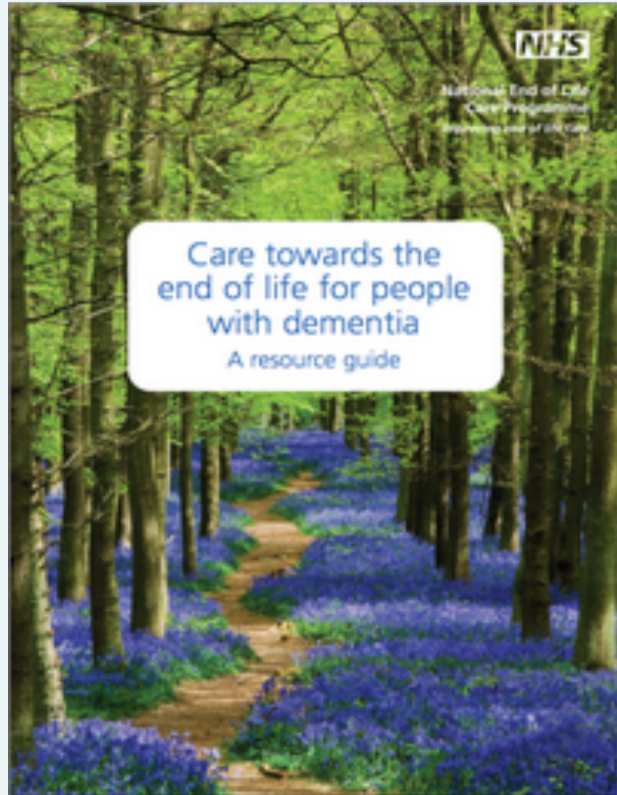


# Dementia & End of Life Care - Project Report -

## Background

The National report 'Counting the cost: caring for people with dementia on hospital wards' (Alzheimer's Society 2009) revealed that outcomes for patients with dementia who are admitted to hospital are poorer than for those admitted for the same reason, but without dementia. Factors include increased length of stay, decreased chance of survival after 6 months, increased chance of discharge to a nursing home, and increasing physical dependence.

In this study 47% of carers reported significant physical deterioration in their relative: weight loss, malnutrition & dehydration, constipation, incontinence, pressure sores & poor mobility were mentioned frequently. The psychological impact of the admission was also mentioned frequently including increased confusion, distress, loss of confidence. This dissatisfaction resulted in 35% of relatives complaining about the care.

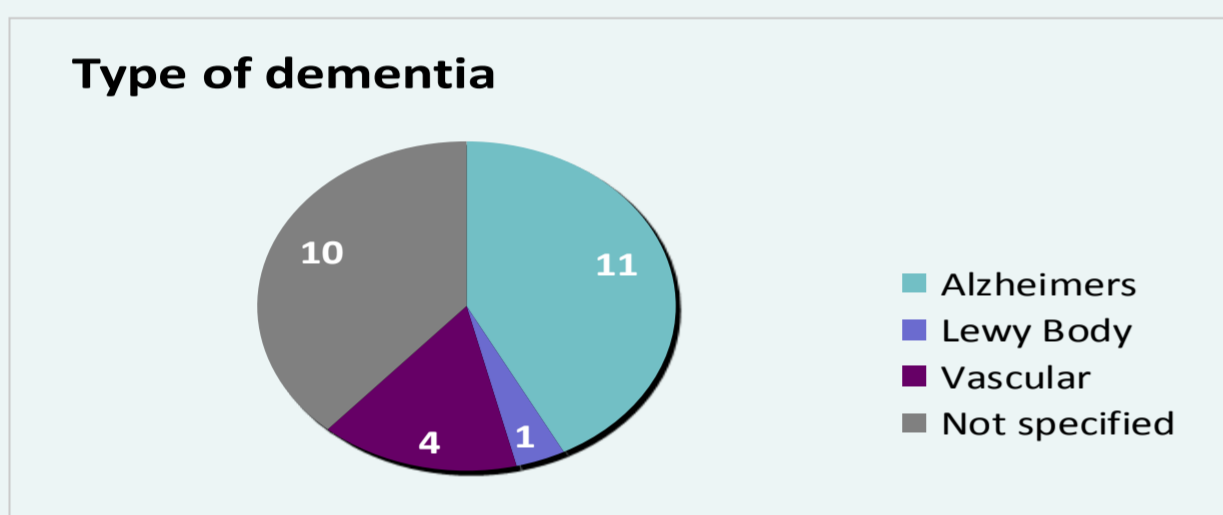


Similarly the National End of Life Care Programme in their report 'Care towards the end of life for people with dementia' (2010) stated "The last few months of life for a patient with dementia are often dominated by pain and distress; physical deterioration and malnutrition; frequent, ineffective and costly admissions to hospital; and an absence of dignity and choice".

It was with this background and commitment to improve dementia care within Stepping Hill Hospital and more equitable access to palliative care where appropriate for patients with dementia that a case note review was undertaken.

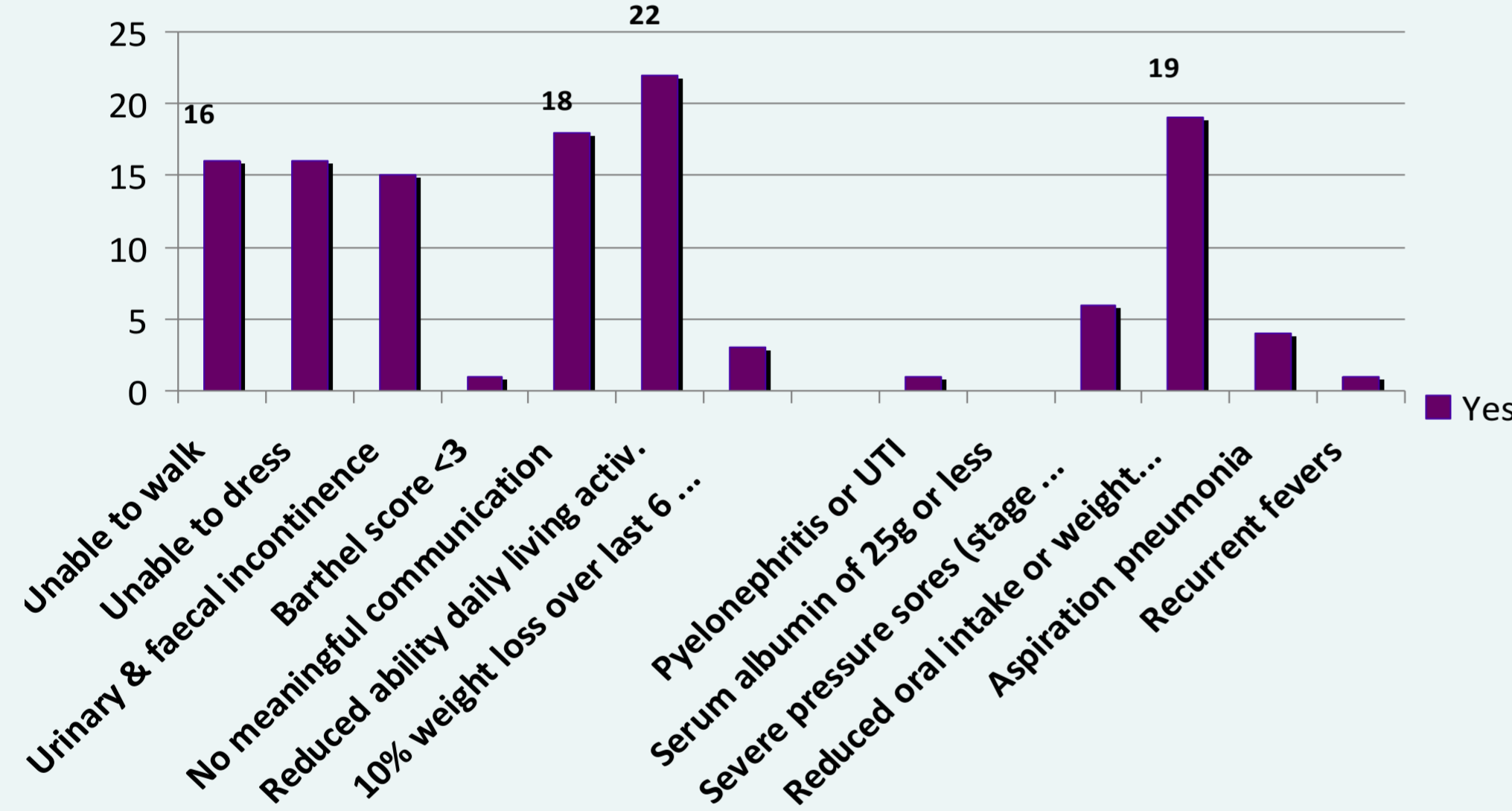
To undertake the audit a facilitator post was created as part of Stockport Palliative Care team and funded as part a Greater Manchester dementia demonstrator site.

26 case notes (patients from Blue Bell, E3, E2, A10, A11, B2, B3, B4, B6, MAU)



Average age of the patients was **85 years** (range 72 – 93 years).

### Recording of specific prognostic indicators in patient notes



## Recommendations

### Use of Prognostic tools

- ❖ Use of prognostic tools to potentially better inform end of life care decisions.
- ❖ Multi-disciplinary team discussions & consideration of all co-existent conditions when discussing patients with dementia can contribute to better quality of care in the last year of life. See [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

### Use of palliative care register for patients with dementia

- ❖ Refer patients with dementia who are in the last year of life to electronic palliative care register →include reference to GSF in hospital discharge letter to GPs.

### Advanced care planning

- ❖ Advance Care Planning: at the right time and in the right way, documented & communicated.
- ❖ Everybody's responsibility.

### Actions undertaken following the audit

- 'Dementia Care in the last year of life' training package developed for E2, E3, A10, A11, M4 and Bluebell.
- Recruited and supported dementia champions in establishing their role and developed training package for the champions.
- Developed and published careful feeding guidelines.
- Updated dementia and end-of-life microsites with various documents.
- Promoted use of Abbey Pain score on the wards.
- Promoted advanced care planning on the ward.

## Results

### Standards included in the audit

#### 1. Prognostic Indicators

To identify if evidence of 'end of life' was being recognised in patients with dementia, and if any reference was made in patient notes to prognostic indicators.

#### 2. Supportive & Palliative Care Register

To rationalise the referral of patients with dementia from hospital to the electronic palliative care register in primary care.

#### 3. End of life care principles.

To identify the degree to which the principles of good end of life care were being used for patients with dementia who are dying in hospital.

#### 4. Advance Care Planning.

To identify Advance Care Planning initiatives, and how they may impact on achievement of the patient's preferred place of care.

#### 5. Carers Communication

To identify the degree of involvement and communication with families/ carers when a patient with dementia is dying in hospital.

### Diagnosing dying

One patient was recognised by the family and the FY2 doctor to be in the dying phase of their illness on 27.11.12.

The Care pathway for the dying patient was not commenced until 6 days later on 03.12.12. During the interim it was written in the notes three times: "family recognising patient is dying"; "Granddaughter (GP) requested LCP"; "She wouldn't want to go on like this"

### Headline results

**Co-morbidities** alongside dementia were evident in this population.

84% (22 patients) were admitted from a **care home**, 6 lived at home (2 alone)

20 out of 26 (77%) were indicated as being '**advanced dementia**', but no specific staging tool was referred to in the notes.

**No evidence** that any of the patients were on the **supportive palliative care register** in GP practice at the time of admission. Stockport Specialist Palliative Care Team was involved with 1 of the 26 patients, and this person had cancer and intractable pain.

Of the expected deaths (n=23) **78% of patients had the Liverpool Care Pathway** for the dying patient in place during the last days of life.

**None** of the patients within the case note review had evidence on admission of an **Advance Care Plan**, or evidence that on admission preferred place of care and preferences for care towards the end of life had been discussed. 2 patients however did have some evidence of ACP discussions during hospital stay, these discussions were in the last days of life.

**DNACPR** decisions were made in 22 of the 26 cases, and for 15 of these patients it was documented in the medical notes that discussions with the family had taken place. There was often a **delay between the DNACPR decision and the discussion**. Discussions were more often with family due to the capacity of the patient being absent.

**End of life drugs** were usually prescribed, however it was noted that medication for pain and agitation was administered more frequently than any other end of life care medication.

### Cause of death

In 50% of the cases the primary cause of death was noted as urosepsis or pneumonia; another 20% (5) had sepsis recorded as secondary cause of death. Making the total deaths from sepsis **70%**.

**Among the case notes there were 5** diagnoses of cancer, though only 1 was recorded as primary cause of death. 3 deaths (cardiac arrest, pulmonary embolus and ischaemic bowel) were classified as sudden. 69% of the patients in this review had dementia as either primary or secondary cause of death. 4 patients had the **primary cause** of death as dementia (15%), and another 14 patients (54%) had dementia listed as **secondary cause** of death.

**Case Study:** 86 year old gentleman, CA prostate & dementia, admitted for pain control. Referred by ward staff to Blue Bell Ward as 'dying' and Care Pathway for the dying patient was suggested. Seen by Specialist Palliative Care team and decision made that patient was "not dying imminently".

**Continued interventions during last 72 hours of life:** arterial blood gas sampling, Speech & Language assessment, cardiac nurse, catheterizations, intravenous antibiotics, NG, X-ray. Moved to Bluebell 10 days later and died after < 24hrs in Bluebell. Care Pathway for the dying patient not in place to manage care in last days.

### Carers communication

- ❖ Involvement of carers in decision-making.
- ❖ Better information for carers on possible disease trajectory for patients with dementia, in order to inform realistic decision-making and accommodate patient preference.

### Other recommendations

- ❖ Guidelines and training for staff & carers around appropriate feeding, hydration & pain management for dementia patients in the last year of life.
- ❖ Dementia training integral to Trust's workforce development plan, to support all levels of staff to deliver high quality care in this challenging area.
- ❖ Dementia-friendly environments: wayfinding, orientation, reminiscence activities, avoiding unnecessary ward moves, use of side rooms for dying patients.
- ❖ Repeated highlighting of 'dignity in care'
- ❖ Increased professional and public awareness of dementia as life-limiting illness for which palliative care principles are highly relevant.

### References

National Dementia Strategy (Department of Health, 2009)  
Commitment to the care of people with dementia in hospital settings (Department of Health & RCN, 2011)

Care towards the end of life for people with dementia (National end of life care programme, 2010)  
the cost: caring for people with dementia on hospital wards (Alzheimer's Society, 2009)  
Gold Standards Framework [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

My life until the end: Dying well with dementia (Alzheimer's Society, 2012)  
**INTRANET Stockport Prognostic Indicator Guide**  
**INTRANET Microsites for End of Life Care, Dementia**  
Acknowledgements: Stockport Specialist Palliative Care Team