Fundamentals of palliative care

Palliative care for people with dementia

Living Every Moment
hospice
New Zealand
WELCOME FROM HOSPICE NZ

Welcome to this training package – we do hope that you enjoy this learning experience and the information here is useful to you in your work.

We would like to take this opportunity to put this education package in context and give you some background to this overall education programme.

In 2009 the Ministry of Health and Hospice New Zealand considered the results of a national stock-take into palliative care service provision.

Nationally, there were two areas of need that required our focus;

• The need for nationally consistent education programmes that support primary palliative care providers.
• The need for revised palliative care standards and an ongoing implementation programme to ensure consistency in the quality of service regardless of locality.

It was agreed Hospice New Zealand was well placed to work on two specific projects to address these needs due to our previous experience and a recent commitment from member hospices throughout the country that these were also priorities for them.

The Minister of Health then allocated a portion of the funding that was available to address difficulties in accessing palliative care services to Hospice NZ for the two projects, this funding commenced on 1 January 2010.

The outcome of both projects will improve the quality and equity of palliative care services available to people and their families and whānau, regardless of the care setting.

This package is part of a 10 part learning series – each contributing to the overall Fundamentals of Palliative Care.

Warm regards,

Mary Schumacher
CEO, Hospice NZ
ABOUT HOSPICE NZ

Hospice NZ exists to support member hospices in their work caring for people who are dying. We are the national organisation whose primary goal is to give voice to the interests, view and concerns of our member hospices.

All hospice services throughout the country are members of Hospice NZ – 30 full members and 4 associate members.

Our purpose is to lead the hospice movement to ensure that every New Zealander has access to quality palliative care.

Our vision is that everyone with a life limiting condition and their families have access to the best possible care.

Our goals;
1. Community engagement – raise awareness and understanding of hospice care through community engagement
2. Leadership – provide national leadership, direction and support through collaboration with members and the wider sector
3. Advocacy – ensure equitable funding and delivery of hospice care
4. Workforce development – support a high performing hospice and palliative care workforce
5. Quality and standards – enhance the quality and standard of palliative care by supporting members to deliver good outcomes for patients, families and whānau.

Our organisational values are a cornerstone to our work;
- Professional
- Respectful
- Caring
- Collaborative
- Honour diversity

www.hospice.org.nz
ACKNOWLEDGEMENTS

Hospice New Zealand was assisted in developing this resource through collaboration with the hospice, primary health, hospital, aged residential care, health of older people and home based support sectors, ensuring the learning packages are ‘fit for purpose’. Both the governance and project teams represent this approach.

Hospice New Zealand wishes to acknowledge the expertise, experience and commitment of members of the Hospice New Zealand Education Governance Group and Education Working Group in developing this version of the Hospice New Zealand Fundamentals of Palliative Care education resource. We sincerely thank them and their trust boards for their contributions of knowledge and time.

The Education Governance Group, chaired by Mary Schumacher, CEO Hospice New Zealand, provided strategic advice on palliative care education and informed the planning of the education programme. The Education Governance Group members were:

**Dr Michal Boyd** – Senior Lecturer, Freemasons’ Department of Geriatric Medicine, University of Auckland and Gerontology Nurse Practitioner, Community Services for Older Adults, Waitemata District Health Board

**Julie Haggie** – CEO, Home and Community Health Association New Zealand

**Dr Marion Taylor** – General Practitioner, Wicksteed House Medical Centre Wanganui and Senior Medical Officer, Hospice Wanganui

**Kate Gibb** – Nursing Director for Older People, Population Health, Canterbury District Health Board

**Dr Brian Ensor** – Director of Palliative Care, Mary Potter Hospice and Clinical Advisor to the Hospice New Zealand Board of Trustees

The Education Working Group assisted Hospice New Zealand with developing the content of the education resource through clinical and technical advice, and expert content advice. The Working Group members were:

**Rachel Hale** – Nurse Practitioner for Older People, Matamata Medical Centre

**Liz Angus** – Community Team Leader, Access Homehealth Limited

**Gayle Elliott** – Clinical Nurse Specialist, Specialist Hospital Palliative Care Service, Southern District Health Board

**Trish Fleming** – Manager, Learning and Development Team, Hospice West Auckland

**Jenny Blyde** – Team Leader, Counselling and Bereavement Service, Hospice Taranaki

**Jan Waldock** – Lead Clinical Nurse Educator, Arohanui Hospice

**Chris Murphy** – Community Liaison and Educator, Mary Potter Hospice

**Dr Oleg Kiriaev** – Geriatrician and Palliative Care Consultant, Totara Hospice South Auckland and Mental Health Service for Older People, Waitemata District Health Board
Sylvia Meijer – Nurse Practitioner and Team Leader, Health of Older Adults, Central Primary Health Organisation

Anne Hampton – Nurse Specialist/Manager, Te Amo Health, Motueka (also representing Te Kaunihera o Nga Nehei Maori – National Maori Nurses Organisation)

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Palliative care for people with dementia

Teaching time: 1 hour

LEARNING OUTCOMES

At the end of the session the participants will be able to;

1. Define what is meant by the term dementia and identify when a person is considered to be at the end stage of their disease
2. Discuss how a palliative care approach can be used in dementia care
3. Discuss the importance of maintaining dignity in a person with dementia
4. Debate the ethical issues faced in dementia care
5. Recognise the effects dementia may have on family, whānau and carers
PRE-SESSION READING AND REFLECTION

Dementia is a progressive life limiting condition. Dementia is the term used to describe brain disorders resulting in a usually progressive loss of brain function.

The symptoms include loss of memory, judgement, intellect and motor skills. There are many different types of dementia (Chatterjee, 2008). The most common ones are Alzheimer’s disease, Vascular dementia and Lewy bodies dementia.

Although in the early stages the clinical symptoms may be different, the end of life stage in all types involves severe physical and cognitive impairment and greater dependence on carers.

A person may live with dementia for many years and the specific needs of these people arise not only from the prolonged disease trajectory and uncertain future but because they lose the ability to express their wishes, verbalise their feelings of pain, discomfort or emotional anguish.

Three areas requiring special attention for people with advanced dementia were identified from literature:

1. Holistic assessment of pain and symptoms in end stage dementia. These assessments are outlined in greater detail in the Pain and Symptom Management learning package. Observational tools should be used for assessment as pain and distress can be emotional, physical or psychological and each person with dementia has their own language of distress. Included in this package are internet references for observational assessment tools that you may wish to review.

2. The burdens and strain experienced by family and carers must be addressed. Carers of people with dementia experience greater compassion fatigue and carer distress than those caring for physically impaired older persons. The person with dementia may well need to go into residential care and this can cause feelings of guilt for family putting their loved ones in care. They may have to cope with challenging behaviour which is ‘out of character’ for their loved one and they increasingly must make decisions and advocate on behalf of their loved one with dementia.

3. End of life decisions for people with advanced dementia may range from the need for the carer to take over tasks such as washing, dressing and feeding to placement in a residential care facility and issues around medical treatment (Baldwin 2006). Many ethical issues arise at the end of life and these are covered in greater detail in the Ethical Issues in Palliative Care learning package but some of the most common ones are discussed in this package. When you are reflecting on the challenges faced when caring for a person with advanced dementia think of the ethical dilemmas you have faced so we can discuss them further during the session. For people with dementia, decisions about end of life care
really needs to be made at the onset of their disease while they still have mental capacity (the ability to make rational decisions) but many people are reluctant to diagnose dementia or discuss the options with people and in the end stages of dementia individuals are no longer able to participate in meaningful discussions and their wishes may not be met.

Carers have to make decisions at a time of crisis and under emotional stress. They will often seek treatment for their loved one and stopping treatment, even though this may be the best option, feels like abandoning their loved one. Carers feel unprepared for their role as proxy decision maker as the discussions have not been had with their loved ones while they were well. Also families often have little understanding of the disease trajectory and feel that letting someone die from untreated pneumonia or lack of food and fluids is unacceptable.

Ongoing communication with health professionals to help them understand the disease process and information about medical treatment options could limit the carer’s uncertainty.

Advance care planning is a process involving discussions throughout the course of an illness and clarifying values and goals to guide decision making.

The taboo of death in our society, the high workloads and staff turnover within residential care are suggested as reasons for the lack of advanced care planning for people (Caron et al 2005). As a result, a significant number of people with advanced dementia will be hospitalised in the last three months of their life.

Specialists in palliative care are skilled in assessing and managing pain and symptoms and have experience in addressing ethical issues such as ceasing active treatment and focusing on comfort and dignity until death. Specialists in gerontology and dementia care are skilled in specific skills related to care and communication with dementia people. Collaboration between both specialties is needed to provide the best end of life care for the people with dementia.

REFLECTION TO BRING TO THE SESSION

1. What are the challenges that face you as you care for people with dementia?

2. Bring a case history of a person you have cared for with dementia. What was your role in caring for this person? How did you make a difference? What were the things you found difficult? Were there any ethical dilemmas that you would like to discuss further?
Have a look at some of the different pain and symptom assessment tools available. References provided below.

**Examples include:**

The Abbey Pain Scale

PAINAD

DisDAT

**POST-SESSION EXERCISE**

**Registered Nurses/Health Professionals:**

Find an article on dementia and share it with other team members at a journal club.

- Briefly outline the key learning points and conclusion from this article
- Outline how the article may improve or develop your practice and how will you implement it into the care of people with dementia in your facility/service
- Create a folder of articles as a resource for your workplace

**Care Assistants:**

Create a list of ways you believe you can improve the quality of life for people with dementia in your workplace, to be included in the resource folder.

**KEY REFERENCES**


Palliative care for people with dementia
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Learning outcomes

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Models of care
Cultural considerations in dementia

- What are the attitudes, values and beliefs you bring to your practice?
- What are your rituals around death and dying?
- What is the organisational culture?
- Discuss the important role of the family at this time

Adapted from: Multidisciplinary Palliative Care Education Programme 2011

What is dementia?

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s disease or a series of strokes.

Dementia in New Zealand

- Approximately 50,000 New Zealanders have dementia
- This number is expected to triple by 2050
- 2 out of every 3 New Zealanders are touched by dementia
- 85% of New Zealanders over 60 are touched by dementia

Alzheimer NZ 2014
Palliative care for people with dementia

**Types of dementia?**

- Alzheimers
- Vascular
- Lewy Body
- frontotemporal
- Other causes

Dementia is an umbrella term used to describe a group of diseases that change and damage our brains (Alzheimers NZ)

**Why is a palliative approach important?**

- Dementia is a progressive illness which can’t be prevented, cured or slowed
- Allows the person to be involved in their advance care planning while they have mental capacity
- Allows the person/family/whānau/carers to develop trusting and honest relationships

**Diagnosing dementia**

- Assessment
- General complexity of needs
- Co-morbidities
- Cultural issues
- Advance directives for care
- Grief and loss
**Why is diagnosing dementia so important?**

- Patient/family are otherwise unaware that they have a life-limiting illness.
- CPR/inappropriate treatment.
- Undignified death with uncontrollable symptoms.
- Inability to focus on palliation.
- Need to plan future care – ACP.
- Complicated family grief.

**Person-centred care**

The person-centred philosophy focuses on the individual rather than on the condition, and on the person’s strengths and abilities rather than losses.

**An important question to ask**

What should I know about you as a person to help me take the best care of you that I can?

Dignity Care
Uncertain 2012
Palliative care for people with dementia

Research shows us

“Palliative care for people with end stage dementia had a number of symptoms for which they did not receive effective palliative care—anaesthesia was infrequently used, dying phase not recognised and some people given antibiotics inappropriately in the last days of life”

Lloyd-Williams and Powner, 2002

Clinical event – infection

- Infections typically develop in people with late-stage dementia—especially aspiration pneumonia and urinary tract infections—these can be treated aggressively with antibiotics or palliative measures of comfort
- At the end of life, decisions need to be made about the balance between the difficulty in administering medicines and the difficulty for the person taking them and the likely benefit of the medicines

Clinical event – eating problems

- Loss of appetite and difficulties with swallowing are a normal part of the disease process in advanced dementia
- Family concerns: malnutrition and subsequent death from starvation
- Should they have feeding tubes for greater comfort and to maintain skin integrity?
Clinical event – pain

- Recognising pain in people with late stage dementia whose verbal communication skills are limited or absent is difficult.
- Studies have shown that pain is significantly under-diagnosed and under-treated in these people.
- The use of an observational pain assessment such as Abbot pain scale is imperative.

Diagnosing dying in dementia

- Why is this important?
- What are the barriers?
- How to approach
- Case studies

How will we know a person with dementia is dying

- Debrinating day by day or faster
- Increasingly drowsy or comatose
- Increasingly bedbound
- Peripherally cyanosed and cold
- Taking increasingly little food, fluid or oral medication
- Altered breathing pattern
  (Reynolds and Mosley 2013).
Palliative care for people with dementia

What are the barriers to diagnosing dying?

- No diagnosis
- Hope of improvement or fear of shortening life
- Pursuing futile or unrealistic interventions
- Difficulty in the concept of dementia as a terminal illness
- Difficulty discussing death
- Poor communication
- Lack of knowledge in palliative care
- Cultural/spiritual barriers
- Medico-legal issues

Duty of care

- Enduring power of attorney important
- Family have no legal right to dictate care but will advocate for person’s wishes
- No law or professional ethical code requires health care providers to give futile or inappropriate treatment, or compromise pain and symptom relief
- A provider’s primary duty is to the unwell person

How can we help?
Care for the carer

- Physically and emotionally exhausting caring for a person with dementia
- Long and sometimes lonely journey
- Lack of support or resources
- Series of losses as memories go

Conclusion

- Concept of dementia as a terminal illness
- Person-centred care/palliative care approach with impeccable assessment and appropriate interventions to relieve suffering
- Importance of advance care planning
- Individualised care plans
- Good communication essential
- Interdisciplinary approach essential

Thoughts to leave you with:

An Alzheimer's Poem
Do not ask me to remember.
Do not try to make me understand.
Let me sit and have you with me.
Kiss my cheek and hold my hand.
I'm confused beyond your concept.
I am cold and sick and lost.
All I know is that I need you to be With me at all cost.
Do not lose your patience with me.
Do not scold or come over.
I can't help the way I'm acting.
Can't be different though I try.
Just remember that I loved you.
That the best of me is gone.
Please don't fail to stand beside me.
Love me till my life's done.