Understanding the palliative care needs of people with dementia

18 January 2007

Introduction to the discussion document

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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.
- The incidence and prevalence of dementia is increasing with the ageing population so we need to address this now.
- Unpaid carers deliver 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.

Prevalence of Dementia by Age

Age	Prevalence
40 – 65	1 – 1000
65 – 70	1 – 50
70 – 80	1 – 20
80 +	1 - 5

Between 50-60% of care home residents will have dementia

Estimated Numbers of People with Dementia in the UK

England	652,600
Scotland	63,700
Northern Ireland	17,100
Wales	41,800
Total	775, 200

It is estimated that by 2010 there will be about 870,000 people with dementia in the UK and that this is expected to rise to over 1.8 million people with dementia by 2050.

Access to Specialist Palliative Care

	2004/5	1996/7
Hospital Support	11%	5%
Day Care	8%	6%
Home Care	5%	3%
Inpatient	5%	

(MDS Access Data)

Where do people with dementia live and die ?

New research* suggests that over half - 54% - of all people with dementia in the UK are resident in care homes

•According to this research this amounts to 368,000 people.

•Implications: by 2039, over a million care home places would be needed to satisfy demand unless there is a change in care patterns – almost certainly unsustainable, given the recent fall in places.

•Conclusion: main function of longstay care for old people is now to provide for advanced cases of dementia, with cosequent requirements for improvement in staff ratios and training.

Macdonald, A & Cooper, B. Long-term care and dementia services: an impending crisis; Age and Ageing, 15 December 2006 pp 1 – 6.

Making the Case for Palliative Care Need at Population Level

Age Bands	65 to 74	75 to 84	85+
Cancer			
Number of deaths	33305	43330	20474
Number with dementia	977	3800	5951
% with dementia	2.90%	8.80%	**29.10%**
Circulatory			
Number of deaths	31548	71469	67962
Number with dementia	941	6319	19992
% with dementia	3.00%	8.80%	**29.40%**
Respiratory			
Number of deaths	9615	21019	18239
Number with dementia	283	1817	5224
% with dementia	2.90%	8.60%	**28.60%**

Making a Case for Palliative Care Need at an Individual Level

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 last days of life. (Lloyd-Williams and Payne, 2002)

Uncertainty in prognosis

- It is very difficult to assess when a person stops living with dementia and starts dying from it
- Important that services do not use expected length of life as part of their eligibility criteria if they are to meet the need of people with dementia.
- Developing methods of predicting the approach of death would enable better planning of care, particularly in moving from actively treating to the palliative approach
- Recommend that checklists of clinical indicators for those who would benefit from a palliative approach eg GSF paper
- Important that these tools are used in all care settings. Gold Standards Framework includes such a checklist and we support the drive to increase uptake of this programme.

General Predictors of End Stage illness [1]

- Multiple co-morbidities (with no primary diagnosis)
- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reduced performance status / Karnofsky score (KPS) < 50%
- Dependence in most activities of daily living (ADL's)

Frailty [7]

- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating Karnofsky score
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, self reported exhaustion

Dementia

- Unable to walk without assistance, and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication, and
- Unable to dress without assistance
- Barthel score < 3 [8]

Plus any one of the following:

10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fevers, Reduced oral intake / weight loss, Aspiration pneumonia

Swallowing, Eating and Drinking

- 80% of people – eating difficulties.
- Artificial feeding neither reduces the risk of aspiration pneumonia, infections, pressure sores or malnutrition.
- Incidence of depression high in advanced dementia. Psychosis in up to 40%. Behaviour disturbance in up to 90%.

Communication & Assessment

- Communication with people with late stage dementia will be a challenge but it is possible
- Research and experience demonstrate that it is possible and worthwhile to communicate with people in the later stages of dementia
- Communication may be in forms that are not verbal and/or difficult to interpret. The time and skill to interpret cues is therefore vital.
- With regard to accuracy it is crucial to understand that to the person with dementia what they are saying or communicating is true and is an expression of their feelings or experience
- It will be a challenge but it is essential to focus on the meaning behind the words
- ?MCA

Supporting relatives

- Carers of people with dementia experience greater strain, distress and higher levels of psychological morbidity than carers of other older people
- Early and ongoing discussions around end of life care between staff and family are essential
- Although uncertainty is a common feature of dying with dementia, ‘not knowing’ is something carers find particularly hard to deal with
- Good palliative care relies on active listening to everyone involved and including family and carers in decisions about care
- It is also important that staff help carers to understand that while their views will be considered they do not have responsibility for end of life decisions
- Carers need access to:-
  - An ‘information prescription’ – signpost carers to sources of info and advice
  - Short-term, home-based emergency respite care
  - An expert carers programme

Care co-ordination

•In order to support the seamless provision of the care package the key worker model should be explored. This would then provide one key contact for patients and carers, a need frequently highlighted by the Alzheimers Society membership

•NICE clinical guideline on supportive and palliative care recommends that nominating a person to take on the role of ‘key worker’ to coordinate care should be developed in whichever location the individual was being cared for

Sharing the Care & Learning

- High proportion of people with a variety of conditions experiencing dementia highlights need for all generalists and specialists to understand and manage dementia.
- Way forward is to enable people to be where they wish to be so need to share training and care
- Its not about specialist palliative care doing it all but involves:
  - All care settings including housing, care homes, hospitals
  - All professional carers