Session two:
Ethical issues in palliative care –
Pre-reading


**Session two**

Ethical issues in palliative care

**Teaching time:** 1-2 hours

**LEARNING OUTCOMES**

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

1. Understand ethical definitions
2. Explain what is meant by an ethical issue
3. Describe the responsibilities of health professionals
4. Give examples of ethical issues we may face
5. Explain the decisions 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 excellence in 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 families.

The third principle is that of justice which relates to fairness in the application of care. It implies that everyone receive the care to which they are entitled medically and legally and 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 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 illness such as heart disease, respiratory disease or cancer they and their family/whanau 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/whanau 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 subcut 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 patient and family 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 illness 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. 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 override 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 subcut 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.

Let’s think back to Mrs G who we met in session one. She is now very unwell and continues to express her wish to die. She 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 she be for comfort care now until her 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 she isn’t getting the subcut fluids anymore?
POST-SESSION EXERCISE

To practice decision making and communication try this as a team allowing everyone time to express their opinion.

You are on a sinking ship and there is only ONE lifeboat available. Posted on the side of the lifeboat is a sign which reads, “Maximum occupancy = 8 people … this boat will sink if over occupied.”

Standing on the deck are nine adults and one child. You must decide who dies. Be prepared to defend your decision.

People on deck:  
- Yourself
- A young mother and infant son
- A 75 year old retired physician
- His 68 year old wife
- A 17 year old, pregnant girl
- A male professional athlete
- A member of the clergy
- A middle aged school teacher
- Her husband, a banker

Who boards the lifeboat and why?
REFERENCE LIST


WEBSITES OF INTEREST

www.patient.co.uk
www.respectingpatientchoices.org.au

PRE-SESSION READING

Bill of Rights (attached)
USEFUL RESOURCES


HELPFUL WEBSITES

Palliative Care Australia [www.pallcare.org.au](http://www.pallcare.org.au)

European Association for palliative care [www.eapcnet.eu](http://www.eapcnet.eu)

Palliative Care – one vision, one voice [www.palliativecarenursing.net](http://www.palliativecarenursing.net)

Palliative Drugs [www.palliativedrugs.com](http://www.palliativedrugs.com)


OTHER RESOURCES


A Guide for Caregivers, Hospice NZ publication

THE DYING PERSON’S BILL OF RIGHTS

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.