Addressing the Palliative Care Needs of People with Dementia

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Addressing the Palliative Care Needs of People with Dementia

or..

Addressing the Dementia Care Needs of People receiving Palliative Care

• Thank you

• Declaration
Overview

- Background
- White Paper EAPC
- 11 “optimal” recommendations
- Current “Palliative Dementia Care”
- Vision and resources...
White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

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on behalf of the European Association for Palliative Care (EAPC)
White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care
1. Applicability of palliative care

Palliative dementia care actively treats distressing symptoms (physical or psychological or emotional), to optimise the quality of life for the person with dementia, and their family, knowing that the underlying cause cannot be cured (ACH Australia 2009)
Domain 2. Person-centred care, communication and shared decision making

Personhood is a standing or status bestowed on one human being by another in the context of relationship – person centred care seeks to support and maintain personhood through relationship and recognising the need for:

• Attachment,
• Comfort,
• Identity,
• Occupation,
• Inclusion

Personhood challenges our care systems

Kitwood T(1997) Dementia Reconsidered: the person comes first OUP
Domain 3. Setting care goals and advance planning

[Image of a Healthcare Passport]

Diagram 6
The period with severe disability may last much longer
The end stage is less clearly delineated
The burden on carers is heavy and long-drawn-out
Behavioural problems - middle period
Physical symptoms - end stages
The “dying bit” may be less complex…..
The combination of dementia and physical needs a challenge if staff not trained in “Palliative Dementia Care”.

Anticipation is challenging
Domain 4. Continuity of care

Diagram 6

GOALS OF CARE

HEALTH PROMOTION AND PREVENTION/RISK REDUCTION

PROLONGATION OF LIFE

MAINTENANCE OF FUNCTION

MAXIMIZATION OF COMFORT

BEREAVEMENT SUPPORT

INTACT MILD MODERATE SEvere AFTER DEATH
• The needs and challenges faced by patients, carers and professional staff change widely over the course of the dementia journey....

• Malcolm aged 51

Malcolm aged 66
Domain 5. Prognostication and timely recognition of dying

Communication skills essential as about managing uncertainty-
The inverse communication law

Frailty
- Individuals who present with multiple co-morbidities with significant impairment in day-to-day living and:
  - Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
  - Combination of at least three of the following symptoms:
    - weakness
    - slow walking
    - significant incontinence
    - exhaustion
    - low physical activity
    - depression

Dementia
- There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:
  - Unable to walk without assistance and
  - Urinary and faecal incontinence, and
  - No consistently meaningful conversation and
  - Unable to do Activities of Daily Living (ADL).

Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.
Domain 6. Avoiding overly aggressive, burdensome or futile treatment

- Clarifying goals of care
- Team and family context
- DNACPR

Court of Appeal DNACPR decision:
Tracey v Cambridge University Hospital NHS FT June 2014

“For a patient not to be consulted about a DNACPR decision, the clinician would have to consider that to do so is likely to cause a patient to suffer physical or psychological harm. Distress alone would not be sufficient.”
Domain 7. Optimal treatment of symptoms and providing comfort

Avoiding under and over treatment
Avoiding distressing transfers if possible
Domain 8. Psychosocial and spiritual support

• Finding the link that matters, affirms, supports, connects…
Domain 9. Family care and involvement
Domain 10. Education of the health care team

- Training Palliative care professionals about dementia
- Training Dementia care professionals about palliative care
- 30% of our hospice patients have cognitive impairment
- ?% of people with dementia have palliative care needs
Education

- Staff working in dementia care services looking for training in end of life care

Collaborative Education

- Staff working in generalist care looking for training in dementia care
Domain 11. Societal and ethical issues
Most patients are currently referred for other reasons—i.e. they may have cancer or heart failure, and happen to also have dementia - “dementia plus”

Palliative care services accepting patients for whom end-stage dementia is the primary diagnosis is still uncommon

Current palliative care model for people with “dementia plus” can almost work with traditional palliative model as patients tend to have a relatively short illness

End-stage primary dementia with its much longer time course poses difficulties within traditional palliative models

Everyone gains through collaborative working, effective communication and mutual respect- but making it happen is a real challenge
## Dementia + “dying with..”

<table>
<thead>
<tr>
<th>Age Bands</th>
<th>65 to 74</th>
<th>75 to 84</th>
<th>85+</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of deaths</td>
<td>33305</td>
<td>43330</td>
<td>20474</td>
</tr>
<tr>
<td>Number with dementia</td>
<td>977</td>
<td>3800</td>
<td>5951</td>
</tr>
<tr>
<td>% with dementia</td>
<td>2.90%</td>
<td>8.80%</td>
<td>29.10%</td>
</tr>
<tr>
<td><strong>Circulatory</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of deaths</td>
<td>31548</td>
<td>71469</td>
<td>67962</td>
</tr>
</tbody>
</table>

Symptom management in patients needs collaboration.
Timing for palliative collaboration?

<table>
<thead>
<tr>
<th>INDEPENDENCE</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>Moderate or Mid-Stage</td>
</tr>
<tr>
<td>Impaired memory; Personality changes; Spatial disorientation</td>
<td>Confusion; Agitation; Insomnia; Aphasia; Apraxia</td>
</tr>
</tbody>
</table>

Advanced Dementia

(Hurley & Volcer, 1998)

BOTH AND not either or
A vision of dementia care....

- Person centred caring - patients and carers
- Compassion and scientific rigor
- Team working, multi-professional - Physical, emotional, spiritual, social
- Working where the person is across a wide variety of settings
- Working with people who often feel “abandoned”
- Managing uncertainty
A vision of palliative care....

• Person centred caring - patients and carers
• Compassion and scientific rigor
• Team working, multi professional - Physical, emotional, spiritual, social
• Working where the person is across a wide variety of settings
• Working with people who often feel “abandoned”
• Managing uncertainty
- Dementia friendly design
- Palliative Dementia Certificate
- Supporting care homes
- Dementia Research Collaborative
- Listening Listening Listening
How can we meet the need?

People with dementia
Carer empowerment
Appropriate Non-intervention
Good Quality
Limited resources
Interventions
Specialist input

Dementia and Palliative Staff

Carers
The Future Balance

People with dementia

Carers

Dementia and Palliative Staff

Non-interventions

Good Quality

Carer empowerment

Interventions

Limited resources

Specialist input
Palliative Dementia Care-
If we focussed resources to apply what we already know and can do……