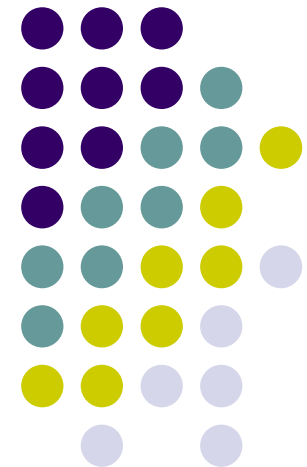


# EVIDEM End of Life Care: Recognising and supporting end of life care for people with dementia living in care homes

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# Aim of EVIDEM eol



**To understand the need for support and end of life care of older people with dementia living in care homes**

- To describe the different characteristics and pathways to death of people with dementia (pwd)
- To describe how end of life is assessed and how context and models of care influence an older person's experience of end of life care
- To describe implementation of existing support tools, and access and use of services.
- To develop educational support tools

# Background



## Evidence suggests that:

- Compared to other patient groups pwd receive less pain relief and fewer medical services
- Decisions to forgo hospital admission are not made till death is imminent
- Carers experience prolonged loss, including loss of choice and control when someone moves to a care home or hospital ( do need a “goodbye” moment).
- Some adapted palliative care tools help reduce admissions to hospital at the end of life.

# Recognising when someone is dying with (or from) dementia



- 883 older people with dementia <1% recorded as having a life expectancy of < 6m but 71% died during that period (Mitchell et al 2004)
- There are prognostic indicators (e.g. age, global deterioration, dehydration, anorexia, loss of function) but little consensus on the reliability and predictive validity of the different indicators
- Difficult to discriminate between the impact of underlying morbidities, different disease trajectories and dementia



# Dementia Diagnosis

| Care Home (n=133) | % dementia recorded in notes |
|-------------------|------------------------------|
| 1 (N=20)          | 80.0 (16)                    |
| 2 (N=25)          | 56.0 (14)                    |
| 3 (N=16)          | 81.3 (13)                    |
| 4 (N=23)          | 100.0 (23)                   |
| 5 (N=34)          | 55.9 (19)                    |
| 6 (N=15)          | 86.6 (13)                    |

- 73.7% of residents at baseline had dementia recorded in their notes.
- For 35.7% of these the type of dementia was not stated
- Not always clear from notes if the person had received a formal diagnosis of dementia
- AD most commonly recorded (38.8%), followed by Vascular Dementia (16.3%)



# Resident Health Status

| Care Home<br>(n=133) | Mean no. Of Long<br>Term Conditions,<br>(SD) | Mean no. Of<br>acute conditions,<br>(SD) |
|----------------------|--|--|
| 1 (N=20)             | 2.55 (1.19)                                  | 0.65 (0.99)                              |
| 2 (N=24*)            | 2.70 (1.47)                                  | 0.29 (0.86)                              |
| 3 (N=15*)            | 1.67 (1.40)                                  | 0.40 (0.63)                              |
| 4 (N=23)             | 1.96 (1.30)                                  | 0.17 (0.65)                              |
| 5 (N=32*)            | 2.97 (1.51)                                  | 0.16 (0.57)                              |
| 6 (N=15)             | 2.07 (1.39)                                  | 0.20 (0.56)                              |

Most commonly recorded long term conditions in care notes were heart disease, arthritis & depression



# Post-Death Analyses (PDAs)

- **3 Components:**
  - Interview guide used with relevant staff member, developed from GSF ADA tool
  - Final care note review from last time point to time of death
  - Medications for last month of life where possible
- **Prompts included:**
  - Surprised?
  - Crisis events
  - Symptom recognition
  - Positives/Negatives

# PDAs: Care Note Reviews

## Symptom Recognition



- Twenty-six deaths to date since start of phase one collection (approximately 20% of sample)
- Most commonly recorded symptoms at point of death were:
  - Increased sleepiness
  - Shortness of breath/breathing difficulties
  - Decreased appetite
  - Decreased mobility
- Pain mentioned in 4 deaths

# Care Note Reviews

## Use of NHS Services



- 16 admitted to hospital at least once in previous year & 7 of these returned and later died in the care home
  - Recorded reasons for hospital admissions included:
    - UTIs
    - Chest Infections
    - Falls
    - Stroke
    - Possible TIAs
- Increased GP visits & OoH
- 11 died out of hours
- Causes of death largely unknown by Care Home

# Care Note Reviews Advanced Care Planning



- All six care homes do not use formal advance care planning
- Preferred place of death only recorded for 12/25 deaths
- Of the 26 people who died, 16 died in the care homes
- A further 6 were either transferred to a nursing home & lost to follow up
- 10 recorded as surprised by death, 1 initially surprised but 'no' after reflection

# Discussions around EOL wishes



| Level of ACP involvement        | Care Home (no. & % within care home ID) |            |           |           |            |           | Totals (%) |
|---------------------------------|---|------------|-----------|-----------|------------|-----------|------------|
|                                 | 1 (N=12)                                | 2 (N=24)   | 3 (N=12)  | 4 (N=22)  | 5 (N=29)   | 6 (N=15)  |            |
| <b>N=114 (15 missing cases)</b> |   |            |           |           |            |           |            |
| Res & Cons & Family**           | 2 (16.7%)                               | 2 (8.3%)   | 1 (8.3%)  | 2 (9.1%)  | 0 (0.0%)   | 1 (6.7%)  | 8 (7.0%)   |
| Res & Cons only                 | 0 (0.0%)                                | 1 (4.2%)   | 0 (0.0%)  | 1 (4.5%)  | 1 (3.4%)   | 0 (0.0%)  | 3 (2.6%)   |
| Res & Family only               | 0 (0.0%)                                | 0 (0.0%)   | 0 (0.0%)  | 6 (27.3%) | 0 (0.0%)   | 0 (0.0%)  | 6 (5.3%)   |
| Cons & Family only              | 0 (0.0%)                                | 2 (8.3%)   | 1 (8.3%)  | 3 (13.6%) | 5 (17.2%)  | 3 (20.0%) | 14 (12.3%) |
| Family only                     | 2 (16.7%)                               | 0 (0.0%)   | 2 (16.7%) | 1 (4.5%)  | 4 (13.8%)  | 2 (13.3%) | 11 (9.6%)  |
| Cons only                       | 5 (41.7%)                               | 11 (45.8%) | 7 (58.3%) | 7 (31.8%) | 16 (55.2%) | 7 (46.7%) | 53 (46.5%) |
| Res only                        | 1 (8.3%)                                | 3 (12.5%)  | 1 (8.3%)  | 1 (4.5%)  | 0 (0.0%)   | 0 (0.0%)  | 6 (5.3%)   |
| No discussion                   | 2 (16.7%)                               | 5 (20.8%)  | 0 (0.0%)  | 1 (4.5%)  | 3 (10.3%)  | 2 (13.3%) | 13 (11.4%) |

# Communication issues NHS staff



- Inconsistencies around use of palliative care frameworks (e.g. DN accounts and Care Home accounts)
- Care homes often not informed when people die in hospital by the hospital staff
- GP makes clear on medical notes if resident is dying but not communicated to care home staff
- Pain management (Shipman effect)

# Communication issues NHS staff continued



- Parallel vs. collaborative working
- GPs are the ultimate decision makers around eol care
- Anecdotal evidence that decisions around medications are not communicated to CHs
- Interviews with some GPs and DNs have made them ‘think more’
- Procedure or best interests?



## Phase two

- 9 month intervention with 3 care homes
- Intervention for integrated working between NHS and care home staff to support end of life care for people with dementia
- Participatory approach informed by findings from phase one



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