**
  - Work with local domiciliary care agencies – matching formal carers to dying people reflecting on culture and ethnicity
  - Providing education and training in end of life care to carers
  - Identify those who would benefit from 24 hour care at home
Taking things forward

- **Call to partnership**
  - **Hospices are already delivering** health and social care for dying people, their carers and families
  - **Hospices have expertise and experience** in local communities across the country
  - **Hospices are working to share** and extend their services and expertise
The end of life care challenge – commissioning for quality support at the end of life
Integrated commissioning for end of life care – resources

**National End of Life Care Programme commissioning tool.**
- Developed for use across all sectors.
- Interactive resource supported by best practice and reference material.
- Practical use by clinical commissioning groups, local councils and end of life care providers.

**The ADASS advisory audit and rating tool.**
- Allows councils to systematically assess and rate progress on delivering the end of life care social care framework and to network best practice.

**TEST – Training; Engagement; Services; Transferability and Sustainability**
- A resource to advise and inform of best practice and learning across the social care projects.

**EoLQuA - End of Life Care Quality Assessment Tool**
- Online tool to monitor developments in end of life care and to disseminate best practice.
- Provides framework for priorities and investment decisions.

**The National End of Life Care Intelligence Network**
- End of life care profiles in local authority areas.
- Data and statistics broken down by age, gender, place of death and cause of death.

**Joint Strategic Need Assessment (JSNA)**
- Some councils now profiling local end of life care information.

**Adult Social Care Outcomes Framework (ASCOF)**
- Prioritise end of life care priorities and outcomes in “local accounts”
Thank You

www.endoflifecare.nhs.uk
www.helpthehospices.org.uk

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Help the Hospices

NHS
National End of Life Care Programme
Improving end of life care