Fundamentals of palliative care

Ethical issues in palliative care
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

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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

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Chris Murphy – Community Liaison and Educator, Mary Potter Hospice

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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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Teaching time: 1-2 hours

LEARNING OUTCOMES

At the end of the session the learner will be able to:
1. Understand ethical definitions, principles and frameworks
2. Explain what is meant by an ethical issue
3. Describe the responsibilities of health professionals in relation to ethics
4. Give examples of ethical issues we may face
5. Explain the decisions considered/made prior to withholding or withdrawing treatment

“A dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong, as well as useless, to resist.”

Stewart Alsop
PRE-SESSION READING AND REFLECTION

Ethical issues in health care particularly affect the elderly for several reasons: older people are sick more often than younger people, suffer more from being in the end stage of various chronic progressive degenerative diseases and are most likely to lack the capacity to make critical decisions when such decisions have to be made. Medical advances have also meant that people live longer with advanced disease but death remains inevitable.

Ethical dilemmas occur when there are at least two conflicting choices of how to deal with something and neither may necessarily lead to a positive outcome. In ethical situations, we may sense our moral self-image is being threatened, which can cause distress. It is therefore very important for us to be aware of our own beliefs and values so we know what we bring to the bedside of the people for whom we care.

There is often no right or wrong answer in an ethical dilemma but it is important there are honest discussions, and there are ethical principles that can help guide the decision making process. Ethical principles are not laws, but guiding principles about what is ‘good’ and what is ‘bad’ that help guide the doctors and other health care team members in their work and decision making.

Excellent communication is the cornerstone of ethical palliative care decision making.

There are four principles of medical ethics, beginning with the principle of beneficence and non-malfeasance, which basically means ‘do good’ and ‘do no harm’.

The second principle is that of autonomy: people with the capacity to make health care decisions should have the right to make decisions about their own care, whether or not those decisions are approved of by their care team or family.

The third principle is that of justice which relates to fairness in the application of care. It implies that everyone receives the care to which they are entitled medically and legally. This can, at times, be difficult to achieve because of the limitations on health care resources.

The fourth principle is that of respect and sanctity of human life and that underpins all the principles. These will be discussed more during the teaching session.

Ethical issues near the end of life (EOL) often arise because of concerns about how much and what kind of care make sense for someone with a limited life expectancy, particularly if the patient is very old. There is often conflict between doctors and nurses and family members about what
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constitutes appropriate care. Many of these conflicts can be avoided by clarifying who makes the difficult decisions to limit care and by advance care planning. Understanding the ethical and legal framework in which such decisions are made can make what appear to be problematic questions into more straightforward answers.

Unfortunately, close to 50 percent of individuals over age 85 have dementia, which usually precludes their understanding many of the issues involved in choosing among treatment alternatives. Also, many cognitively intact elderly are delirious during an acute illness and are incapable of complex discussions about their care when important decisions must be made.

In these situations, a surrogate must be identified to speak on behalf of the older person. “The experience of decision making can be a tremendous emotional burden for family members, likened to a long arduous, unwelcome journey over unfamiliar territory filled with unrecognisable landmarks” (Forbes et al, as cited in Lopez 2009).

Advance care planning (ACP) involves advance preparation for life's unexpected emergencies. Regardless of age, advance care planning provides greater control over decisions that affect a person's future and takes into consideration the person's beliefs and preferences in the event they are unable to make decisions on their own.

A person's choice in end of life care is a fundamental right. Advance care planning encourages the person to communicate their choices to their family and health professionals and offers them a formal way of recording their preferences. It is entirely voluntary and they may change their mind and their plans at anytime.

End-of-life issues such as the kind of care we want and organising financial and legal affairs are things all of us need to address no matter what the status of our health is today.

When people are diagnosed with a life limiting condition such as heart disease, respiratory disease or cancer they and their family and whānau are often prompted to make their choices known earlier than they may have ordinarily. Big issues confront them as they think about their death, or that of someone they love.

They have the right to make their own decisions about their care even if we do not agree it is the right course of action.

Our attitudes, culture and beliefs about religion, pain, suffering, loss of consciousness, and leaving behind those we love all impact on the choices we make. Things can just be left to unfold but it can be hard to make good decisions when patients/family/whānau are under stress. Planning ahead makes it easier to make the important choices for end of life care.
ACP and advance directives (AD) cover preferences for life sustaining treatments such as artificial feeding (e.g. nasogastric tube or subcutaneous fluids), assisted breathing; resuscitation in the event of a cardiac arrest, kidney dialysis, antibiotics or any other invasive procedures. The medical and nursing staff would discuss these with the person their family and whānau as appropriate.

A person can say they do not want their life prolonged if they are unlikely to recover their physical and mental health and will need to be cared for by others. They can make specific directives that they wish to occur in the event of being diagnosed with a life limiting condition such as cancer or a major stroke, in an accident or severe injury, if they are in a prolonged state of unconsciousness, have a diagnosis of dementia and so on.

They may choose only palliative care where the focus is entirely on comfort and dignity and support for family and whānau. They can also say if they want their life prolonged as long as possible. However a health care provider may have no option but to over-ride their wishes when final deterioration and death are inevitable.

**REFLECTION TO BRING TO THE TEACHING SESSION**

What are your attitudes, values and beliefs about religion, pain, suffering, withdrawal of treatment such as subcutaneous fluids and death?

It is important for us to reflect on this as our own culture and beliefs may be quite different to those of the people we care for and our work colleagues and understanding the differences can prevent misunderstanding.

Think about a person who is very unwell and continues to express their wish to die. They can manage very little food and fluid and has been having subcutaneous fluids overnight for the past 10 days. It has been decided these should cease and the person will receive comfort care now until their death.

How do you feel about this decision?

What will you say to a family member who isn’t aware of the decision, when they ask you why their loved one is not getting the subcutaneous fluids anymore?

**POST-SESSION EXERCISE**

Discuss as a care team any ethical dilemmas that you are faced with in your care setting and work together to find solutions. Make sure everyone’s opinion is heard as you will now have learnt that there is not just one solution to most dilemmas. Good communication skills are vital when discussing ethical issues, respecting what each person says.
KEY REFERENCES


Mohindra, R. (2006). The obligation to treat, personal autonomy, and artificial nutrition and hydration. *Clinical Medicine, 6* (3), 271-3


I have the right to be treated as a human being until I die.
I have the right to be cared for by those who can maintain a sense of
hopefulness however changing its focus may be.
I have the right to express my feelings and emotions about my approaching
death in my own way.
I have the right to participate in decisions concerning my care.
I have the right to expect continuing medical and nursing attention even
though ‘cure’ goals must be changed to ‘comfort’ goals.
I have the right not to die alone.
I have the right to be free from pain.
I have the right to have my questions answered honestly.
I have the right not to be deceived.
I have the right to have help from and for my family in accepting my death.
I have the right to die in peace and with dignity.
I have the right to retain my individuality and not be judged for my decisions,
which may be contrary to beliefs of others.
I have the right to discuss and enlarge my religious and or spiritual
experiences, whatever they may mean to others.
I have the right to expect that the sanctity of the human body will be
respected after death.
I have the right to be cared for by caring, sensitive, knowledgeable people
who will attempt to understand my needs and will be able to gain some
satisfaction in helping me face my death.

*This Bill of Rights was created at a workshop on ‘Terminally Ill Patient
and a Helping Person’, in Lansing, Michigan.*
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Learning outcomes

1. Understand ethical definitions, principles and frameworks
2. Explain what is meant by an ethical issue
3. Describe the responsibilities of health professionals in relation to ethics
4. Give examples of ethical issues we may face
5. Explain the decisions considered made prior to withholding or withdrawing treatment.

Models of care
Cultural and spiritual considerations

Consider:
- The attitudes, values and beliefs that you bring to your practice?
- Your stance around death and dying?
- What does your organisational culture consist of?
- The important role of the family at this time?
- How spirituality impacts on ethical decision making?

Adapted from Waitakata Palliative Care Education Programme 2011

Death and dying in modern times

- Dying and death happens to us all. Illness and death have always been part of human experience.
- Medical advances make end of life decision making more difficult.
- As the nature of illness has changed, so too has dying.
- Dying is an important phase of life, one in which people have the right to expect quality of life to ensure a death with dignity occurs.

Definitions

- Ethics
- Do not resuscitate (DNR) or allow natural death (AND)
- Informed consent
- Advance care planning
- Advance directives
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Ethical issues

- Challenging issues such as:
  - determining capacity
  - ensuring informed consent
  - ensuring confidentiality
  - withdrawing/withholding life sustaining treatments
  - continuing futile treatments

Using ethical guidelines means we can help people make decisions about the care they would like.

An ethical problem is a situation involving conflict about the right thing to do. Any health care decision that involves competing values is an ethical problem.” (Cameron, 2002 p37)

Palliative care

- Quality of life
- Value of life
- Meaning of life

“It is not death itself which people fear so much as the manner of their dying.”

— Gustave Flaubert

NFR/Do Not Resuscitate (NFR/DNR) or Allow Natural Death (AND)

- NFR policy is framed in times of crisis, often offered when death is imminent and at a time when the person may be too unwell to be involved in the decision and focuses on NOT doing something
- AND (Allow Natural Death) is a positive choice – not last resort

“Allow natural death” versus “do not resuscitate” – three words that can change a life.” Nausner et al 2000. Journal Medical Ethics 26:24-34.
Allowing natural death (AND)

AND has caused a great deal of debate

The literature continues to support that AND is:

- A kinder, gentler approach that would benefit everyone
- Positive action of what we are doing rather than what we are not going to do
- It reflects a model of care in which death is not seen as a failure of treatment

Informed consent

In order to be valid it must be:

- given by a competent person
- informed
- obtained without coercion

Competency is a clinical judgement made by a doctor.
It may fluctuate from time to time, especially in palliative care

People have the right to accept or refuse information

When people do not have competence, family can contribute to the informed consent

What is advance care planning? What is an advance directive?

- Advance care planning (ACP) is the voluntary process of preparing for likely scenarios near the end of life. It usually includes assessment of end-of-life wishes and discussion about a patient's understanding of their medical history and condition, values, preferences, and personal and family resources.

- Advance directives contain instructions that consent to, or refuse, specified medical treatment in the future. Advance directives are defined in the Code of Health and Disability Services Consumers' Rights as written or oral directives in which the patient makes a choice about a possible future health care procedure, and which are intended to be effective only when the patient is no longer competent. For this reason, advance directives are also referred to as ‘living wills’.

http://www.advancecareplanning.org.nz
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Ethical values

- Client well-being
- Client choice
- Privacy and confidentiality
- Respect for life
- Maintaining commitments
- Truthfulness
- Fairness

College of Nurses Ontario Practice Standards (2009)

Our responsibility

- Naming and clarifying ethical issues is an important part of all our roles
- Building trust between ourselves, the person, their family and whānau and all other members of the care team is vital to identifying and resolving ethical issues

Respect

- Respect for individuals is one of the most basic principles in ethics
- Treating them as the unique person they are and creating a care plan (incorporating their beliefs, values and goals) with them and those important to them reflects that uniqueness

What does respect mean to you? How might this look in practice?
The "I"s"

- The I of the client: look at me and hear what I am really saying.
- The I of the family and whānau: remember I am often the eye and ears for my family member.
- The I of the health worker: I have a responsibility to keep an eye on the ball at all times.

Kathy Peri, Lecturer/Researcher in Gerontology

Ethical decision making framework

- Assessing the person/family/whānau’s knowledge
- Teaching the person/family/whānau about care alternatives
- Examining the person/family/whānau’s values and beliefs about dying
- Discussing the person/family/whānau’s beliefs and choices
- Recording the person/family/whānau’s care choices and proxy

Ethical guidelines for assisting patients with end-of-life decision making (Cairns, 2004)

Autonomy

- Recognises an individual’s right and ability to decide according to their beliefs, values and life plan
- Decisions are unique and may be different from the course that is deemed "right" or "wise"
- Gaia: truth-telling and exchange of accurate information about their health status, options, planned care and future expectations is essential treatment options
- Informed consent for care
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**Beneficence = Doing Good**

- Prevention/removal of harm
- Positive acts to maximize treatment/care benefits
- Sensitive interpersonal support
- Acknowledge, respect and value the person as a unique human being

**Non-maleficence = Do no harm**

- Avoid deliberately causing harm
- Offer information in a sensitive way
- Cease treatment that is no longer effective and causing patient suffering

**Justice = fairness/deserved**

- The principle of justice implies a consideration for common good and societal considerations
- Describes what individuals are legitimately entitled to and what they can claim
- Sometimes justice may serve to limit autonomy: what the individual wishes, chooses, or feels entitled to may not be possible or allowable in the context of the society.
Palliative care ethical discussions

- Comfort care vs active treatment
- Nutrition and hydration
- Palliative sedation
- Limitation of treatment
- Care rationing

Nutrition and hydration at the end of life

- Symbolism of food and fluid
- Fears of starvation
- Organs slow down in preparation for death
- Burden of hydration outweights the benefits
- Little link between hydration and hunger and dry mouth
- Mouth care with familiar tastes

To feed or not to feed?

- There is no evidence that artificial nutrition prolongs survival in advanced disease
- Studies showed that people in hospice care who refuse food and fluids usually die a 'good death' within two weeks (Garzani et al 2003)
- Further studies have shown that starvation and dehydration might also have anesthetic benefits produced by the generation of endorphins and the action of ketones
- There is no right or wrong answer
- Each person and their significant others are unique and need education and understanding. Compromise is important
Ethical issues in palliative care

Mythbusters

- Main argument is that it is unethical to let a person starve or thirst to death.
  Reality – the person is dying from a chronic, incurable illness not dehydration.
- The person will suffer intolerable dry mouth and thirst.
  Reality – all dying people have a dry mouth.
- There is no correlation between the complaint of dry mouth and the biochemical changes caused by dehydration.
- A dry mouth is not relieved by parenteral fluids but is by good and frequent mouth care.

Palliative sedation – principles of double effect

- Some dying people experience suffering as a result of symptoms that are difficult or impossible to control.
- They can be offered palliative sedation in order to relieve or palliate unusually difficult symptoms such as pain or breathlessness.
- Role of double effect:
  - the act must be considered good or at least morally neutral
  - the intention is only the ‘good effect’ and not the ‘bad effect’

The good result (e.g., relief of suffering) must outweigh the untoward outcome (e.g., hastening death).

Symptom control at the end of life

- Healthcare workers are sometimes reluctant to administer medication to a dying person for fear of “killing them” but it is imperative good symptom control is maintained.
- Medications for symptom control that cannot be taken orally need to be continued subcutaneously and extra medication charted for breakthrough symptoms.
- Anticipatory prescribing when people are deteriorating allows nurses to respond to patient distress without delay.
- Bereavement can be complicated if relatives have to see their loved ones in distress.
- In ethical terms, a person has the right to be free from suffering and the clinician has a responsibility to ease that if happens.
Withholding or withdrawing treatment

- No one is obliged to live by technological means – a competent person may refuse any treatment
- A treatment that is no longer effective in achieving its goal should be stopped
- Treatments start and stop – if a treatment becomes futile with time, or has no clear benefits, then stopping that treatment must be considered
- A doctor is not ethically obliged to provide a treatment that is unlikely to provide benefit to the person

You are important too

- Ethical dilemmas may challenge our own values and beliefs
- Work as a team – need to trust and support each other and consider all options
- Open communication – share in decision making, confront difficult issues in non-judgemental way
- Share your feelings and concerns with other staff
- Conflicts may be inevitable but should not be seen as negative but rather as opportunity for growth and improvement
- Have strategies to preserve emotional and physical health

Conclusion

The unwell person is the central figure in ethical decision making

Life is a process with death as an integral part of the continuum

Ethics, or principles of moral conduct, are not fixed and static, but subject to change and interpretation

Social, historical, cultural, racial, political, professional and spiritual influences all shape the ethical beliefs that affect the actions of health care providers and the person, their families and whānau.