Palliative care and dementia – rethinking how we do it

Dementia: Rethink, Review, Renew
Southern Dementia Network Symposium

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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
- Now recognised as a terminal illness
- So what are the challenges?
- How do we understand them?
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
- Reaching out
- 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
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

EDUCATION OPPORTUNITY FOR STAFF

The local hospice is offering the Hospice New Zealand Fundamentals of Palliative Care education resource to all staff. There are nine learning packages, delivered in 1 to 2 hour education sessions. The information is aimed at all staff within a residential aged care facility, registered and unregistered, including administration and support staff. It is a truly multidisciplinary education resource. Certificates will be awarded for each session attended.

ESSENCE OF PALLIATIVE CARE
This package is an important introduction to all packages. It defines palliative care and end of life care and discusses the palliative approach that is the underlying philosophy of care for residents with life-limiting illness.

ETHICAL ISSUES IN PALLIATIVE CARE
Ethical issues occur in end of life care but with the right skills and decision making processes staff will be enabled to assist residents and families in the best way possible.

PAIN AND SYMPTOM MANAGEMENT
Residents with advanced disease may experience symptoms which will have a significant impact on their quality of life. In this session, we will discuss observable assessment of symptoms, causal diagnosis and management of care and ongoing monitoring.

PALLIATIVE CARE FOR PEOPLE WITH CHRONIC ILLNESS
Offered people live with advanced disease that impacts on their quality of life. It is only in recent years that greater recognition of the needs of people with chronic illness other than cancer has been documented. This session looks at the challenges for people with chronic illness and ways to improve their quality of life.

PALLIATIVE CARE FOR PEOPLE WITH DEMENTIA
Residents may live with dementia for many years and the needs of these people require special attention and a palliative approach. In this session, we will discuss how to assess, monitor and manage the needs of people with dementia. This includes assessment of pain and symptoms in people with dementia, how to give effective care, and decision making skills in end of life care.

COMMUNICATION SKILLS
We all communicate everyday but how often do we think about the impact that communication has on those around us? In this session, we will explore how we communicate and what can cause challenges as we communicate with residents and their families and other members of the team.

LAST DAYS OF LIFE
Inevitably, residents will die and care provided during this time hastened the life that has profound effects on the resident, the family and on the care team. We have only one chance to get it right. This session will assist staff in developing the skills to make those last hours positive memories for family.

LOSS AND GRIEF
Although death is inevitable as we are all death denying. In our work we must face death and grief often and the importance of the care we give at the end of life and after death will be explored during this session. We will also look at our own grief and the importance of self-care.

CARING FOR OURSELVES
These in the caring professions are compassionated and caring individuals working with people who are suffering and are therefore at risk of stress and turnover. This session is therefore designed to provide staff with time to reflect on their wellness and look at ways to maintain it.

PLEASE TALK TO YOUR MANAGER ABOUT THIS EDUCATION OPPORTUNITY.
What we know isn’t happening well
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
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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


*Journal of Alzheimer's Disease*
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

- 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

Sleeman K et al (on behalf of the GUIDE_Care project) (2014) Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010

*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

But what about you in all of this?
Balance

Having balance in all aspects of life is the key to achieving personal health and well-being:

• Personal development
• Work
• Social
• Spiritual
• Physical
• Emotional
• Thinking
• Intentional recreation

This does not happen automatically but needs to be considered carefully and regularly
Your wellness

Every day, make time for the things and people that energise you
What rethinking will you do?