PALLIATIVE DEMENTIA CARE: CHALLENGES AND OPPORTUNITIES FOR PALLIATIVE CARE PRACTITIONERS

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Overview of the presentation

- Palliative care - a changing focus in practice
- Why dementia is an important issue for practitioners
- What challenges us as practitioners
- Opportunities for the future
Palliative care- changing focus
40 million people need palliative care worldwide
2.1 million children need palliative care worldwide

‘we have only one chance to get end-of-life care right for an individual and at present this chance is sadly being missed on too many occasions’

Clare Henry, CE, National Council for Palliative Care, UK
Elder care – an international health challenge

600 million older persons worldwide
Doubled by 2025
2 billion by 2050
The extent of the problem in Europe

- Low birth rates versus a rapidly ageing population
- Growth in multi-morbid illness, including non-communicable neurological disease
- Dementia – greatest global challenge for 21st Century Health and Social Care
- 47 million people worldwide live with Dementia
- +10 million in Europe
- 30 million by 2050.
- 1:3 people born today will develop Dementia at some stage (Alzheimer’s UK)
- Global cost estimated at $818 billion
- 85% of costs relate to family and social care, not medical care.
World Health Organisation definition of palliative care (revised)

An interdisciplinary approach to improving the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’

What does that definition mean?

<table>
<thead>
<tr>
<th>Change from</th>
<th>Change to</th>
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<tbody>
<tr>
<td>Terminal disease</td>
<td>Advanced progressive disease</td>
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<td>Short life prognosis (weeks or months)</td>
<td>Life-limiting</td>
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<td>Curative versus palliative</td>
<td>Shared and combined care together</td>
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<td>Disease OR palliation</td>
<td>Disease AND palliation</td>
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<td>Prognosis as referral point</td>
<td>Complexity as referral point</td>
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<td>Patient and family as care recipient</td>
<td>Patient and family as care planner</td>
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<tr>
<td>Specialist service alone</td>
<td>Service across all settings</td>
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Palliative Care as a Public Health issue
The challenges of palliative dementia care
Why Dementia is a problem of care

- Largely affects those over 65 – concomitant disease.
- Impacts on physical capacity, psychosocial engagement and neuropsychiatry.
- Impact on memory, behaviour, eating, sleeping, etc.
- The challenge of care and cohabitation.
- Place of care at end-of-life is often a challenge in terms of choice and time.
- The issue of ‘prolonged dwindling’.
The issue of ‘prolonged dwindling’

- Challenge of dying trajectory
- Fit to pathways of care
- Cost to practitioners
So what does that mean for palliative care?
When should PC be initiated?

Here?  Here?  Or here?  No right or wrong answer

Diagnosis  

..... But important to actively think about it

Ongoing treatment and palliative care not necessarily contradictory

Death
Dementia – core domains and optimal care (van der Steen et al; Pall Med 2014,28(3), 197-209).

- Person centred and holistic approaches to care
- Communication and symptom management for comfort
- Shared decision-making for setting goals and advance planning
- Family care and involvement
- Education
- Diagnosing dying

NB: Timing of palliative care involvement unclear
The place of Primary Care Services in palliative dementia care

- National survey of GP’s capacity to deliver on dementia care in the community.
- Lack of knowledge, poor resources and poor team coordination.
- Managing the complexity of family.
- Managing issues of public awareness versus reality of provision.
Place of care and place of death
(see Morin et al., 2017 Pall Med, 31(6), 526-536)

- Wide international variation (e.g., Japan versus Greece)
- Professional care-giving needs to be nuanced to a range of different settings
- Prolonged dwindling often an older frail nursing home population
- Preparing primary care professionals
- Beyond education – support and guidance
- How prepared is palliative care to meet these needs?
Opportunities for the future
A definition of integrated care

“Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the care givers (paid and unpaid)”

Integrated model of palliative care
Criteria for specialist intervention

**Figure 4. Criteria for SPC Intervention**

- Back to conventional service if stable
- Needs and Demands at the conventional service
- Multidimensional assessment: complexity
- Therapeutic plan and indication of resources
- Role in care:
  - Shared / Exclusive
  - Case Management
  - Advance care planning
  - Continuity
  - Emergency

+ Support of the referent team
New knowledge on ACP

- Delphi process (109 experts)
- ‘...the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers and to record and review these preferences if appropriate’ (pg e543)
5 of the 41 recommendations considered strong

- Explore extent to which personal representatives have leeway in decision-making
- Healthcare professionals included in clinical elements of decision-making
- Clarity of format of written document
- Degree of self-efficacy
- Use of healthcare
Advance Care Planning – sharing of knowledge and resources
Relational autonomy presupposes:

- ‘the rich complexity of human relations... recognizes the moral significance of the actual ties that bind people in their various relationships’
Reflections on autonomy and decision-making?

- Relational ethics focuses on people (not individuals) and the commitments between them.
- Relational ethics does not aim to solve ethical problems but moves to ask ethical questions.
Education and Engagement
(www.professionalpalliativehub.com)
Key messages for our colleagues beyond palliative care

- The context and practice of palliative care is changing
- Palliative care continues to work in partnership with others
- Much of the growing evidence around the benefits of palliative care comes through Oncology - but that is changing
- Dying is an important part of the work we do – but it is not all we do
- Patient outcomes improve when collaboration is the primary driver of care.
“You matter because you are you and you matter to the last day of your life. We will do everything we can to help you die peacefully and to help you live until you die”.

Thank you