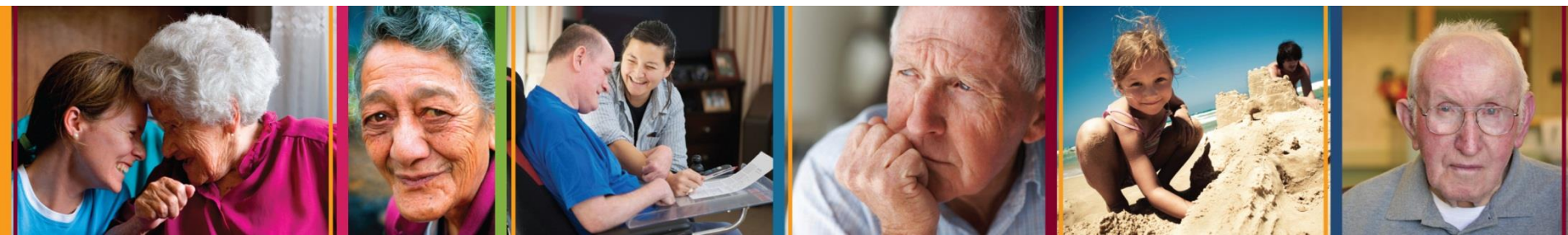


Palliative care and dementia – rethinking how we do it

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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?

**Worried
someone
close
to you
is losing
their
memory?**



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



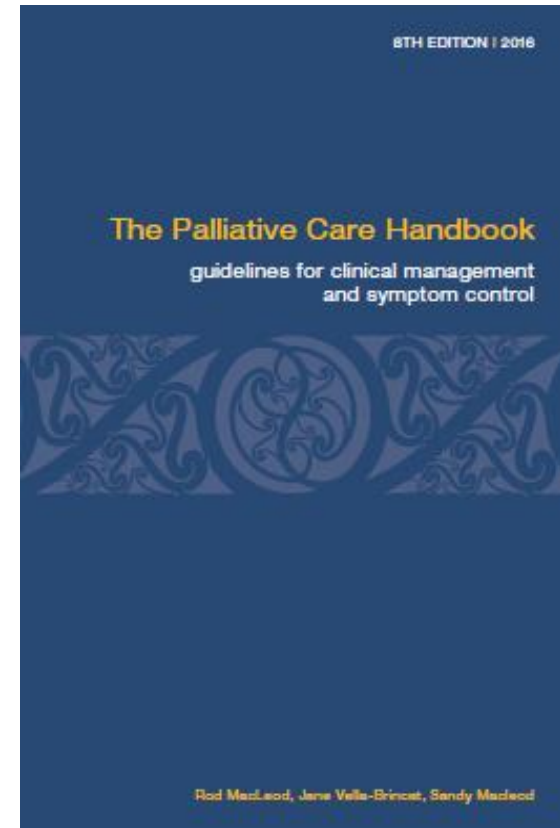
Domain 9

Family care and involvement



Domain 10

Education of the health care team



Domain 11

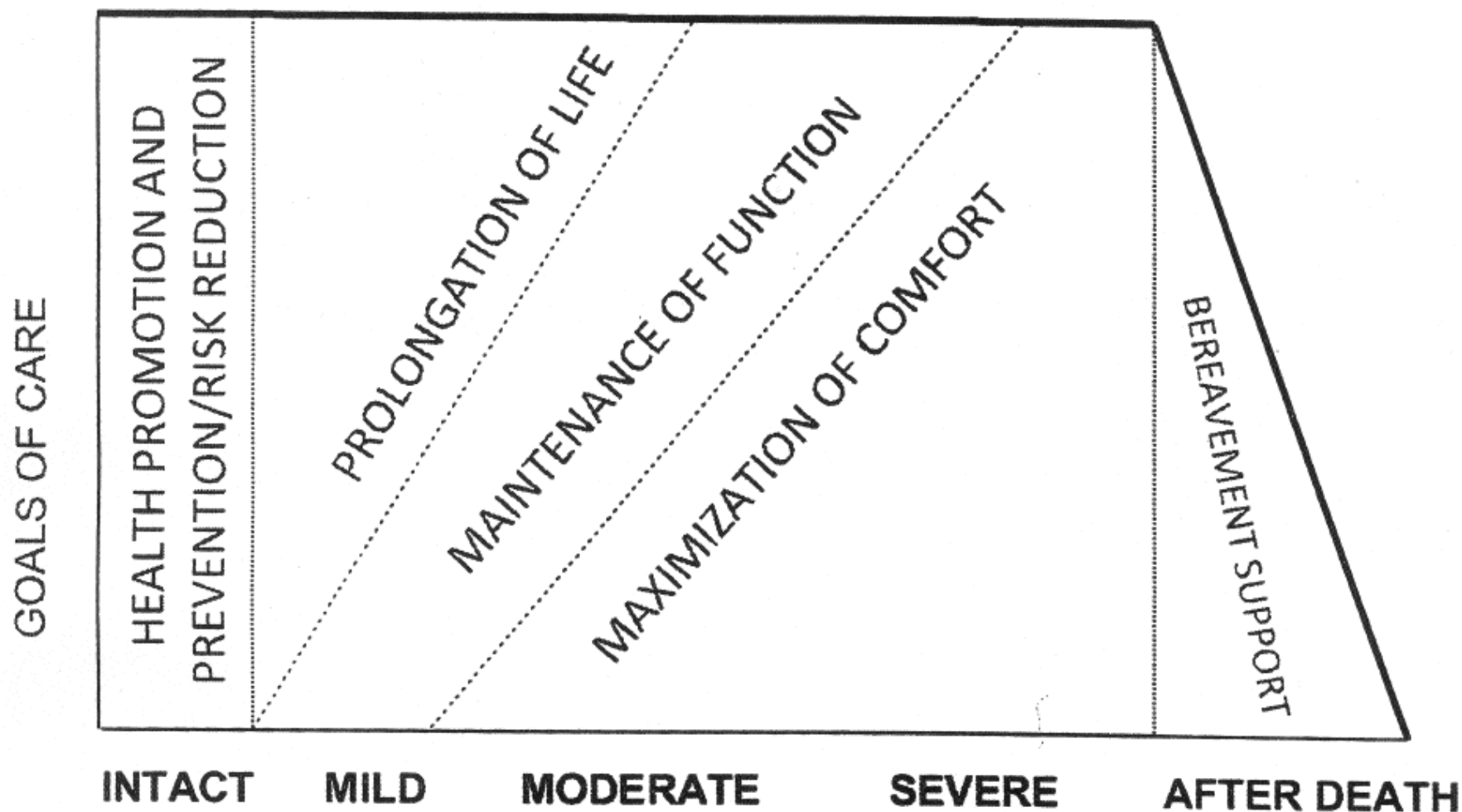
Society and ethics



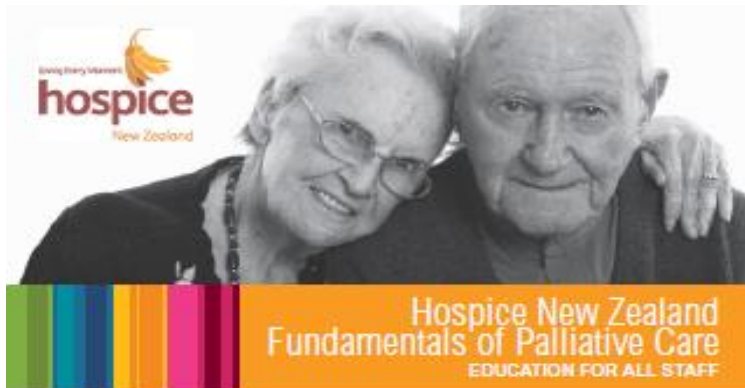
eth·ics (eth'iks) *n.*
The study and philosophy on the determination of right conduct with life, etc. 3. A



Dementia progression and suggested prioritisation of care goals



Fundamentals of palliative/end of life care



The local hospice is offering the Hospice New Zealand Fundamentals of Palliative Care education programme. This involves 10 learning packages, delivered in 1 to 2 hour education sessions.

The information is aimed at all staff, registered and unregistered, including administration and support staff. It is a 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 to care that is the underpinning philosophy of care for people with a life limiting condition.

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 people, and families and whānau, in the best way possible.

PAIN AND SYMPTOM MANAGEMENT

People with advanced disease may experience symptoms which will have a significant impact on their quality of life. In this session we will discuss the importance of assessment of symptoms, careful planning and management of care, and on-going evaluation.

PALLIATIVE CARE FOR PEOPLE WITH CHRONIC ILLNESS

People live with advanced disease that impacts on their quality of life. In recent years there has been a greater recognition of the needs of people with chronic conditions other than cancer. This session looks at the challenges for people with advanced chronic disease and ways to improve their quality of life.

PALLIATIVE CARE FOR PEOPLE WITH DEMENTIA

People may live with dementia for many years and the needs of these people require special attention and a palliative approach throughout their disease trajectory. Staff will learn skills in the holistic assessment of pain and symptoms to avoid stage dementia, how to minimise the burdens and obtain support from family/careers and decision making skills in end of life care.

COMMUNICATION SKILLS

We all communicate every day, 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 people, families and whānau, and other members of the team.

LAST DAYS OF LIFE

Inevitably people will die and care provided during the last days and hours of life has profound effects on people, and their family and whānau and on the care team. We have only one chance to get it right and this session will assist staff in developing the skills to make those last hours result in more positive memories for family.

LOSS AND GRIEF

Although death is inevitable as a society we are still death denying. In our work we 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 also look at our own grief and the importance of self care.

CARING FOR OURSELVES

Those in the caring professions are compassionate and caring individuals working with people who are suffering. Therefore, they are at risk of stress and burnout. This session is designed to provide staff with time to reflect on their wellbeing and look at ways of maintaining it.

INTRODUCTION TO SPIRITUAL CARE

All staff have the potential to offer spiritual care. Each meeting with a person with a life limiting condition offers a chance to attend to the spiritual needs of that person. The need to be treated with dignity, the need to be "heard" and the need to have any spiritual distress noticed and addressed appropriately. This session is an introduction to how to meet the spiritual needs of the people for whom we care.



Ministry of Health

New Zealand Government

Te Ara Whakapiri

Principles and guidance for the
last days of life

Released 2017

health.govt.nz

PLEASE TALK TO YOUR MANAGER ABOUT THIS EDUCATION OPPORTUNITY



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

Durepos P, Wickson-Griffiths A, Hazzan AA et al (2016) Assessing palliative care content in dementia care guidelines: a systematic review. *Journal of Pain and Symptom Management*. doi: 10.1016/j.jpainsymman.2016.10.368



What we know isn't happening well

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

Durepos P, Wickson-Griffiths A, Hazzan AA et al (2016) Assessing palliative care content in dementia care guidelines: a systematic review.

Journal of Pain and Symptom Management. doi: 10.1016/j.jpainsymman.2016.10.368



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

van der Steen JT et al (2014) Factors associated with initiation of advance care planning in dementia: a systematic review. 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)]

van Soest-Poortvliet MC et al. (2015) Comfort goal of care and end-of-life outcomes in dementia: A prospective study.

Palliative Medicine 29(6) 538–546



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

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

Van der Steen J, Deliens L, Koopmans R, Onwuteaka-Philipsen BD (2017) Physicians' perceptions of suffering in people with dementia at the end of life.

Palliative and Supportive Care. doi: 10/1017/S1478951516000985



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
-
- Davies N, Maio L, Rait G, Illiffe S (2014) Quality end of life care for dementia: what have family carers told us so far? A narrative synthesis
Palliative Medicine
doi: 10.1177/0269216317748844journals.sagepub.com/home/pmj
 - Broady TR, Saich F, Hinton T (2018) Caring for a family member or friend with dementia at the end of life: a scoping review and implications for palliative care.
Palliative Medicine.
doi: 10.1177/0269216317748844journals.sagepub.com/home/pmj

But what about you in all of this?



What rethinking will you do?

