

Kim Wrigley & Elaine Horgan

Living and Dying with Dementia

“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



Where do People with Dementia Live and Die?

- Research suggests that over half (54%) of all people with dementia in the UK are resident in care homes with most people dying in long term care or hospitals
- Approximately 19% of people with dementia die at home
- It is estimated that approximately 100,000 people with dementia die each year in the UK



Gold Standards Framework (GSF)

The Gold Standards Framework is a palliative care tool developed by Professor Keri Thomas. It is a framework based on identifying palliative care patients using a team approach to assess and plan care.

A key recommendation of *'improving Supportive and Palliative care for Adults with Cancer'* (NICE 2004)

www.goldstandardsframework.nhs.uk



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

Gold Standards Framework in Care Homes



- GSF for Care Homes developed directly from the work with primary care teams during 2003-2004
- A modified version was developed for GSF in care homes based on identifying, assessing and planning care using the 7c's
- Phase 1 April- December 2004 **12 Care homes with nursing**
- Phase 2 June 2005- February 2006 **100 Care homes with nursing**
- Phase 3 June 2006- February 2007 **200 Care homes with nursing**
- Phase 4 Greater Manchester June 07 – Feb 08 **20 Care homes with nursing**
- Phase 5 North West October 08-April 09 **36 Care Homes with Nursing**



North West Care Home Model

- Identifying pilot care homes (Criteria)
- Scoping of PCT Support
- Registration of the care homes onto the National GSF Care Home Programme
- Tailored a programme of education to support the GSF model
- Incorporated implementation time theory to practice
- GSF meetings

Education Programme

• Session One	Session Two	Session Three
<ul style="list-style-type: none"> – Principles of Palliative care – GSF in Practice – Assessing palliative care needs – Case Study GSF in Practice – Communication Skills in dementia – Communication skills 	<ul style="list-style-type: none"> • Holistic Assessment of Symptoms (Total Pain) • Assessing Pain for people with dementia • PEPSICOLA • Out of Hours procedures • Significant Event Analysis using reflective practice • Advance care planning • Advance care planning communication skills training 	<ul style="list-style-type: none"> • Diagnosing Dying • Diagnosing Dying in dementia • The Care Home Experience: (walk through the pathway from a home using the pathway) • Variance Recording • Preparing for end of life care needs (Symptom management/anticipatory prescribing/sub cut medication / role of the community Macmillan nurse) • Workshops (End of Life Care Scenarios) <p>Syringe driver training to follow</p>

Uncertainty in prognosis

- It is very difficult to assess when a person stops living with dementia and starts dying from it
- 90% of PWD will have bronchitis or pneumonia as cause of death
- Developing methods of predicting the approach of death would enable better planning of care, particularly in moving from actively treating to the palliative care approach
- Prognostic indicators guidance are recommended such as are seen in the Gold Standards Framework

Dementia

- Unable to walk without assistance, *and*
- Urinary and faecal incontinence, *and*
- No consistently meaningful verbal communication, *and*
- Unable to dress without assistance
- Barthel score <3
- Reduced ability to perform activities of daily living

Plus any one of the following:

10% weight loss in the previous six months without other causes, pyelonephritis or UTI,

Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fever, Reduced oral intake / Weight loss, Aspiration pneumonia

Criteria for use of the LCP

All possible reversible causes for current condition have been considered:

The multiprofessional team has agreed that the patient is dying, and two of the following may apply:-

The patient is bedbound

Semi-comatose

Only able to take sips of fluid
tablets

No longer able to take

Signs and behaviours that suggest a patient with dementia is dying (Regnard and Hockley 2003)

- Deteriorating day by day or faster
- Increasingly drowsy or comatose
- Increasingly bed – bound
- Peripherally cyanosed and cold
- Taking increasingly little food, fluid or oral medication
- Altered breathing pattern

Common Symptoms

Below are examples of the most common symptoms experienced by people who have dementia:

- 1, 65% experience pain
- 2, 60% experience confusion
- 3, 80% experience fatigue
- 4, 60% experience depression
- 5, 70% experience incontinence



Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale : While observing the resident, score questions 1 to 6.

Name of resident :

Name and designation of person completing the scale :

Date : Time :

Latest pain relief given was.....at.....hrs.

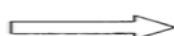
- | | |
|--|--|
| <p>Q1. Vocalisation
eg whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3</p> | <p>Q1 <input style="width: 40px; height: 20px;" type="text"/></p> |
| <p>Q2. Facial expression
eg looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3</p> | <p>Q2 <input style="width: 40px; height: 20px;" type="text"/></p> |
| <p>Q3. Change in body language
eg fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3</p> | <p>Q3 <input style="width: 40px; height: 20px;" type="text"/></p> |
| <p>Q4. Behavioural Change
eg increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3</p> | <p>Q4 <input style="width: 40px; height: 20px;" type="text"/></p> |
| <p>Q5. Physiological change
eg temperature, pulse or blood pressure outside normal limits,
perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3</p> | <p>Q5 <input style="width: 40px; height: 20px;" type="text"/></p> |
| <p>Q6. Physical changes
eg skin tears, pressure areas, arthritis, contractures,
previous injuries
Absent 0 Mild 1 Moderate 2 Severe 3</p> | <p>Q6 <input style="width: 40px; height: 20px;" type="text"/></p> |

Add scores for 1 - 6 and record here



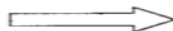
Total Pain Score

Now tick the box that matches the
Total Pain Score



0 - 2 No pain	3 - 7 Mild	8 - 13 Moderate	14 + Severe
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Finally, tick the box which matches
the type of pain



Chronic	Acute	Acute on Chronic
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Research

“Patients with end stage dementia had a number of symptoms for which they did not receive effective palliative care - analgesia was infrequently used, dying phase not recognised and some people given antibiotics inappropriately in the last days of life”

Lloyd – Williams and Payne, 2002



Findings from Evaluation JMLU

- A reduction in unscheduled hospital admissions at the end of life
- Breaking bad news to families –the importance of good communication skills
- Diagnosing dying in a resident with dementia- the challenges and benefits
- The value of the multi disciplinary team discussion
- Symptom assessment and management with residents who are unable to verbally communicate -the challenges and benefits

Achievements

Staff from local acute trust buddying staff in a local mental health trust to provide end of life care out of hours.
Ensuring a patient died in familiar surroundings with familiar staff

13 care homes who have completed the North West care home programme have now gained accreditation with the National GSF team

Local staff from the care homes involved in the National GSF programme have gone on to deliver session on the education programme for future homes. After completing the train the trainer syringe driver course 1 care home now provides syringe driver training to other local care homes and holds a supply of syringe drivers specifically for care homes in their PCT



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)



NICE Clinical Practice Guideline

Dementia 2006

- Health and social care professionals should incorporate a palliative care approach from the time of diagnosis until death for people with dementia
- They should consider physical, psychological, social and spiritual needs to maximise the quality of life of the person with dementia and their family
- Palliative care professionals, other health and social care professionals and commissioners should ensure that people with dementia who are dying have the same access to palliative care services as those with dementia
- Primary care teams should ensure that the palliative care needs of people with dementia who are close to death are assessed and that the resulting information is communicated within the team and with other health and social care staff



Key points

- All professionals need to be aware of and be able to manage dementia as a significant co-morbidity in a range of conditions
- Sharing knowledge, expertise and skills between different professional groups for patient benefit
- The incidence and prevalence of dementia is increasing with the ageing population so we need to address this now
- Unpaid carers still deliver much of the care for people with dementia
- Palliative care models developed for people with cancer may well not be appropriate for those with dementia



The End of Life Care Strategy July 2008

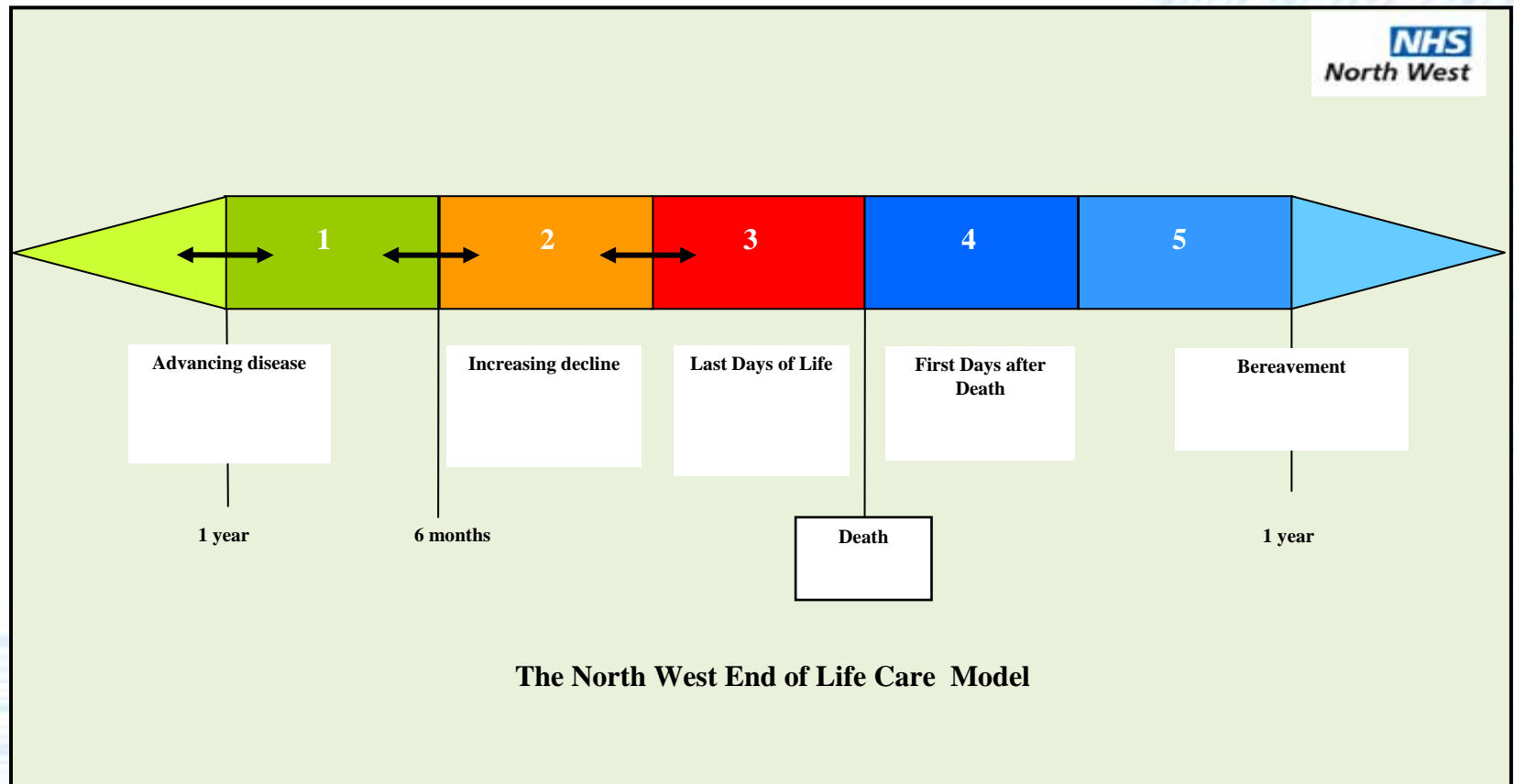
- **The Strategy**
 - Covers all conditions
 - Covers all care settings (e.g. home, hospital, hospice, care home, community hospital, prison etc)
- Has been developed within the current legal framework



Points for a Commissioner

- It is vital that PCT'S appraise themselves with data/costs relating to people with dementia and place of death. In particular where this occurs in hospital.
- PCT support for care homes is a vital part of successful implementation for world class end of life care.
- Proactive commissioning is needed that focuses on the patients journey as a pathway as recommended in the next stage review.
- Financial investment in substantive posts, dedicated to supporting end of life care and development is required to continue to build on the implementation of the end of life care tools.

The North West End of Life Care Model



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Thank You

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