# Learning Support

## Palliative care

<table>
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<tr>
<th>Course Code</th>
<th>Description</th>
<th>Level</th>
<th>Credits</th>
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<tr>
<td>28738</td>
<td>Describe the key principles of palliative care and a support worker’s role</td>
<td>Level 3</td>
<td>3 credits</td>
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<td></td>
<td>in a palliative approach to care.</td>
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<tr>
<td>29523</td>
<td>Apply a palliative care approach in a health or wellbeing setting.</td>
<td>Level 4</td>
<td>8 credits</td>
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**Careerforce**

Issue 2.1
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Acknowledgement

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Introduction

The recommended learning about palliative care is attendance at and participation in the Hospice New Zealand’s Fundamentals of Palliative Care education programme, which provides a wide range of education on palliative care.

If you have previously attended these workshops, or are not able to attend the workshops, and you are working in palliative care, this learning support will assist you achieve the unit standards.

Fundamentals of Palliative Care

There is a self-learning component before the formal education sessions. Ten learning packages are delivered in one to two hour education sessions. The ten topics are listed below.

- Essence of palliative care.
- Ethical issues in palliative care.
- Pain and symptom management.
- Palliative care for chronic illness.
- Palliative care and dementia.
- Communication skills.
- Last days of life.
- Loss and grief.
- Caring for ourselves.
- Introduction to spiritual care.

Post-session learning activities ensures people take the information and experiences back into their work environment.

For more information on the Fundamentals of Palliative Care education programme, talk to your local hospice or see Hospice New Zealand’s education webpage [www.hospice.org.nz](http://www.hospice.org.nz) which includes contact details.
How to use this learning support

This learning support assists you in your learning and prepares you for the unit standard assessment. It is yours to keep.

Make it your own by writing notes that help you remember things, or where you need to find more information.

This learning support is organised within the same ten topics as the Fundamentals of Palliative Care education programme.

Each topic has:

• a brief introduction.
• relevant definitions.
• links to media files such as podcasts and YouTube videos to listen to and watch.
• websites and resources for more information.

You’ll find information about the unit standard assessments on the next page.

More resources

The tips in the notes column lead to more information and resources.

Hospice New Zealand has lots of helpful resources on their website. [http://www.hospice.org.nz/resources/useful-links](http://www.hospice.org.nz/resources/useful-links)

If you are enrolled with Careerforce to do a palliative care unit standard you can have access to MyPath which also has this learning material.

You might find it helpful to talk to your workmates or supervisor about how this information applies to your work.
Preparing for the unit standard assessments

This learning material is helpful for doing the unit standards assessments.

US 28738 Describe the key principles of palliative care and a support worker’s role in a palliative approach to care (level 3, 3 credits).

To attain US 28738 you need to be able to describe:

• the key principles of the palliative care approach.
• the total suffering model.
• care in the last days of life.
• a support worker’s role in a palliative approach to care.
• opportunities and challenges faced in a palliative context.

You will answer theory questions on this knowledge.

US 29523 Apply a palliative care approach in a health or wellbeing setting (level 4, 8 credits).

To achieve US 29523 you must demonstrate that you:

• understand ethical issues in palliative care.
• work with the interdisciplinary team.
• support a person using a palliative care approach.
• support a person during the last days of life.
• support the person and their family/whānau.
• report any change in a timely manner.
• practice and implement self-care.

You must be working in a palliative care as you will be observed providing support. This will be for two situations, one for palliative care and one for the last days of life. This can be two separate people or it can be the same person at different stages of their care, and their relevant family/whānau.

You can provide your job description and documents like meeting minutes to illustrate your role as part of a team.

You will also answer theory questions.
Essence of palliative care

Dame Cicely Saunders, founder of the modern hospice movement, said “How people die remains in the memory of those who live on.” Palliative care can relieve the suffering of the person and their family.

Watch the short video animation which compares palliative care to the foundation of a bridge. www.youtube.com/watch?v=lDHhg76tMHc

Palliative Care

Palliative care is for people of all ages with a life-limiting or life-threatening condition which aims to:

- optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs.
- support the individual’s family/whānau, and other caregivers where needed, through the illness and after death.

Important features of palliative care are that it should be:

- available wherever the person lives.
- provided by all health care professionals, supported where necessary by specialist palliative care services.
- provided in a way that meets the unique needs of individuals from particular communities or groups. This includes but is not limited to Māori, children and young people, immigrants, those with intellectual disability, refugees, prisoners, the homeless and those in isolated communities.

Palliative care is provided according to a person’s need and palliative care services are generally provided by an interdisciplinary team who works with the person who is dying and their family/whānau.

Useful definitions

Here are some definitions and explanations of the meaning of some common terms (given in bold below). There are more definitions in the New Zealand Palliative Care Glossary (2015) from the Ministry of Health at www.health.govt.nz/publication/new-zealand-palliative-care-glossary

Palliative care is for people of all ages with a life-limiting or life-threatening condition.

The palliative care approach embraces the definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with the person and their family, and respects the wishes of the person about their treatment and care.
**Life-limiting condition** is a condition for which there is no reasonable hope of cure and from which the person is expected to die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers.

**Life-threatening condition** is usually of short duration with an acute or unexpected onset. Curative treatment may be feasible but can fail. It may or may not occur in the context of a pre-existing life-limiting condition.

The **total suffering model** means using an holistic approach where the whole person is looked at, not just one part of the person.

Anne Morgan described total suffering in 2004 as a ‘clockwork mechanism’ as various aspects of suffering interact with others. Each aspect is interdependent and must be viewed as a whole – just as with a clock if one cog is affected the clock can no longer function effectively no matter how much we wind it.


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**End of life** is that period of time prior to death. The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. End of life care is guided by the person’s needs and goals, and is the responsibility of all who work within the health sector. It covers the full range of clinical services provided from the point when a life-threatening condition or illness is diagnosed until after the death.

**Last days of life** is the period when a person is dying. It is the period in which death is imminent and may be measured in hours or days.

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Palliative pathways

There is a distinction made between palliative care and end of life care. The palliative approach to care should be introduced when it is thought that people are entering the final phase of life, but are not yet at end of life. Except in the case of sudden events, this phase should be recognised weeks or months prior to death and would be heralded by changes such as decreasing mobility, reduced appetite, and social withdrawal.

The following flowchart shows the pathways for the palliative approach to care. Note that if a person's health improves, they may then revert to an earlier pathway.

Source: Adapted from The Palliative Approach Toolkit (University of Queensland, 2012)
Ethical issues in palliative care

Ethical issues near the end of life often arise because of concerns about how much and what kind of care is appropriate for a person with a limited life expectancy. Ethical dilemmas may challenge the values and beliefs of carers.

Ethical issues that may arise when providing support to a person may include but are not limited to – artificial nutrition and hydration, palliative sedation, limitation of treatments, do not resuscitate (DNR) or allow natural death (AND), informed consent, advanced care planning, advance directives.

Here are some definitions and explanations of the meaning of these terms (given in **bold** below).

**Artificial nutrition and hydration** is a medical treatment which may be refused. People who die at home and in hospices generally do not receive artificial hydration, whereas in hospitals and aged residential care facilities artificial hydration is becoming common practice. Refusal of food and fluid is a natural part of the dying process.

**Palliative sedation** has the sole purpose of relief of intractable suffering which cannot be managed with other medications. It produces sedation. The good effect of relieving suffering must outweigh any untoward outcome, like hastening death.

**Limitation of treatment** is stopping any treatment which is no longer effective, and not starting any treatment which is futile or inappropriate. Decisions about offering, withholding or withdrawing treatment are made by the clinician in the person’s best interests. The person also has the right to refuse treatment.

**Allow Natural Death** (AND) is an instruction that allows a natural course of events to occur. It is an active, positive position embodying the hope that dying will occur peacefully and naturally as possible, surrounded by loved ones. It is a positive action of what is being done, rather than what is not going to be done. The term Allow Natural Death may be used as an alternative to Do Not Resuscitate (DNR).
Informed consent is the right to information and disclosure of truth and for the person to be able to make wise choices. People who are competent and have the capacity to make health care decisions have the right to make decisions about their own care, whether or not these decisions are approved by their care team or family.

Advance care planning is thinking about, talking about and planning for future health care and end of life care. Focused on the individual, it involves the person and the health care professionals responsible for their care. It may involve the person’s family/whānau and/or carers if that is the person’s wish. Individuals can express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available. You can find more about this at [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

Advance Directive is consent or refusal to specific treatment(s) which may be offered in the future when the person no longer has capacity to make their own decisions. This may be written or oral. Advance Directives are defined in the Code of Rights. They may also be referred to as ‘living wills’.

The following links discuss ethical issues and provide some case studies.

[www.scu.edu/ethics/focus-areas/bioethics/resources/palliative-care-an-ethical-obligation/](http://www.scu.edu/ethics/focus-areas/bioethics/resources/palliative-care-an-ethical-obligation/)


*Terminal Dehydration* - A nine minute podcast dealing with the ethical issue of hydration at the end of life.

Pain and symptom management

High-quality palliative care involves relieving the distressing symptoms and the physical pain of a person with a life-threatening or life-limiting condition.

This is a specialised area, involving:

- pain assessment and management.
- other symptoms.
- pharmacology.

Pain is often unrecognised and under treated, and cognitive and communication difficulties may make assessment difficult. There are several tools available for pain and symptom assessment. Early recognition of symptoms is paramount.

The carer’s role is to Identify the problem, think of a possible cause, and manage the symptoms in the best possible way.

Often the focus is on the pain rather than the person. Using the concept of total suffering, an holistic approach where the whole person is looked at, should be taken. You can read more about that at this website. http://mobcdhb.palliativecare.org.nz/Total%20Suffering.pdf

The concept of total pain is explored in this article

www.fmhs.auckland.ac.nz/assets/fmhs/soph/goodfellow/docs/total_pain_handout.pdf

Note that you should treat warily the section on ‘Treating physical pain’ as this is from 2007 and drugs have advanced.

The latest resource for pain and symptom management is:

The Palliative Care Handbook guidelines for clinical management and symptom control (2016)


Please note that this is a specialised resource and drugs may require a RN or GP to administer.
Palliative care for chronic illness

The *Healthy Ageing Strategy* (2016) vision is that “older people live well, age well, and have a respectful end of life in age-friendly communities”. It takes a life-course approach that seeks to maximise health and wellbeing for all older people. [www.health.govt.nz/publication/healthy-ageing-strategy](http://www.health.govt.nz/publication/healthy-ageing-strategy)

Traditionally palliative care concentrated on the needs of cancer patients, yet approximately 75% of the population die from something other than cancer. With an ageing population, there is increasing recognition of the need for palliative care for people dying of other conditions. Many will have uncomplicated deaths, but as we live longer, we can expect increasing numbers of people with more complex conditions, including dementia, requiring more specialised care.

Chronic diseases include heart disease, respiratory disease, pneumonia, cerebrovascular disease, diabetes plus complications, chronic liver disease, ischaemic diseases, end stage renal disease, immune diseases and muscular diseases. A person may have a number of comorbidities ie potentially life-limiting illnesses.

View *A Good Death* a 26 minute film about end of life care for a person with Chronic Pulmonary Obstructive Disease [http://agooddeath.co.nz/](http://agooddeath.co.nz/)

End-of-life care for patients with chronic disease


Professor D. Robin Taylor, Professor of Respiratory Medicine, at the Dunedin School of Medicine, University of Otago, called for a paradigm shift in the way that health care organisations and their staff provided care for patients with chronic illnesses, who are dying.

In 2015 this was revisited to question whether this paradigm shift has occurred in New Zealand. Professor Taylor is continuing his research on end of life care at the University of Edinburgh. Dr Syed Hussain, Respiratory Physician and Advanced Care Planning “clinical champion” at Auckland City Hospital, comments on how far we have come in the provision of end-of-life care, and how much further we need to go. [www.bpac.org.nz/BPJ/2015/February/end-of-life.aspx](http://www.bpac.org.nz/BPJ/2015/February/end-of-life.aspx)
Palliative care and dementia

Dementia is a progressive life-limiting condition with a progressive loss of brain function that may include memory loss, and difficulties with thinking, problem-solving and language.


The framework has three guiding principles:
- following a person-centred and people-directed approach.
- providing accessible, proactive and integrated services that are flexible to meet a variety of needs.
- developing the highest possible standard of care.

The publication also highlights five key elements for effective dementia care:
- awareness and risk reduction.
- assessment, diagnosis, early intervention and ongoing support.
- living well.
- meeting challenges to maximise wellbeing.
- end of life.
Dementia: End of Life Care

Decisions about end of life care need to be made at the onset of the disease, while the person has the mental capacity to make rational decisions.

Advance care planning is thinking about, talking about and planning for future health care and end of life care. Focused on the individual, it involves the person and the health care professionals responsible for their care. It may involve the person’s family/whānau and/or carers if that is the person’s wish. Individuals can express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available. You can find more about this at www.advancecareplanning.org.nz

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People with dementia have been recognised as having significant unmet palliative care needs. End of life for those with dementia is often not well recognised. Recognising pain when people may have limited or no verbal skills is difficult.

This 10 minute UK video is about recognising and understanding those in the end of life stage. Decisions: End of life care

www.youtube.com/watch?v=3zKADdgcf14

Dementia carers

Caring for someone with dementia can be a long, stressful, and intensely emotional journey. As the disease advances, the person’s needs will increase and your caregiving responsibilities will become more challenging. You need to look after yourself or the demands may wear you down.

These articles from Australia and USA are helpful for self-care.

Taking care of carers


Tips for Alzheimer’s caregivers

www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm
Communication skills

Communication is an essential part of health care – talking, listening and the messages conveyed by our body language. Communicating about death and dying is a sensitive issue.

What to say and do

This American video gives you 10 steps of what to say and do in a short six minute clip.

*The Human Connection of Palliative Care: Ten steps for what to say and do*  [www.youtube.com/watch?v=7kQ3PUyhmPQ](http://www.youtube.com/watch?v=7kQ3PUyhmPQ)

*What can I say, what can I do* - an information brochure for families and friends from Palliative Care Australia


Providing advocacy

Everybody has the right to information, as set out in the Code of Rights. People also have the right to refuse information. Some people want to know everything; others don’t want to know very much; some only want their family/whānau to know. People need as much information as they indicate they want to make informed choices. Decisions can be hard to make and need time.

Some New Zealand examples of providing advocacy for people and their family/whānau are at  [http://advocacy.hdc.org.nz/case-studies/health-services/hospicepalliative-care](http://advocacy.hdc.org.nz/case-studies/health-services/hospicepalliative-care)

Breaking Bad News

The A-B-C-D-E of breaking bad news is outlined here


Using humour

In this film, [www.dyingmatters.org/page/last-laugh](http://www.dyingmatters.org/page/last-laugh) the veteran stand-up comedian Alexei Sayle talks to four people whose life expectancy is less than a year, discovering how humour not only helps them to manage their illness but breaks down the isolation and frustration they feel when professionals, friends and even family treat them with kid gloves.
**Last days of life**

Carers must know the difference between the focus of palliative care and care in the last days of life.

A palliative approach to care aims to optimise an individual’s quality of life until death. Care in the last days of life is the period when a person is dying and death is imminent. The focus of care changes from extending the quality of life to improving the quality of life.

**End of life** is that period of time prior to death but the duration can never be precisely defined in advance. The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. End of life care is guided by the person’s needs and goals, and is the responsibility of all who work within the health sector. It covers the full range of clinical services provided from the point when a life-threatening condition or illness is diagnosed until after the death.

**Last days of life** is the period when a person is dying. It is the period in which death is imminent, and may be measured in hours or days.

An essential reference for the last days of life is *Te Ara Whakapiri: Principles and guidance for the last days of life* which defines what adult New Zealanders can expect as they approach the end of their life, whether at home, or in residential care, hospitals or hospices.

It is available from the Ministry of Health or Hospice New Zealand [www.hospice.org.nz/resources/te-ara-whakapiri](http://www.hospice.org.nz/resources/te-ara-whakapiri)

*Te Ara Whakapiri Toolkit* is for care in the last days of life, including:

- a baseline assessment and care-after-death checklist (*Care in the Last Days of Life*)
- ongoing plans of care (*Ongoing Care of the Dying Person* to be used in health care settings and *Home Care in the Last Days of Life* to be used in the person’s home)
- the *Recognising the Dying Person Flow Chart*
- a list of principles for general medical management planning (*Medical Management Planning – General Principles*)
- the *Bereavement Risk Assessment Tool*
- a *Discharge Checklist* (for people going home to die)
- symptom-management flow charts (covering pain, agitation, delirium and restlessness, nausea and vomiting, excessive respiratory tract secretions and dyspnoea/breathlessness).

The toolkit also includes information for patient/family/whānau such as:

- *When Death Approaches*
- *Dying at Home*
Loss and grief

Health workers meet death as part of work and the care given at end of life and after death for the person will be etched on family/whānau minds forever.

As Dame Cicely Saunders, founder of the modern hospice movement, said “How people die remains in the memory of those who live on.”

Grief is our response to loss. There are many losses during the dying, grieving and bereavement period, for the person, their family/whānau, carers, GPs and other health professionals.

“Loss and grief are a package deal” is what Elaine Mansfield says in her 16 minutes TED talk Good grief! What I learned from loss

www.youtube.com/watch?v=PBzEwf1k59Y

Coping with loss and grief

In a 16 minute podcast Australian widowers Fred and Jim talk about coping with grief and loneliness after the death of their wives.


This article on Suffering, loss and grief in palliative care offers some communication strategies


Mid Central Health DHB has a publication called Palliative Care Bereavement Support Guidelines


Nurse Maude Hospice in Christchurch has patient information on bereavement support (Christchurch-based)


An Australian webpage is How to help someone who is greiving


Health Navigator – Grief and Loss has details of brochures and factsheets available in NZ

www.healthnavigator.org.nz/health-a-z/grief-loss/?tab=7480
Caring for ourselves

People caring for others are compassionate and caring individuals and they are at risk of stress and burnout. It can be difficult watching a person who was vigorous and healthy deteriorate to someone needing help with walking, bathing, feeding and so on. It is particularly hard for those caring for a member of their family.

Your wellbeing is your responsibility – you cannot support others if you are not well yourself. You have choices you make each day to maintain your wellness, around nutrition, exercise and relaxation.

A guide for carers is information and support for people caring for someone with a life-limiting condition in New Zealand.

It includes chapters on being a caregiver, caring for a loved one, circles of support, home nursing tips and practical matters.

You can download this as individual chapters or as a full booklet.

www.hospice.org.nz/resources/a-guide-for-carers

This Australian resource has information for carers and family, including videos on a variety of topics, which are available in several languages


It also has information on self-care for carers (or nurses).


This is an American self help website site www.helpguide.org/

Search the topics A-Z for ‘grief’ and ‘stress’

www.helpguide.org/home-pages/grief.htm

www.helpguide.org/home-pages/stress.htm

They also have a section for Alzheimer’s carers

www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm

An American resource A LifeCare Guide to Helping Others Cope with Grief includes helping co-workers with grief


Think about

How well do you care for yourself?

Talk

Talk with a colleague about how you care for yourselves.

More info

There are lots of resources on taking care of yourself. Make sure you do.
Introduction to spiritual care

Everyone has the potential to offer spiritual care, attending to the spiritual needs of the person; the need to be treated with dignity, the need to be heard, the need to have any spiritual distress noticed and addressed.

Spirituality is not necessarily about religion. Exploring one’s own spirituality helps you to support people you care for.

Spiritual care - the care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires. (NHS Education for Scotland, 2009).

This definition is from Spirituality in nursing care: a pocket guide published by the Royal College of Nursing in UK but it is applicable to all carers.


Caring for ourselves

Talk with your colleagues – they may have good self-care tips to share.
## Glossary

### Key words

<table>
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<td><strong>Code of Rights</strong></td>
<td>sets out rights for people who use health, disability and aged care services. It is about making sure that people are treated fairly. People can plan ahead to ensure their rights are taken care of when they can no longer make decisions, for example, with an advanced directive.</td>
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<td><strong>Do Not Resuscitate (DNR)</strong></td>
<td>an order which indicates that a person — usually with a terminal illness or other serious medical condition — has decided not to have cardiopulmonary resuscitation (CPR) attempted in the event their heart or breathing stops. The term allow natural death (AND) is gaining favour as it focuses on what is being done, not what is being avoided.</td>
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<td>that period of time prior to death. The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. End of life care is guided by the person’s needs and goals, and is the responsibility of all who work within the health sector. It covers the full range of clinical services provided from the point when a life-threatening condition or illness is diagnosed until after the death.</td>
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<td>Living will</td>
<td>consent or refusal to specific treatment(s) which may be offered in the future when the person no longer has capacity to make their own decisions. This may be written or oral. It is also called an advance directive.</td>
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<td>Palliative care</td>
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<td>the sole purpose of relief of intractable suffering which cannot be managed with other medications. It produces sedation. The good effect of relieving suffering must outweigh any untoward outcome, like hastening death.</td>
</tr>
<tr>
<td>Total suffering model</td>
<td>how various aspects of suffering interact with others, are interdependent, and must be viewed as a whole. Using the concept of total suffering means an holistic approach where the whole person is looked at, not just one part of the person.</td>
</tr>
</tbody>
</table>