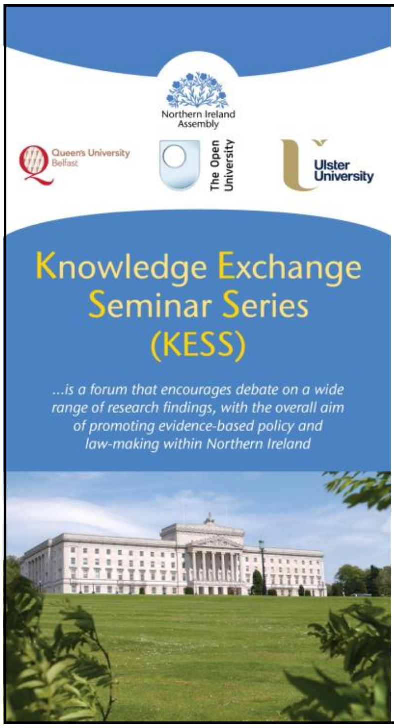

PROVIDING END OF LIFE CARE FOR DEMENTIA – TOWARDS A MODEL OF BEST PRACTICE IN PRIMARY CARE

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Research Team

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Background

- Dementia is a life limiting disease without curative treatments
- Worldwide health issue
  - **35.6million** cases 2010 expected to double by 2030
  - **19,000** in NI (2011)
  - As NI population ↑ = dementia major public health & societal issue
- Role of GPs
  - Gatekeepers to range of healthcare professionals & diagnostic tests
  - Early identification of dementia – ensure interventions commenced
  - GPs need **GOOD KNOWLEDGE** of dementia
  - Be aware importance of **EARLY** diagnosis
  - In Mental Health Services for Older People (2005) survey **LESS THAN HALF** of GPs surveyed felt had enough training to diagnose & manage dementia

Background

- Palliative Care Community
  - Traditionally focussed on advanced-stage cancer patients
  - Good quality end-of-life care should be integral part for **ALL** living with chronic illnesses, including dementia
- Adopt **Palliative Approach**
  - Has potential to promote anticipatory care planning (**including ACP**)

  1) **Early care guidance** - ensure needs of individual & their families are met throughout illness trajectory
  2) **Adaption** of palliative care knowledge & expertise by **ANY** healthcare professional
  3) **Integration** within healthcare systems in which evolving end-of-life care needs are **recognised & addressed**

Background

- Comparing disease trajectories of cancer patients with dementia
  - Cancer patients: substantial decline functioning last months/weeks
  - Dementia patients: prolonged ‘dwindling’ & severe disability may persist for years
- EAPC(2014):**White paper defining optimal palliative care in older people with dementia**

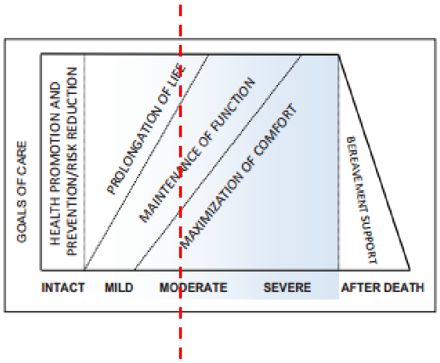
Core Domains

1. Applicability of palliative care
2. Person-centred care, communication & shared decision making
3. Setting care goals & advance planning
4. Continuity of care
5. Prognostication & timely recognition of dying
6. Avoiding overly aggressive, burdensome or futile treatment
7. Optimal treatment of symptoms & providing comfort
8. Psychosocial & spiritual support
9. Family care & involvement
10. Education of the health care team
11. Societal & ethical issues

→ **57 Recommendations**

EAPC

Figure: Dementia progression & suggested prioritizing of care goals



Changing care goals & priorities throughout dementia trajectory

GP Survey

- **INVESTIGATE GPS’ PERCEPTIONS OF PALLIATIVE CARE FOR INDIVIDUALS LIVING WITH DEMENTIA**
- Conducted in Northern Ireland 2013
- Sample based on GP surgeries with more than 30 registered dementia patients
- Altogether sample comprised 340 GPs representing 174 practices
- Postal questionnaire – based on EAPC core domains:

“Care for Dementia Patients at the End of Life”

GP Survey

Care for Patients with Dementia at the End of Life

A survey about physicians’ priorities in caring for people with dementia at the end of life

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A. **24 statements -** perceptions of dementia as a terminal illness, communication, ACP, & decision-making: chose strongly disagree to strongly agree.
B. **Domains of palliative care in dementia -** perceived importance of these aspects of care, the significance of them as a barrier in practice, & the challenge of addressing the barriers
C. **Barriers & Solutions –** 3 of the most significant barriers to the provision of palliative care in dementia, and potential solutions.
D. **Respondent characteristics**.

Results

- **138 responses = response rate 40.6% (138/340); 60.9% of surveyed practices (106/174)**
- 57.4% male; 43.6% female; ave. age 49.3yrs; ave. time in practice 24.7yrs
- In statements <u>describing ACP about future care at end of life for dementia</u>:
  - GPs divided on whether ACP should be initiated at diagnosis & if it should be frequently reviewed
  - 82.7% - GP should take initiative to introduce ACP
  - 90.2% - should be an agreed format for ACPs
  - 79.7% - GPs needed training to improve their knowledge to involve families in caring for dementia at the end of life

Results – Section C

<u>Theme 1</u> Lack of knowledge & understanding	▪ Level of family/carer understanding ▪ Recognition that dementia is a palliative condition by HCPs, families and the public ▪ HCP understanding, education & training ▪ Level of public understanding
<u>Theme 2</u> Limited availability of resources	▪ GP resources – practice & time pressures ▪ Access to community staff & resources ▪ Funding
<u>Theme 3</u> Mismanagement of appropriate care	▪ Inappropriate medical treatments, interventions & hospitalisations ▪ Difficulty of assessments, diagnosis & prognosis ▪ Lack of standardised guidelines & information
<u>Theme 4</u> Poor interdisciplinary team approach	▪ Team communication, integration & access to specialist support ▪ Continuity of care
<u>Theme 5</u> Family support & involvement	▪ Family, carer & patient support ▪ Family resistance & disagreements

Implications for Practice

Theme 1. Enhanced Education

- Interventions to promote **GP knowledge & skills** to match complex requirements of dementia
  - Insufficient basic & post-qualifying training in dementia
  - **Education healthcare team** highlighted as core domain by EAPC
- Need to be more knowledgeable & proactive with ACP
- **Public education** essential – to improve community awareness
- Educational strategies directed – patients & family carers to enable shared decision-making & optimal timing ACP discussions

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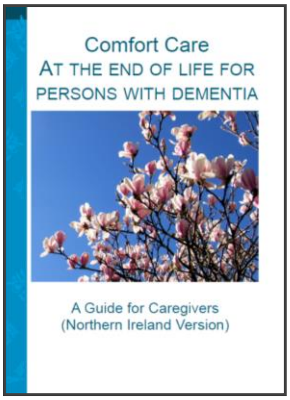
Comfort Care Booklet

- Current care home study by QUB (Prof Kevin Brazil, PI):

“Promoting Informed Decision Making & Effective Communication through Advance Care Planning for People with Dementia and their Family Carers”

- Booklet - **‘Comfort Care at the end of life for persons with dementia’**
- Originally developed in Canada by Arcand & Caron (2005)
- Demonstrated **high level of acceptability** in other countries
- Identified as **best practice instrument** by World Health Organisation European Office
- Adapted for NI context

Comfort Care Booklet



Comfort Care
AT THE END OF LIFE FOR
PERSONS WITH DEMENTIA

A Guide for Caregivers
(Northern Ireland Version)

Section 1. The Natural Evolution of Dementia

Section 2. Decisions About the End of Life

Section 3. Relief of Symptoms

Section 4. The Final Moments

Section 5. After the Death

Implications for Practice

Theme 2. A Shared Care Model

- **Substantial multidisciplinary support**
- Core good clinical practice is good interdisciplinary team work
- Poor communication & poor integration can impinge palliative care
- Personalised shared care plan
  - Facilitate access between **primary care, emergency services, secondary care** and **social services**
- GPs in a commanding position identify early signs of dementia & access HCPs
- **Integrated & holistic team approach** needed to improve patient outcomes
  - EAPC core domain

Key Messages

- **GPs are in a pivotal position to initiate & adapt care for an individual living with dementia**
  - Gatekeepers to other health services - specialist services
  - GPs have expressed limited confidence in their assessment and knowledge of dementia
- **HCPs & family carers have difficulty in characterising dementia as a terminal illness**
  - Palliative approach would be beneficial
- **Is there sufficient GP dementia training & HCP support?**
  - Perceived dementia knowledge deficit
  - Resource shortfalls
  - Conflict with and within families
  - Poor integrated team care

Key Messages

- **A personalised shared care & support plan of treatment goals can facilitate holistic care**
  - ACP – a mechanism to **facilitate** communication & decision-making
  - Optimal timing – delivered on an **individual** basis
  - Discussions can be enhanced by educational strategies
- **Shared Care Model**
  - Integration - GP services & primary care, emergency services, secondary care & social services
  - Improve access to quality palliative care
  - A necessity to provide best practice end of life care for dementia
  - Require **co-operation**, **communication** & **integration** by and between allied HCPs.

For any further information please refer to:

Carter G, van der Steen JT, Galway K, Brazil K. (2015) ***General Practitioners' perceptions of the barriers and solutions to good quality palliative care in dementia***. Dementia: the International Journal of Social Research and Practice.

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van der Steen JT, Radbruch L, Hertogh CM, et al. (2014) ***White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.*** Palliative Medicine. 28(3):197-209

Thank you!

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