Palliative care for people with chronic illness
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)

We thank Anne Morgan, Hospice New Zealand Practice Development Advisor, for her role as content coordinator and writer of the education resource.

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Palliative care for people with chronic illness

Teaching time: 1 hour

LEARNING OUTCOMES

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

1. List the common chronic illnesses that may cause distress for those for whom you care
2. Discuss the effect chronic illness has on a person’s quality of life using the model of total suffering
3. Describe challenges faced by people with advanced:
   - Cardiac disease
   - Neurological disease
   - Respiratory disease
   - Cancer
   - Renal disease
   - Liver disease
PRE-SESSION READING AND REFLECTION

Why is palliative care available for cancer patients and not for everyone with a terminal illness?

This is a commonly asked question but it is really only in recent years that greater recognition of the needs of people with chronic illnesses other than cancer have been documented. The specialty of palliative care has traditionally grown out of oncology and there has been little research into the needs of people dying from causes other than cancer.

People with chronic illness have as many similar and distressing symptoms as people with cancer. In addition they often have a worse or equally bad prognosis. Although there is an increasing recognition of the need for palliative care in terminal non-malignant conditions at present <10% of people receiving specialist palliative care services are from this group.

People dying from cancer generally have a gradual deterioration over time and it is usually obvious when they are entering the last days of life.

In contrast, people with chronic disease often deteriorate over a longer period of time; sometimes years or even decades and frequently interspersed by acute episodes that are consequently managed in more acute settings.

Good palliative medicine for all patients requires:

- The recognition and communication that prognosis is short. Prognostication is difficult; however, the question ‘Would I be surprised if this patient died within the next year?’ can be a useful prompt for discussion, decision-making and care planning with the patient
- Collaboration between specialties to evolve effective symptom management and models of care for the increasing number of people living and dying with advanced, progressive disease
- Well-structured, coordinated and adequately resourced delivery of health and social care (Kite & Hicks, 2005).

Prescribing for this group of people is complex. Medical treatments may provide good palliation near the end of life for people with chronic diseases such as cancer, cardiac, respiratory, neurological and renal failure. Drugs for symptom management are also usually needed. The balance between benefits and burdens of all medical treatment in the palliation of symptoms needs to be clear. A team approach to the planning of care is therefore very important.

The importance of non-cancer palliative care cannot be over emphasised. Approximately 75% of the population die from something other than cancer.
Some of this number may die suddenly but most are likely to develop a progressive life-threatening disease. Palliative care is then required to help maintain their quality of life until they die. This is particularly likely in a population where the proportion of older people is increasing and multiple illnesses are becoming more common.

One of the greatest dilemmas is knowing when the advanced and terminal stage of a disease is reached. Negotiating a change from active to palliative treatment with a person's informed consent is vital but fraught with difficulty because defining the transition is not easy.

Communication and decision making with the person and the family can often be difficult in chronic illness. Engaging in sensitive discussions can help to avoid futile treatments that may cause side effects. They can promote and ensure comfort and dignity by alleviating the symptoms and improving quality of life.

**REFLECTION TO BRING TO THE TEACHING SESSION**

Reflect on a person you are caring for who has a chronic illness.

What have you observed about the challenges that face them?

Bring to the session a brief case scenario and an outline of the needs facing this person and how you have met those needs.

**POST-SESSION EXERCISE**

Choose a person with a chronic illness (e.g. heart disease, respiratory disease, MND, kidney disease, stroke) in your care and seek their permission to talk with them about living with chronic illness.

What does the person identify as some of the major challenges they face and what do they find helpful when managing their illness. From reflecting on what you learnt in the teaching session how might you help this person with the issues they identified.
KEY REFERENCES


Mitsumoto, H. & Rabkin, J. (2007). Palliative Care for Patients with Amyotrophic Lateral Sclerosis “Prepare for the Worst and Hope for the Best”. JAMA, 298 (2), 207-216

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Learning outcomes

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Models of care
Cultural and spiritual considerations in chronic illness

- 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 Waikato Palliative Care Education Programme 2019

Overview

- How palliative care fits in chronic disease management
- There are multiple life threatening diseases
- Care versus cure
- Transitions to palliative approach

Illness trajectories

- Important for planning palliative care services
  - Got et al (2007) have explored dying trajectories in heart failure
- Role of Palliative Care being re-evaluated:
  - Not simply end of life or last days of life care
  - Not restricted to cancer or to hospices
  - Not a "time in the sand"

"Illness Trajectories and Palliative Care"
Murray et al, BMJ 2005
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Trajectories as described by Lynne 2003

Survival time/prognosis – the reality

Prolonged dwindling

- The numbers of people living with various chronic conditions will increase markedly in the next decade
- These people are likely to lose the ability to care for themselves long before death;
  - intensive personal care during period of dependency,
  - imposing substantial burdens on paid and unpaid (family) caregivers
  - occasional episodes of acute illness or gradual loss of ground and eventual death
Challenges for future care

- Need equity of services for all people
- Multiple co-morbidities
- Complexity of issues especially prognosis
- Increasing elderly population in NZ
- Increasing number of elderly with dementia
- Need dignity, respect and fairness throughout the patient’s end of life journey
- Team approach
- Advance care planning
- Realistic goal setting
- Workforce issues

Leading causes of death

- What diseases do you think people might have that could be considered chronic illness?
- Are there any differences in the general care you might provide to these people?

What issues do people with chronic illness face?

- Unpleasant and sometimes hard to manage symptoms
- Often have their disease for many years with episodes of crisis requiring hospital admissions
- Concern about giving opiates for chronic non-malignant pain
- Need for earlier palliative approach to care
- When to stop treatment?
- The last days of life are often difficult to predict and/or recognise and death may happen quickly
- Specialist support
- Care burden (family and health professional)
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Effects on quality of life

- Physical suffering
- Inability to enjoy remaining life
- Simple tasks become a challenge
- Isolated from loved ones
- Unable to fulfill remaining life goals
- Worst fears about dying become a reality
- Delirium of hope changes for any quality of life
- Quality of life becomes different

Common needs and challenges for people with chronic illness

- Physical
- Social
- Psychological
- Spiritual

Important considerations

- Advance care planning
- The need for early recognition of symptoms
- Pain is often poorly assessed and under treated particularly in the older person
- Diagnosis of dying is difficult in chronic illness but necessary otherwise death often becomes unrecognised
- Cognitive and communicative difficulties near peoples needs are often unmet
- Attitudes towards expectation of symptoms as we age both by people and health professionals
- Depression – often undiagnosed – poor screening
- Involve family and whānau all the way along
- Include specialist support
**Cancer**

- What does the person really want?
- ACP/Goal setting
- Age alone does not preclude treatment
- Evaluation of organ function – toxicity
- Treatment goals – context of:
  - co-morbidities
  - functional status
  - side effects vs benefits
- Palliative treatment – chemotherapy and radiation

**Advanced cardiac disease**

Common symptoms and issues:
- dyspnoea, cough
- lethargy, fatigue
- nausea, constipation, anorexia, cachexia, weight loss
- poor mobility
- insomnia
- confusion, depression, anxiety, fear
- dizziness, postural hypotension
- fluid retention
- poor quality of life
- frequent hospital admissions

**End stage renal disease (ESRD)**

- The prevalence of chronic kidney disease is increasing especially among the elderly
- End of life is rarely discussed
- With advance care planning, people can be enabled to make the choice of stopping or not starting dialysis
- While dialysis in ESRD prolongs life it does not always improve quality of life and is not always possible
- Chronic pain is common for people with ESRD and impacts on virtually every aspect of their quality of life
- The need for palliative care for people with ESRD is increasingly recognised
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**Opioids in ESRD**

- Good understanding of pain medications is essential in ESRD
- Most opioids are metabolised by the liver and the metabolites are excreted by the kidneys
- Do not use codeine or pethidine
- Metabolites of morphine are active and will accumulate, potentially causing serious toxicity
- Codeine is generally safe to use in milder renal failure (<10% excreted renally)
  - in ESRD the dose is reduced (50%)

**Advanced neurological disease**

- Motor neuron disease
- Stroke
- Parkinson's disease
- Huntington's disease
- Multiple Sclerosis
- Brain injury
- Dementia

**Advanced respiratory disease**

- The most common respiratory disease is Chronic Obstructive Pulmonary Disease (COPD)
- Clinical course not easy to predict
- Life span can be decided
- Life becomes very difficult for people, family and whānau
- Advance care planning is important
Diagnosing dying

- What do you see in people that makes you think they may be dying?
- What do you do once you believe a person is dying?
- What are some of the barriers to diagnosing dying in your workplace?

Death for many with chronic illness

- Often in crowded hospital wards where busy medical and nursing staff can devote little attention to them
- People who die from chronic illness have as many complex care needs as those with advanced cancer and yet very few receive specialist palliative care
- Advance care planning is often lacking and those people feel less able to articulate their concerns and wishes about how they would like to die

Decision making as their illness progresses

- What is most appropriate for the person?
- What is the primary goal of care – prolongation of life or improving quality of life?
- Who should decide?
Conclusion

- Chronic illness markedly affects the quality of life for the person, their family and whānau.
- Palliative care can provide comfort and relief of suffering.
- Excellent communication with all health care workers involved in a person’s care.
- Person-centred care is important.

A thought to leave you with:

Caring for the dying is like building the most beautiful sandcastle in the world, but always being fully aware that the tide will inevitably take its course and leave only memories of what was.

Pema Chödrön