End of Life Care for People with Dementia in Care Homes

Liverpool John Moores University Evaluation (LJMU)

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End of Life Care Initiative

December 2003 – December 2007

£12m announcement from DOH

- Gold Standards Framework (GSF) Liverpool Care Pathway (LCP) and Preferred Place of Care (PPC)
- Extend the boundaries of palliative care provision

Approach – 'skill up' and support DNs, GPs, hospital ward staff and care home providers

NHS End of Life Care Programme

The care of all dying patients must improve to the level of the BEST (DOH2005)

- Greater choice for patients, irrespective of their diagnosis, in where they wish to live and die.
- A decrease in the number of emergency admissions of patients who expressly wish to die at home
- A decrease in the number of older people transferred from a care home to hospital in the last week of life
- Use of Gold Standards Framework (GSF) and Liverpool Care Pathway (LCP) and Preferred Place of Care (PPC)

NHS North West

(Formally Greater Manchester Strategic Health Authority)

- Identified Mental Health Services as a key priority
- Initially aim to focus on people with dementia in a care home setting
- Roll out a more generalist approach to end of life care
- Working in partnership with Health, Social care, voluntary and the Independent Sectors
- Implement the 3 National Tools: Gold Standards Framework, (GSF) Liverpool Care Pathway (LCP) and Preferred Place of Care (PPC)

Why Dementia?

- There is currently limited research evidence about the quality of dying for people with dementia in long term care settings (nursing homes).

- Three main areas of difficulties to providing good palliative care with advanced dementia in nursing and residential homes;
  - Communication,
  - Organisation (systems)
  - Education (specialist knowledge and skills).
    - (Hughes and Robinson 2006)

Who is affected by dementia?

Approximately 750,000 people in the UK currently. Of these approximately 18,000 are under 65 years of age.

1 in 20 over 65

1 in 5 over 80

Alzheimer's type dementia makes up 55% of all cases

St Luke's Cheshire Hospice

The Evidence

"*people with dementia often die with inadequate pain control, feeding tubes in place and without the benefits of hospice care*" (Sachs et al 2004)

People with dementia have 4-6 times the mortality than those cognitively intact (Morrison. R.S., Siu. A.L. 2000)

Evidence to suggest people with dementia receive poorer end of life care (Sampson et al 2006, Ouldred., E., Bryant. C. 2008)

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People with dementia are less likely to receive palliative care and few experience hospice care
(Aminoff. B.Z., Adunsky. A. 2005, DoH 2008)

70% of hospital beds are occupied by older people

AND

50% of these experience some degree of cognitive impairment, dementia or delirium

AND

This group have worst outcomes (DOH 2009)

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Dementia is rising up the agenda

- DOH National Strategy for dementia (2007)
- Improving Services and Support for People With Dementia National Audit Office (2007)
- NICE Dementia service Guideline (2006)
- Raising the standard Royal College of Psychiatry (2006)
- Everybody's Business CSIP (2005)

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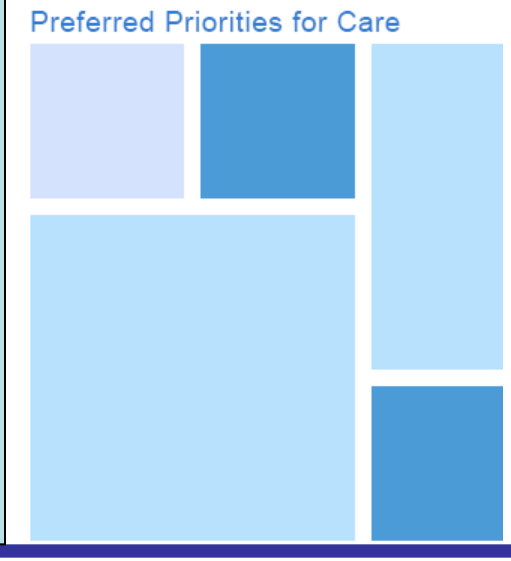
End of Life Care Tools

the gold standards framework

A locally-based system to improve and optimise the organisation and quality of care for patients and their carers in the last year of life



A hand-held document that allows the patient to record their preferences and priorities for care at the end of life

LIVERPOOL Care Pathway

Promoting best practice for care of the dying

A multi-professional document that is commenced when the team diagnose that the patient is in the last few days of life

The Gold Standards Framework

1 Aim – one chance to aim for the best for all – one **'Gold Standard'** to aspire to for ALL patients nearing the end of life

Processes of GSF – all involving improved communication

1. **Identify** patients in need of palliative/supportive care towards the end of life
2. **Assess** their needs, symptoms, preferences and any issues important to them
3. **Plan** care around patients needs and preferences and enable these to be fulfilled, in particular allow patients to live and die where they choose

The Key Tasks or 7 Cs of the Gold Standards Framework

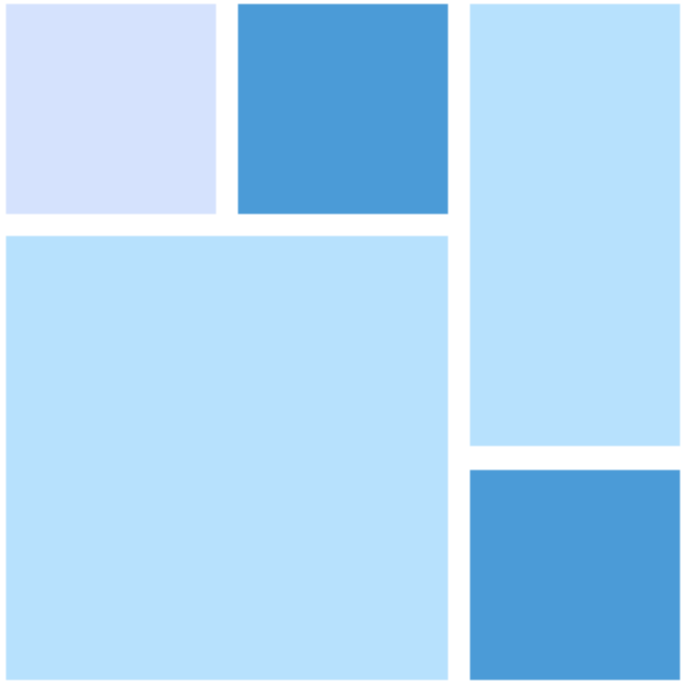
- Communication
- Co-ordination
- Control of symptoms
- Continuity out of hours
- Continued learning
- Carer support
- Care of the dying

Liverpool Care Pathway (LCP)

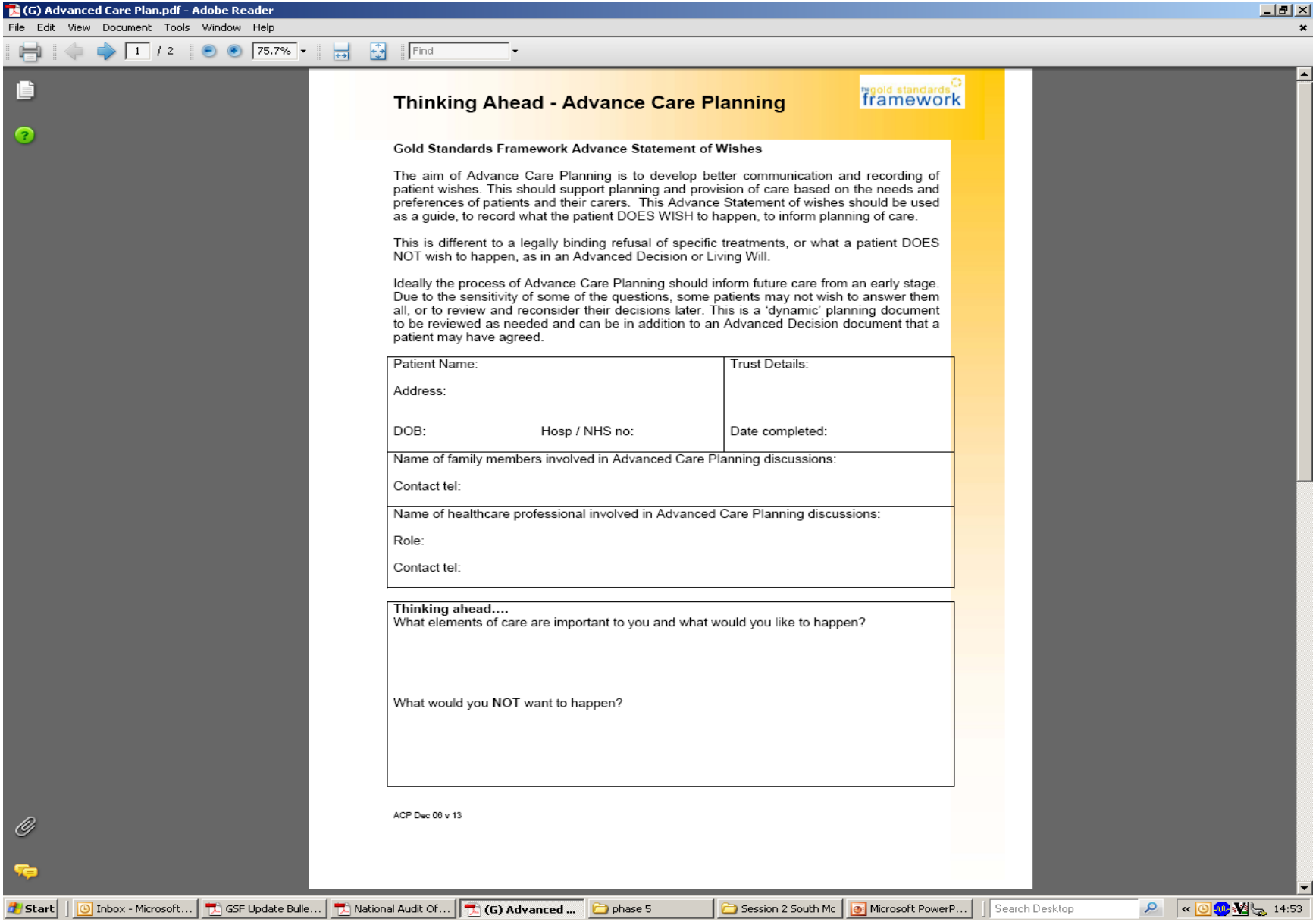
- The Liverpool Care Pathway is a holistic plan of care developed to transfer best practice in hospice care to all settings, addressing the care required in the last days/ hours of life.

www.mcpcil.org.uk/liverpool_care_pathway

Preferred Priorities for Care



GSF Thinking Ahead Document



Background

- Phased development of the GSF
- Reduce unscheduled hospital admissions
- Improve the education and training of care staff in end of life care
- Promote interprofessional working with the palliative care team / primary health care team
- Identify the disease trajectory of the patient with dementia.

Care Homes Receive a programme of education and training for all grades of staff on end of life care

Session 1	**Session 2**
•Principles of Palliative Care •Introduction to GSF •Prognostication •Dignity •Basic Communication Skills	•Holistic Assessment of Symptoms •Assessment of Pain (Dementia) •Advance Care Planning •Reducing Hospital Admissions •DNACPR/NVOD
Session 3	**Session 4**
•Diagnosing Dying •Walk through the LCP •Anticipatory Planning •Symptom Management •Case Scenarios •Bereavement Support •Spirituality	•Reflective Practice •Palliative care across all disease groups •Communication for people with dementia •Pain Assessment in dementia •Sustainability (Accreditation)

Care settings

- Recognising the dying phase
- Dementia as a terminal illness
- Use of equipment e.g. syringe drivers
- Symptom management
- Other issues such as Hydration and nutrition and pressure area care
- Who's who in the palliative care team and how they can be accessed.
- Advance Care Planning with family carers/relatives

Economic Assessment

- Reduction in the transfers to acute hospitals for palliative care.
- Dementia residents dying in a care setting increased from 48%-63%
- Increase number of patients (where expressed) died in their preferred place of death.

Carer statements

- *Molly died peacefully and at 'home'. The staff "made the difference, they knew her very well and were like part of her family….some staff came to her funeral".*

- *James - trust in the care staff and the relationship they had with her husband was the deciding factor in being able to meet his care needs at the end of life. His wife felt that James was part of the care setting 'family'.*


Quality
Quality
Quality
Quality

Recommendations

- There is a need for a sustained educational programme for all staff in LTC settings
- The need for continuity and stability of the care team – sustainability is resource dependent
- Continued data collection to confirm economic benefits of using the end of life care tools.
- Access to specialist palliative care services to support care staff
- The need for further research!

“You matter because you are you. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but to live until you die.”

Dame Cicely Saunders

1912 - 2005

Thank You

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The following is the direct link to the End of Life executive summary:
http://www.ljmu.ac.uk/BLW/BLW_Facultytopleveldocs/EoL_Report_Executive_Summary.pdf

The following is the direct link to the End of Life report:
http://www.ljmu.ac.uk/BLW/BLW_Facultytopleveldocs/EoL_Report.pdf

www.alzheimers-research.org.uk

The National Council for Palliative Care (2005) Guidance on the Mental Capacity Act 2005: Hobbs, London.
www.ncpc.org.uk