Caring for people with dementia at the end of their lives

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Overview

• What is dementia?
• Some (useful) statistics
• The role of palliative care in dementia
• The experience of dying with dementia
• How can we improve care?
What is dementia?

- Dementia is not just forgetfulness
- Dementia is a progressive neurodegenerative disease
- The experience is unique for each individual but comprises:
  - Short term memory problems
  - Difficulties in day to day function
  - Speech and language problems
Global challenge

NUMBERS OF PEOPLE LIVING WITH DEMENTIA WORLDWIDE ON THE INCREASE

44m people worldwide have dementia and this is predicted to rise to 135m by 2050\textsuperscript{17}.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of People with Dementia in the UK</th>
<th>Number of Family Carers of People with Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>850,000</td>
<td></td>
</tr>
<tr>
<td>2050</td>
<td>706,000</td>
<td></td>
</tr>
</tbody>
</table>

45,000 people in Wales
Why is dementia becoming more common?

[Graph showing prevalence of dementia in UK by age group for men and women]
Why is this important for end of life care?

- 30% of those over the age of 60 will die with dementia (Brayne et al 2006)
- 50% of those with dementia admitted to UK acute hospital die, within 6 months (Sampson et al 2012)
- People who died with dementia in Wales in 2012 spent more than 50 days of their final year of life in hospital (Marie Curie 2014)
- Older people will have increased multiple health conditions and frailty
Dementia has become a leading cause of death

61,000 people died of dementia - 11.6% of all recorded deaths

Dementia and Alzheimer’s disease leading cause of death for both men and women over 80

(ONS Deaths Registered in England and Wales 2015)
Deaths due to dementia will increase

Etkind et al 2017
Where do people with dementia die?

Table 1. Place of death for people with underlying cause of death listed under ICD-10 F00-F99: Mental and behavioural disorders

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Percentage of all deaths (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>5.8</td>
</tr>
<tr>
<td>Hospital</td>
<td>38.0</td>
</tr>
<tr>
<td>Care home</td>
<td>52.8</td>
</tr>
<tr>
<td>Hospice</td>
<td>0.0</td>
</tr>
<tr>
<td>Other communal establishment</td>
<td>3.1</td>
</tr>
<tr>
<td>Elsewhere</td>
<td>0.3</td>
</tr>
</tbody>
</table>


Marie Curie 2015
Reversal of the trend to towards death in hospital for care home residents

Sleeman et al 2016
Possible reasons for changing trends

- Increase in nursing home beds (compared to residential)
- Increased documenting of dementia on death certificate
- Gold Standards framework and other programmes
- Changes in commissioning: care home “in-reach”
- “Discharge to die” policies and “fast tracking” from acute hospitals
Is death in usual place of residence a good marker of quality?

- Evidence not clear
- Most people with dementia want to die in their own home but do not want to die in a care home
- How do we measure quality of dying
  - VOICES Survey
  - Carer satisfaction
  - Carer grief
  - Research tools
What do people with dementia want?

… look after me with care …
  don’t treat me like a vegetable … like a mad person

… change, feeding, some people … is not right … if I am unwell and not enjoying my life and a vegetable … I would be better off dead.
  … when I … am that bad

… that’s a nice place to die … home …

Harrison Dening et al 2013
The role of palliative care in dementia
Policy drivers

• UK National End of Life Care Programme and Policy (2004)
• Preferred Priorities for Care (2007)
• Ambitions for Palliative and End of Life Care (2015)
• Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman (2015)
• Review of Choice in End of Life Care (2016)
• Welsh palliative and end of life care delivery plan (2017)
• Together for a dementia friendly Wales (awaited)
  – More detail – should form its own theme
  – Hospice should be “open and available” for people with dementia
Alzheimer’s Society Cymru consultation response: 
Together for a Dementia Friendly Wales 2017-22
Palliative care

“The active total care of patients whose disease is not responsive to curative treatment.

Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount.

The goal of palliative care is achievement of the best quality of life for patients and their families.”

World Health Organization, 1990
EAPC White Paper on Palliative Care in Dementia
Palliative care is holistic care
Palliare
Why is dementia different?

• Not recognised as a terminal illness
• Many losses occur *before* death
  – Personality
  – Personhood
  – Autonomy
  – Capacity
• Trajectory
• Uncertainty
• Funding
• Legislation and governance
• Local variation
What is “advanced” dementia

A biomedical model

• Severe cognitive impairment
• Able to speak only a few words
• Mobility limited
• Double incontinence
• Difficulties swallowing
• Pressure sores

A psychosocial model

• May still recognise some family and friends
• Able to enjoy sensory experience
• Continue to express a sense of self
• Able to make meaningful connections
## Symptoms of advanced dementia

<table>
<thead>
<tr>
<th>Symptom</th>
<th>18 months</th>
<th>last 30 days</th>
<th>last week</th>
<th>last week</th>
<th>last 4 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnoea</td>
<td>46%</td>
<td>39%</td>
<td>~</td>
<td>35%</td>
<td>~</td>
</tr>
<tr>
<td>Pain</td>
<td>40%</td>
<td>26%</td>
<td>18%</td>
<td>52%</td>
<td>50%</td>
</tr>
<tr>
<td>Pressure Ulcers</td>
<td>39%</td>
<td>47%</td>
<td>70%</td>
<td>~</td>
<td>27%</td>
</tr>
<tr>
<td>Agitation/restlessness</td>
<td>54%</td>
<td>20%</td>
<td>72%</td>
<td>35%</td>
<td>56%</td>
</tr>
<tr>
<td>Aspiration</td>
<td>41%</td>
<td>~</td>
<td>~</td>
<td>~</td>
<td>~</td>
</tr>
<tr>
<td>Eating problems</td>
<td>86%</td>
<td>~</td>
<td>95%</td>
<td>~</td>
<td>~</td>
</tr>
</tbody>
</table>
The impact on family carers

- Provide over half of the dementia care in the UK
- £12.4 billion
- Health
- Finances
- Pre-death grief and loss
- Feelings of relief …and guilt after bereavement
Planning for the future
Managing uncertainty

Barclay et al BJGP 2014
The system and the individual

PwD at home

Supported by:
- Family carers
- Social carers
- Falls team
- District nurses
- GPs
- Admiral nurses
- Mental Health Services for Older People

PwD in a care home

Supported by:
- Family carers
- Social carers
- Community matron
- District nurses
- Falls team
- GPs
- Mental Health Services for Older People

Medical or social crisis occurs

Example:
- Carer respite
- Carer breakdown
- Illness of carer
- Urinary tract infection
- Fall
- Dehydration
- Confusion

Emergency services called

Supported by:
- Camidoc
- NHS Direct
- Ambulance service
- GPs

PwD admitted to hospital

Supported by:
- Rapid response team
- A&E staff
- Medical Admissions staff
- Care of the elderly multi disciplinary team

PwD discharged from hospital

Supported by:
- Care of the elderly multi disciplinary team
- Hospital matron
- Discharge team
- Social care assessors
- Community matron

Does the PwD die in hospital?

no

Supported by:
- Family carers
- Social carers
- Falls team
- District nurses
- GPs
- Mental Health Services for Older People
- Admiral nurses
- Mental Health Services for Older People
- Community matron
- District nurses
- Falls team
- GPs
- Mental Health Services for Older People
- Family carers
- Social carers
- Falls team
- District nurses
- GPs
- Mental Health Services for Older People
- Community matron
Advance care planning

“ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individuals agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care”

• Top-down policy
• Implementation issues
  – Training
  – Confidence
  – Paperwork
  – Reluctance to commit (Sampson and Burns 2014)
Recent evidence on advance care planning

For

• Policy push
• It seems like a good idea (!)
• It gives people choice and control
• It gives a sense of relief and less worry (Poppe 2013)
• In other disease i.e. cancer it influences preferred place of death (Deterring 2011)

Against

• Lose capacity relatively early (Harrison Dening 2016)
• False promise-can’t deliver
• Proxies find it stressful (Fetherstonhaugh 2017)
• Proxies are not good at predicting (Harrison Dening 2017)
• Professional ownership (Robinson 2015)
• Response shift (Jongsma 2016)
Possible solutions
Living and dying with dementia in Wales

Living and dying with dementia in Wales:

Barriers to care

- Strategy
- Advance care planning
- Hospitals
- Care homes

Data from the NHS Wales Informatics Service shows just 3.8% of people who died in Wales in 2012 with dementia as their underlying cause of death were recorded as having a palliative care diagnosis or having received hospital-based specialist palliative care, which is appropriate for people with more complex needs.
Possible solutions-system level

• English vanguard projects-7 focussing on care homes
  – Reduce hospital admission
  – Improve general health
  – Improve end of life care

• Care coordination in dementia
  – Inconclusive evidence base
  – Difficulties in implementation
  – Not widely adopted the UK

Commissioning is key
Possible solutions within care homes

• Gold standards framework
  – Quality improvement programme
  – After death analysis
  – Interactive training workshops
  – Assessment and accreditation

• 6-Steps model-training and quality improvement
  1. Discussion as end of life approaches
  2. Assessment care planning and review
  3. Co-ordination of care
  4. Delivery of high quality services
  5. Care in the last days of life
  6. Care after death
Namaste care programme

- ‘To honour the spirit within’
- **Namaste care** (Stacpoole et al. 2014)
  - Music
  - Therapeutic touch,
  - Food treats and scents.
  - Families supported to acknowledge the progression of dementia in the positive context of seeking to provide quality of life.
- No additional staff or expensive equipment is required
- Decreased behavioural symptoms
- HTA trial commencing
Hospice enabled dementia care

- Increasingly important strategic consideration
- Hospices are unclear about their role and managing symptoms such as agitation and capacity issues
- They have fewer links with mental health services
- Key ingredients:
  - External facilitation
  - Care coordination role
  - Education and training
- 15 current services identified (increasing) (Amador et al 2016)
Marie Curie and dementia care in Wales

- Specialised dementia service in Hywel Dda
- Collaboration between Marie Curie and Hywel Dda Health Board
- Helps patients with end-stage dementia access palliative and end of life care services
- Supports multi-disciplinary teams to meet the care needs of people with dementia in hospitals, at home and in care homes.
- Aids the safe transfer of care across care settings
Conclusions- end of life care in dementia is:

- A huge international issue
- A political issue
- A human rights issue
- A personal issue
Thank you!

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