A good death with dementia

Dr Juliette Brown
Dr Cate Bailey
East London NHS Foundation Trust;
for NHSE London End of Life Clinical Network
Key messages:

20 – 30 % of us dying over 65 will die with dementia

Dementia deaths are different – frailty, immobility, dependence

90% of deaths are in care homes and hospitals

Half are outside of usual place of residence

Planning is poor, as is symptom control

Simple things make a difference

Intelligent commissioning: service standard checklist
Dementias

Progressive, terminal, neurodegenerative diseases

Affecting 835,000 people (UK) 67,000 (London)

Planning ahead is difficult

Capacity lost

Behaviours that challenge demand specific skills

Communication

Dependence, incontinence, nutritional issues, immobility, pain, agitation, distress, superimposed delirium

Somebody has to decide about treatment thresholds – more or less effectively and compassionately
Clinical course of the dementias

Alzheimer’s Society 2014

Health status

Crisis

Decline

Death

Time

Dementia

Cancer (typical)
Different disease, different models of care

Good end of life synonymous with good dementia care, but:

‘Dementia is still not regarded as a terminal condition’

Symptom burden persists

Dementia doesn’t fit standard palliative models or hospice models

Good EoL in dementia follows strong local leadership, co-ordinated and integrated services

In-reach to care homes – can work and can contribute to admission avoidance

Hughes, JC, Volicer, L and van der Steen, JT (2018)

Complexity and gaps: The high-hanging fruit of dementia and palliative care research Palliative Medicine Vol 32 (3) 591-593
‘People living with dementia die with dignity in a place of their choosing’
Figure 1. Dementia or Cognitive Impairment by Age at Death with 95% CIs

http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0030397
Dying with dementia

1/3 over 65 die with dementia \(^2\) 6% of 65 – 69 and 40% of 85-89

ONS: 18% of all deaths over 65 years (72,504 people in England in 2014) Leading cause of death for women; 2\(^{nd}\) leading cause of death for men; 15.4% of women who died in 2016 in the UK; 8.0% of men

Estimate of 25% of people in acute hospital have dementia at any one time

In 2016/17: 57% of PwD in London had an inpatient admission\(^1\)

Dementia in 56% of residential home population, 77% of nursing home population \(^3\)

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1 Public Health England, Dementia Profile; NHSE, 2016; 2 Brayne et al, 2006; 3 Stewart et al, 2014
90% die in care home or hospital

In 2014, 73,189 died with a mention of dementia in England (PHE national dementia and EOLC intelligence network)

<table>
<thead>
<tr>
<th>Place of death</th>
<th>% deaths with dementia (65+)</th>
<th>% all deaths (65+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care home</td>
<td>58%</td>
<td>25%</td>
</tr>
<tr>
<td>Hospital</td>
<td>32%</td>
<td>49%</td>
</tr>
<tr>
<td>Hospice</td>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>Home</td>
<td>8%</td>
<td>21%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Respiratory disease (38%), circulatory disease (36%) and cancers (9%) were mentioned for deaths with a mention of dementia, respectively.
In London

Place of death 2016 – Dementia 65+

(PHE national dementia and EOLC intelligence network)

<table>
<thead>
<tr>
<th>Place</th>
<th>London</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>42.1%</td>
<td>30.9%</td>
</tr>
<tr>
<td>Home</td>
<td>13.5%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Care Home</td>
<td>42%</td>
<td>57.6%</td>
</tr>
</tbody>
</table>
Not often in usual place of residence....

% Deaths in Usual Place of Residence- dementia 65+ 2016
London – trend in place of death (%)
People in London with dementia die in care homes and hospital <50% in UPR
UPR proxy for PPD
Aim: move EoL care out of hospitals and improve EoL care in care homes
‘People living with dementia die with dignity in a place of their choosing’
Pain, agitation, distress

Prospective cohort study in nursing home in London with 85 participants

Pain (11% at rest, 61% on movement) and significant agitation (54%) common and persistent. Aspiration, dyspnoea, septicaemia and pneumonia increased.

People with advanced dementia lived with distressing symptoms. Service provision was not tailored to their needs.

Care homes acting as hospices without hospice level care, poorly served by secondary healthcare services; GPs not supported by specialist services. Longitudinal multidisciplinary input could optimise symptom control and quality of life.

How to improve?
A Tale of Two Bettys
Betty 1

- 85 year old retired machinist living alone
- Son lives a long way away, but is concerned about Betty’s cognition
- Betty falls and NOF → hospital
- Develops delirium, unsafe to go home, placed in care home
- Discharge summary suggest referral to DMC
- No regular care home GP (duty doctor system), doesn’t get referred to DMC
- Staff complete admission process but can’t speak to son initially and aren’t sure what to complete in terms of care preferences
- Remains confused over next year or so, sometimes worse when has UTI, becoming less mobile, often appearing to be in pain when staff wash or dress
- Staff note coughing after eating but no SALT available
- Develops chest infection (secondary to aspiration) and is transferred to hospital
- Discharged from hospital with advice on risk feeding and decision that she would not be appropriate for ITU or resuscitation but unclear if this has been discussed with NOK
- 2 months later becomes drowsy and febrile again → no GP available to review, staff not sure what to do so she is transferred to hospital and dies in hospital from aspiration pneumonia
Betty 2

- 85 year old retired machinist living alone; son lives a long way away, but speaks to local GP about referral to DMC
- Diagnosed with Alzheimer’s dementia and meets with staff for ACP and makes an LPA
- Lives at home with care package TDS until #NOF
- Decision in hospital with son to move to care home after discharge
- Care home reviews all existing ACP paperwork, CMC documentation and preferences with son (LPA)
- Dementia diagnosis documented in care home paperwork
- Care home has good relationship with local GP and monthly MDT with geriatricians, SALT, physio, palliative care nurses
- 6 months in care home—becoming frailer, mostly bedbound but also resistance to personal care managed with increased analgesia before hoisting, pressure relieving mattress arranged. Identified in MDT as approaching last 6 months of life and unnecessary medications are reviewed and stopped
- 2 months later – noted to be coughing after food → discussion with SALT and son and agreement for “at risk” feeding
- 3 months later – “chesty cough” and increased confusion – treated with PO antibiotics by GP after review of preferences and discussion with LPA (preference not to be admitted to hospital), palliative drugs prescribed. Recovers though increasingly frail.
- 1 month later – again “chesty cough” and very drowsy (unable to take anything PO). GP visits, discusses with palliative care nurse and palliative drugs prescribed, preferences again reviewed, visited by priest and son
- 2 days later dies peacefully in care home
Treating pain, distress, attending to nutrition and hydration, mobility and the person

Observe and actively treat pain - PAINAD and Doloplus-2 are recommended by BGS. Regular analgesia - not prn

Educate to understand behaviours – aggression, agitation - in context (ABC, PIECES) and give person centred care

Maintain function; pressure care; falls prevention; contracture prevention

Gain access to physiotherapy and equipment;

Understand appetite changes (recognition and concentration) swallowing and chewing

Recognise decline and delirium

Use Gold Standards Framework
Care planning and CmC

Early ACP at diagnosis involves discussion on prognosis and natural history of dementia

Early ACP aims at involving people in decisions

Later ACP aims at using information held, and best interests to maximise quality of life and later, comfort

Care planning is a process; promotes data sharing

Use CmC for dementia care planning - now integrates with EMIS, visible to 111 and LAS

Potential to upload ‘this is me’ with care plan

11,329 people living with dementia have a CMC record

Early use of CMC likely to promote better care and better co-ordination of care
How to improve?
case find, care plan, treat symptoms, recognise deterioration, understand needs, support staff and families
Simple things that make a difference?

MDT in care homes – monthly GP / pharmacy / geri + psych - found to reduce admissions

Case find (Dear GP and DiaDEM), Education on recognition of delirium, on hydration and nutrition

Support in care planning, treatment of symptoms

Proactive analgesia, reduce polypharmacy (STOPP/START)

ACP / Co-ordinate my Care

In-reach from specialisms

Understanding the OOH options

Compassion (UCL Marie Curie Care), IDEAL, CHALLENGE (Cardiff and Marie Curie PC Research Centre) – described as ‘hospice enabled’

Start with the bigger homes, those with proactive GP, those with the most admissions

In reach to care homes (and home)
Avoid admissions and
Aim for a better death in UPR
### Commissioning checklist

<table>
<thead>
<tr>
<th>Measure: Diagnosis rates</th>
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<tbody>
<tr>
<td>Measure: CmC</td>
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<tr>
<td>Measure: Care home provision</td>
</tr>
<tr>
<td>Provide: MDTs to care home and at home</td>
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<tr>
<td>MDT assessment includes:</td>
</tr>
<tr>
<td>• LPA / ACP / CmC / patient centred</td>
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<tr>
<td>• Anticipatory care plan / crisis plan / OOH support / goals of care</td>
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<tr>
<td>• Medication review and proactive analgesia</td>
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<tr>
<td>• Understanding behaviours</td>
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<tr>
<td>• Recognising delirium</td>
</tr>
<tr>
<td>• OT, PT, SALT, dietician</td>
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<tr>
<td>• Inreach / access palliative specialist and access to geri / psych in-reach</td>
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<tr>
<td>• Family engagement; spiritual and psychological</td>
</tr>
<tr>
<td>• Education / carer support / staff development</td>
</tr>
<tr>
<td>• Leadership</td>
</tr>
<tr>
<td>• Facility for regular review and recognition of change</td>
</tr>
<tr>
<td>Measure: Inpatient admission / avoidance</td>
</tr>
<tr>
<td>Measure: Death in UPR</td>
</tr>
<tr>
<td>Measure: satisfaction with EoL care</td>
</tr>
</tbody>
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Key messages:

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Planning is poor, as is symptom control

Simple things make a difference

Intelligent commissioning
References

Alzheimer's Society (2014) Living and dying with dementia in England: Barriers to care


NHS England 2016 Dementia Well Pathway

NHS England 2016 Enhance Health in Care Homes Framework


Accessing data, guidance, tools

https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#

NHS Transformation Framework
NICE, DoH, NHSE, Dementia Partnerships
EAPC recommendations
OECD / WHO framework
We have identified ten key objectives of dementia policy for countries to consider:

1. **Risk reduction**
   - The risk of people developing dementia is minimised
   - First symptoms appear

2. **Diagnosis**
   - Dementia is diagnosed quickly once someone becomes concerned about symptoms

**Progression of dementia**

**Early dementia**
- Living in the community and relying on informal care
  - Communities are safer for and more accepting of people with dementia
  - Those who wish to care for friends and relatives are supported

**Advanced dementia**
- Greater need for formal care services and specialised accommodation
  - People living with dementia live in safe and appropriate environments
  - People living with dementia can access safe and high quality social care services

**End of life**
- End of life care for people with dementia presents specific challenges
  - People living with dementia die with dignity in the place of their choosing

**Care coordination and the role of technology**
- Care is coordinated, proactive and delivered closer to home
- The potential of technology to support dementia care is realised
Standards

NICE - Dementia: supporting people with dementia and their carers in health and social care Clinical guideline [CG42] September 2016 – palliative approach from diagnosis, needs assessment at EoL, carers support, symptom control

NICE – Dementia: support in health and social care Quality standard June 2010 - involved in decisions, assessed by primary care at EoL

NICE - Care of dying adults in the last days of life NICE guideline [NG31] December 2015

DoH - End of Life Care Strategy 2009 - specialist palliative care services

DoH – Prime Ministers Challenge on Dementia 2010 – co-ordinated EoL care

Dementia Partnerships – dementia atlas, resources, good practice, knowledge sharing

Clinical Network for Dementia London – Commissioners Checklist, 2015 – EoL planning in care plans

Gold Standards Framework – training, learning, accreditation

OECD Dementia Pathway, 2015 – access to EoL care outside of hospital, training for care home staff
### NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

#### PREVENTING WELL
Risk of people developing dementia is minimised

- “I was given information about reducing my personal risk of getting dementia”

#### DIAGNOSING WELL
Timely accurate diagnosis, care plan, and review within first year

- “I was diagnosed in a timely way”
- “I am able to make decisions and know what to do to help myself and who else can help”

#### SUPPORTING WELL
Access to safe high quality health & social care for people with dementia and carers

- “I am treated with dignity & respect”
- “I get treatment and support, which are best for my dementia and my life”

#### LIVING WELL
People with dementia can live normally in safe and accepting communities

- “I know that those around me and looking after me are supported”
- “I feel included as part of society”

#### DYING WELL
People living with dementia die with dignity in the place of their choosing

- “I am confident my end of life wishes will be respected”
- “I can expect a good death”

#### STANDARDS:

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<tbody>
<tr>
<td>Risk Reduction(6)</td>
<td>Memory Assessment(1)(2)</td>
<td>Liaison(2), Advocates(3)</td>
<td>Supporting Carers(2)(4)(6)</td>
</tr>
<tr>
<td>Health Information(4)</td>
<td>Concerns Discussed(3)</td>
<td>Housing(3)</td>
<td>Carers Respite(2)</td>
</tr>
<tr>
<td>Supporting research(5)</td>
<td>Investigation(4)</td>
<td>Hospital Treatments(4)</td>
<td>Co-ordinated Care(1)(5)</td>
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<tr>
<td></td>
<td>Provide Information(4)</td>
<td>Technology(5)</td>
<td>Promote independence(1)(4)</td>
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<td></td>
<td></td>
<td>Hard to Reach Groups(3)(5)</td>
<td>Safe Communities(3)(5)</td>
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#### RESEARCHING WELL
- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

#### INTEGRATING WELL
- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer’s Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

#### COMMISSIONING WELL
- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

#### TRAINING WELL
- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

#### MONITORING WELL
- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set ‘profiled’ ambitions for each.
- Use the Intensive Support Team to provide ‘deep-dive’ support and assistance for Commissioners to reduce variance and improve transformation.
European Association for Palliative Care White Paper, 2014 Delphi study, expert consensus in 11 domains

1. Recognition of terminal nature (improves care)
2. Patient centred perspective
3. Planning and goals of care
4. Coordination
5. Recognition of dying
6. Avoidance of futile treatment
7. Robust symptom control - Specialist palliative care teams may support staff in long term care settings in dealing with specific symptoms
8. Emotional, psychological, social, spiritual needs
9. Involving families
10. Education for carers
11. Wider social and ethical issues