Palliative care and dementia – rethinking how we do it

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Learning objectives

At the end of the presentation participants will be able to:

❖ Understand the role of palliative care in the care of people with dementia near the end of life

❖ Identify the ways in which physical, psychological, social and spiritual needs of patients and families can be met

❖ Identify ways that health professionals can effectively care for themselves in this area of work.
Dementia

• 35.6 million people worldwide
• Double by 2030
• Is a terminal illness
• 29% increase in five years in NZ
• 48,182→62,287 (2016)
• 2188 deaths (2016)
• So what are the challenges?
• How do we understand them?
Since 2001, death rates from heart disease and stroke have halved for both males and females. Over the same time deaths from dementia and Alzheimer’s have increased by 60% in males and have doubled in females [Public Health England report]

In 2015, heart disease was the most common cause of death among men in England and Wales but Alzheimer’s and dementia are now the most likely among women

Commonest cause of death for women in Australia

Last year, 61,686 (11.6%) out of a total of 529,655 deaths registered in England and Wales were attributable to dementia [Office for National Statistics]
Understanding palliative care

Palliative care is an approach that improves 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
✓ provides relief from pain and other distressing symptoms
✓ affirms life and regards dying as a normal process
✓ intends neither to hasten nor postpone death
✓ integrates the psychological and spiritual aspects of patient care
✓ offers a support system to help patients live as actively as possible until death
✓ offers a support system to help the family cope during the patient’s illness and in their own bereavement
What does that mean?

✓ Quality of life
✓ Quality of dying
✓ Early engagement
✓ Outreach
✓ Prognostication
✓ Active engagement
✓ Unfamiliar and threatening?
What is optimal care?

2013 White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

Jenny T van der Steen, Lukas Radbruch, Cees MPM Hertogh and others on behalf of the European Association for Palliative Care (EAPC)

*Palliative Medicine. doi: 10.1177/0269216313493685*
Domain 1

Applicability of palliative care
Domain 2

Person centred care
Domain 3

Setting goals and advance care planning
Domain 4

Continuity of care and care coordination
Domain 5

Prognostication

Timely recognition of dying
Domain 6

Is transfer to hospital a good idea?
Are all the medications really needed?
Hydration is inappropriate in the dying phase [mouth care is, however, an often neglected area of care]
What is the role of antibiotics?
Domain 7

Optimal treatment of symptoms and provision of comfort
Domain 8

Psychosocial and spiritual support
Domain 9

Family care and involvement
Domain 10

Education of the health care team
Domain 11

Society and ethics
Dementia progression and suggested prioritisation of care goals

- Health promotion and prevention/risk reduction
  - Prolongation of life
  - Maintenance of function
  - Maximization of comfort
  - Bereavement support

- Intact
- Mild
- Moderate
- Severe
- After death
Fundamentals of palliative/end of life care

Te Ara Whakapiri
Principles and guidance for the last days of life
What we know isn’t happening well

A review of clinical practice international dementia care guidelines (11CPGs; 3779 citations)

– Coverage of most aspects of care
– Preferred place of care and death **missing**
– Peri-death care **missing**
– Family education on what to expect **missing**
– Support for funeral planning **missing**

What we know isn’t happening well

- Existing guidelines did not address grief and loss among family members.
- Spiritual care was absent or minimal within these guidelines.
- Lack of content for psychological issues such as sexuality and intimacy within reviewed guidelines.

Integrated palliative care outcome scale for dementia – IPOS-Dem

http://pos-pal.org/maix/
Integrated palliative care outcome scale for dementia – IPOS-Dem

http://pos-pal.org/maix/

- a comprehensive and acceptable caregiver-reported measure to detect symptoms and problems in dementia

- is suitable for caregiver staff without professional training as it has been refined and tailored to maximise caregiver expertise, ready for further psychometric testing
IPOS-Dem

- Pain
- Shortness of breath
- Weakness or lack of energy
- Nausea
- Vomiting
- Poor appetite
- Constipation
- **Dental problems**
- Sore or dry mouth
- **Drowsiness**
- **Poor mobility**
- Swallowing problems
- Skin breakdown
- Hearing aid/foot problems/glasses etc

- Difficulty communicating
- Sleeping problems
- Diarrhoea
- Hallucinations
- Agitation
- Wandering
- Any other symptoms
- Anxious or worried
- Depressed
- Loss of interest
- At peace
- **Interact with others**
- Enjoy activities
- Weight loss
Understanding advance care planning

- Family factors influence completion (initiative or lack of it – willingness or reluctance)
- Ethnic minority status and family distance may be barriers
- Continuity of care and health care systems also affect initiating ACP
- Professional caregivers may initiate ACP early if strategies consider these things

Comfort goal of care

- When a comfort care goal was established shortly after admission and the patient died within 6 months, the families were more satisfied with end-of-life care.
- A comfort goal was not associated with quality of dying.
- A focus on comfort may help in preparing for the end of life, and this may increase family satisfaction with end-of-life care.

[28 long-term care facilities (the Dutch End of Life in Dementia study)]

Understanding where people with dementia die

- More commonly in care homes
- Age (older), gender (male), availability of hospital and nursing home beds and enrolment in hospice influence place of death
- Limited evidence of patients’, carers’ and healthcare providers’ views on preferred location of death

Badrakalimuth V, Barclay S (2013) Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis.

*Age Ageing.* doi: 10.1093/ageing/aft151
One English study of 388,899 deaths – most people died in care homes (55.3%) or hospitals (39.6%)

A pattern of increasing hospital deaths reversed in 2006

Home and hospice deaths are rare

*BMC Neurology* 14:59
Understanding how they die

- Pain (52%) [previously reported rate 12-76%]
- Agitation (35%) [previously reported rate 20-54%]
- Shortness of breath (35%) [previously reported rate 8-80%]
- Pain and agitation associated with the lowest quality of life
- Death from respiratory infection was associated with the largest symptom burden

330 nursing home residents – questionnaires completed by physicians within two weeks of death

Hendriks S et al. (2014) Dying with dementia: symptoms, treatment and quality of life in the last week of life.

*Journal of Pain and Symptom Management* 47: 710-720
Did they suffer?

Again from the DEOLD study

- 103 physicians reporting on 330 patients with dementia who had died
- Physicians felt the person had suffered in 13.8% of cases
- Unexpected death and death with pneumonia were strongly associated with suffering
- Earlier identification of the beginning of the dying process would allow time to better prepare for approaching death, which would provide a source of comfort

Understanding the carers’ views

- We need more information about carers’ views about end-of-life care for people with dementia
- Carers experience high levels of stress, strain and burden
- Carers views are mixed and lie on a spectrum of acceptance of their relative as actively dying with dementia
- Greater investment is needed in bereavement research and practice
- Professionals need to be mindful of the different relationships carers may have with the person with dementia

  *Palliative Medicine*
  doi: 10.1177/0269216317748844journals.sagepub.com/home/pmj

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But what about you in all of this?
What rethinking will you do?