



End of Life Care
Programme

End of Life Care Programme

Claire Henry
National Programme Director
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Epidemiology of dying in England



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- Approx 530,000 deaths pa
- Cause of death
 - 25% cancer
 - 19% heart disease
 - 14% respiratory disease
 - 11% strokes and related disorders
 - 31% other

Office of National Statistics summer 2004
Statistics relate to 2003



Societal Changes

- Life expectancy increasing
- More older people living alone
- More people living with multiple chronic conditions
- More retired people
- Less experience of death and dying

Why do patients not die in their place of choice?

- Inadequate assessment of patient needs and preferences eg psychological, social and spiritual
- Poor coordination of care
- Poor face to face communication
- Lack of information
- Lack of 24 hour, 7 days a week district nursing
- Inadequate communication between day and out of hours medical services
- Inadequate equipment
- Aging carers or poor family support

Government and other initiatives



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- NSFs and NHS Cancer plan
- Health Select Committee Inquiry - palliative care
- NICE Guidance on Supportive and Palliative Care
- Population based needs assessment
- nGMS Contract
- Communication skills training programme (NHSU)
- Chronic disease management and self care
- Network Support and Development Programme
- Modernisation programmes
- Building on the best

End of Life Care Programme

Aims

To extend the boundaries of palliative care provision...for all patients regardless of diagnosis

By enabling more patients to live and die in the place of their choice

Command paper Building on the best 2003

National Leadership

- Led by Professors Mike Richards and Ian Philp
- Supported by:
 - Programme Director
 - Steering group

Representation includes clinical leads, SHA Nurse Directors, Department of Health, Cancer Action Team, Primary Care Trust, patients and carers

Outcomes

Skill up and support generalists

Increase use of end of life care tools eg GSF, LCP, PPC/ACP and others to increase learning

Choice

Greater choice for patients eg place of care

Secondary care

Decrease the number of emergency hospital admissions for patients wishing to die at home

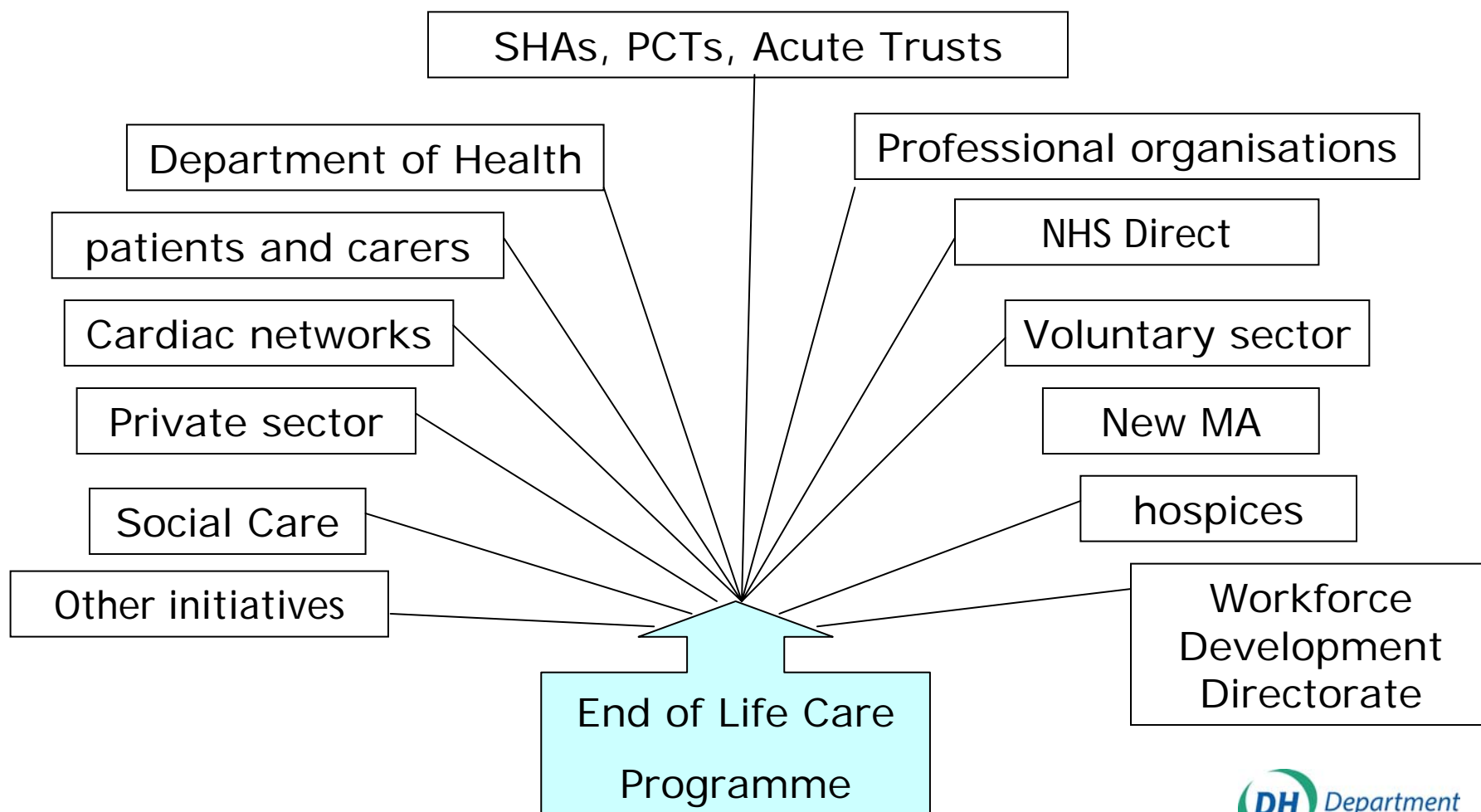
Care homes

Decrease the number of transfers from Care Homes to hospital in last week of life

Core principles

- All dying people not just cancer patients
- Time 'not a quick fix'
- Continue to build local capacity, capability and clinical leadership
- Change management - measurement and evaluation
- Knowledge management
- Develop an integrated approach for patients and carers
- Focus on local needs and priorities

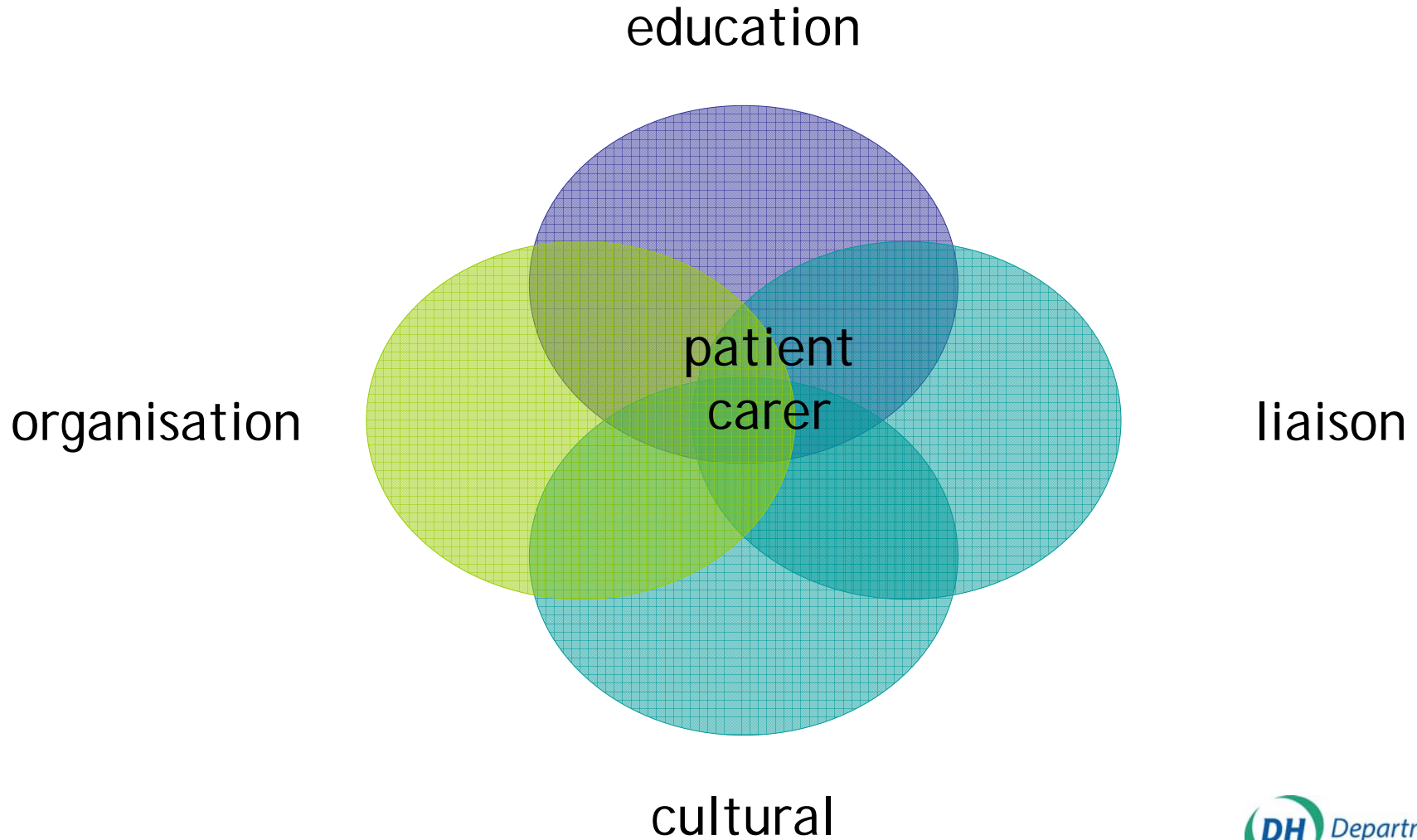
Partnership working



End of Life Care (EoLC)



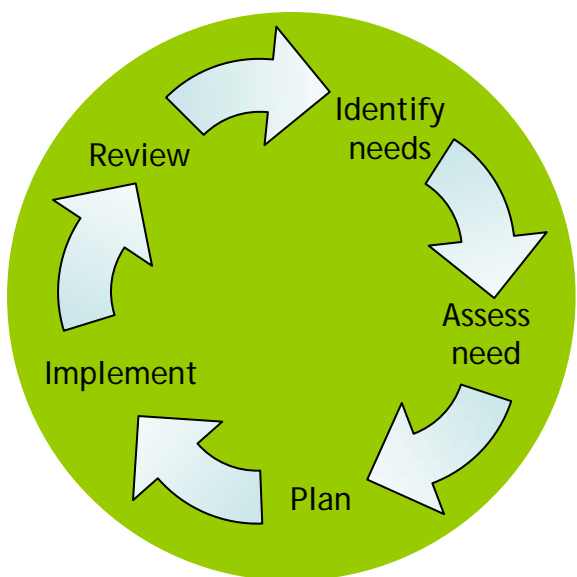
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Tools

- Gold Standards Framework (GSF)
- Preferred Place of Care (PPC)
- Liverpool Care pathway (LCP)

Patient Pathway



Preferred Place of Care (PPC)

Gold Standards Framework (GSF)

Liverpool Care Pathway (LCP)

Preferred Place of Care (PPC)

- This is a tool to determine and record patient and carers' wishes in relation to their care and ultimate place of death
- It originated from the Palliative Care Education Programme to evaluate the effectiveness of teaching on place of death (Cancer Plan 2000)

PPC

The intention at the outset was that the 'Preferred Place of Care' would:

- Record patient choice
- Would allow reviews at different points in their trajectory of care
- In a variety of differing health and social care settings

PPC document

Content

- Information for patients and carers
- Name and address (removed following death)
- Minimal demographic data for analysis purposes
- Family situation
- Carers needs
- Resource implications for services can be determined and used to plan future provision

Benefits of using the PPC



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- Patients and family have choices
- Choices and changes recorded
- Care trajectory is monitored
- Education needs of patients, carers and professionals can be identified and met
- Meets many NICE recommendations

Outcomes of PPC

- 66 died in the place of their choice
- 55 at home
- 8 in hospice
- 3 in Community Hospital
- 73 PPC document returned

Liverpool Integrated Care Pathway (LCP)



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- Developed to transfer the hospice model of care into other care settings focusing on the last few days of life
- It is a multi professional document which provides an evidence base framework for end of life care
- Empowers generalists in providing end care life

Components of LCP

- Comfort measures and symptom control
- Psychological/insight measures
- Religious/spiritual support
- Communication with patient/family
- Communication with the health care professional

(Liverpool care pathway users guide)

LCP 10 Step Programme Implementation Process



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1. Establish the project endorsement
2. Develop the documentation
 - consensus
3. Retrospective audit/base review
4. Induction/education programme
5. Implementation/pilot the document
6. Reflective practice
7. Evaluation and training needs analysis
8. Maintenance education programme
9. Training the teachers
10. Ongoing analysis and feedback

Benefits of LCP

- Supports measurable improvements in the quality of end of life care
- Empowers doctors and nurse to deliver optimum care
- Facilitates multi professional communication
- Informs and influences education programmes
- Informs standard setting and benchmarking for end of life care



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Progress to date

EoLC current position

- Identified local SHA lead(s)
- Agree locally mechanisms to establish a steering group
 - Cancer and palliative care networks
- Link up with other relevant work
 - Modernisation programmes, pilots, clinical networks, existing EoLC programmes, social care providers, other SHAs
- Identify existing use and spread of tools
 - Using local and national information

EoLC current position(2)

- Establish monitoring and evaluation mechanisms
 - baseline
- Develop and agree implementation plan
 - priority areas
 - timescales
 - resources (13 May 2005)

Links with other work

Voluntary Sector Cancer, Workforce development directorates, Primary Care Trusts, Clinicians, Mental Health, Coronary Heart Disease, Older People, Emergency Care, Diabetes, Expert Patient, Prisons, Ethnic Minority Communities, Care Homes, Ambulance Services, Chronic Disease Management/Long Term Conditions, Renal Services

Priorities identified by SHAs

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- Care homes
- Primary care
- All settings
- Acute care
- Mental health
- Chronic Disease Management/Long Term Conditions
- Older people
- Coronary Heart Disease, Respiratory, Renal
- Minority communities
- Emergency care and people with learning difficulties

Role of the national support team



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- Support local SHA teams and advise on adaptation and roll out of tools focusing on the patients journey
- Support spread programme by identifying training needs
- Engage with key stakeholders
- Knowledge management
- Clinical experts
- Ensure national programme stays on track

Next steps

- Support local implementation
- Developing a website - share learning good practice resources and updates
- Facilitators' introductory pack and training package
- Workshops
- Support measurement and evaluation (keep it simple)
- Raise awareness of the EoLC programme
- Continue to working with key stakeholders

Next Steps (2)

- Develop an integrated approach to end of life care
- Setting up a sub group on care homes chaired by Ian Philp to develop and implement approaches that will improve end of life care in care homes

In summary End of Life Care Programme will.....

NHS

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Continue to strive to develop and
implement an integrated patient
focused approach to end of life
care for all patients irrespective of
their disease



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Contact details

Claire Henry

Programme Director

Mobile: 07768 145952

Sally Cook

Programme Administrator

Office Tel: 0116 222 5103

Fax: 0116 222 5101

Mobile : 07770 544899

www.modern.nhs.uk/cancer/endoflife

End of Life Care Programme

St John's House, 3rd Floor

East Street

Leicester LE1 6NB

Keri Thomas, National Clinical Lead

Gold Standards Framework (GSF)

Helen Meehan, Lead Nurse

Office Contact: Katherine Jarvis

Tel: 0121 465 2029

Email: info@goldstandardsframework.co.uk

John Ellershaw, National Clinical Lead

Liverpool Care Pathway (LCP)

Deborah Murphy, Lead Nurse

Office contact: Carole Eaton

Tel: 0151 801 1490

Email: lcp@mariecurie.org.uk

Les Storey - National Lead

Preferred Place of Care (PPC)

Mobile: 07836 799094

Email: lstorey@uclan.ac.uk

