

**YOU CAN ADDRESS ETHICAL
AND LEGAL ISSUES**

Learning objectives

- Review principles of medical ethics
- Explore the ethos and ethics of palliative care
- Discuss the concept of a balance between benefit and burden
- Discuss common ethical dilemmas
- Understand the importance of legal frameworks and support

Medical ethics

- guide health professionals in decision making
- apply to all medical care
 - assume greater importance when caring for patients at end of life
- not culturally dependant
- guiding principles not laws

Principles of medical ethics

- Respect for autonomy
 - patient choice and control
- Beneficence
 - do good
- Non-maleficence
 - minimise harm
- Justice
 - fair use of available resources balancing needs of individual with wider society

Principles of medical ethics

Patient Autonomy

- What does the patient want? Does the family understand the patient's preferences?

Beneficence

- Is it a benefit perceivable to the patient?

Non – Maleficence

- Will doing it harm the patient?

Justice

- Is it a fair utilization of resources?

Principles of medical ethics

■ Respect for autonomy

- patient choice and control
- dependant on informed consent and accurate information
- requires excellent communication
- needs trust and truth telling

Principles of medical ethics

■ Beneficence

- do good
- often our focus in clinical care
- includes
 - delivering effective and beneficial treatments for pain or other symptoms
 - providing sensitive support to patients and families
 - maintaining confidentiality
- if not of benefit then may be futile care

Hippocratic oath

- “What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about”

Principles of medical ethics

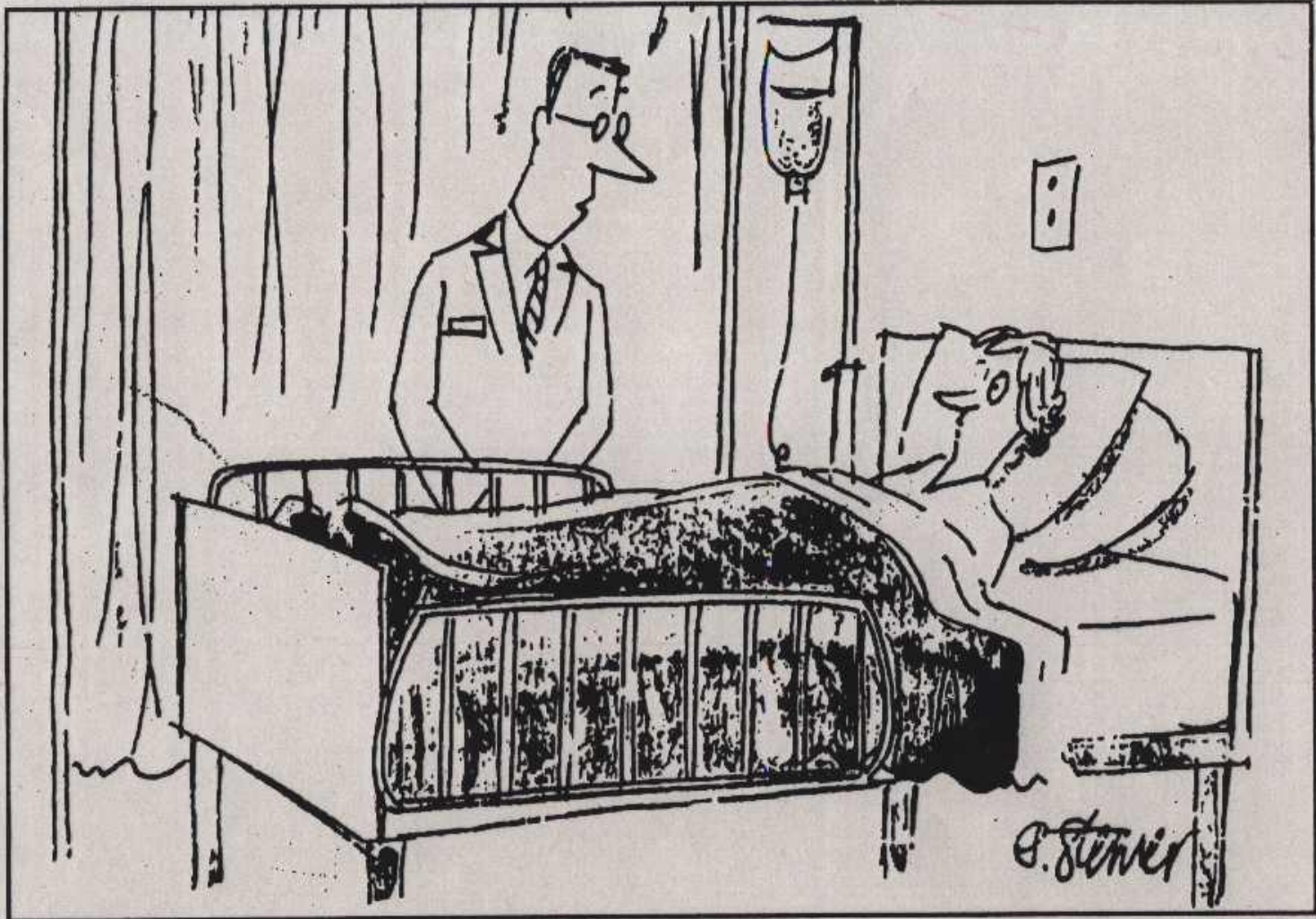
■ Non-maleficence

- minimise harm
- includes
 - offering information in an insensitive way
 - continuing aggressive treatment not suitable to the patient's condition
 - withholding or withdrawing treatment
 - interventions that have social or financial drain
 - interventions that prevent patients goals being met

Communication

- Communications, like tumours, may be benign or malignant. They may also be invasive, and the effects of bad communication with a patient may metastasise to the family. **Truth is one of the most powerful therapeutic agents available to us**, but we still need to develop a proper understanding of its clinical pharmacology and to recognise **optimum timing and dose in its use**. Similarly, we need to understand the closely related metabolisms of hope and denial.

Simpson M quoted in Twycross 'Introducing Palliative Care'



"Medical ethics do not allow me to assist in your death. I am, however, permitted to keep you miserable as long as possible."

Principles of medical ethics

■ Justice

- fair use of available resources
- balancing needs of individual with wider society
- involves balance of rights, priorities, equality
- issues will be very different with resource limitations but principle the same

Principles of medical ethics

■ Justice

■ Human rights

- The right to life, liberty, security of persons
- The right to food
- The right to express opinions
- The right to practice a religion
- The right to health
- The right to marry and found a family
- The right to education

Universal Declaration of Human Rights and United Nations Charter

The Dying Persons' Bill of Rights

1. I have the right to be treated as a living human being until I die.
2. I have the right to maintain a sense of hopefulness, however changing its focus may be.
3. I have the right to express my feelings and emotions about my approaching death in my own way
4. I have the right not to die alone
5. I have the right to be free from pain
6. I have the right to have my questions answered honestly
7. I have the right not to be deceived.
8. I have the right to have help from and for my family in accepting my death
9. I have the right to die in peace and dignity
10. I have the right to retain my individuality, and not be judged for my decisions which may be contrary to beliefs of others
11. 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

Ethics in palliative care

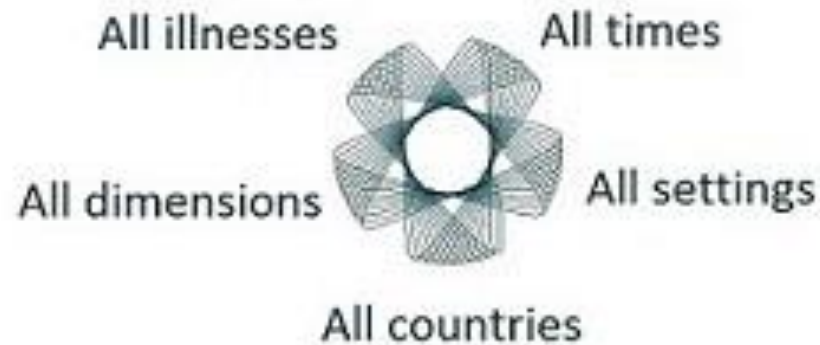
Why is it important?

- vulnerable patients and families
 - *may lack respect for autonomy, power issues*
- desperate for help
 - *may accept 'harm' quality of life vs survival*
- unequal access to resources
 - *issues of justice and torture*
 - *lack of access to pain control deemed inhumane and degrading treatment*
- holistic issues often ignored

Ethics in palliative care

What values in palliative care help good ethical practise?

- patient and family focus, compassionate communities, human rights, equality, quality of life, teamwork, community empowerment
- care for all



Application of principles

- benefits vs burdens
- balance of ethical issues
 - dilemma when these in conflict
- best interests of patient
- perspective of needs of wider society



Common ethical dilemmas



Common ethical dilemmas

- nutrition and hydration
- financial costs of treatment
- withdrawal of treatment
- appropriate interventions
- collusion
- colleagues who offer unrealistic hope
- confidentiality
- ?requests for euthanasia

Ethical scenarios

- What are the ethical principles involved in this scenario?
- How will you approach this situation?
- What are the **benefits and burdens** that influence your approach?

Case scenario

- *Use a relevant case scenario from your local setting*

Legal issues

- Health care workers must work according to the code of medical ethics and within the legal frameworks in their setting
- Many patients have holistic needs that relate to their human rights and legal protection
- Information and resources about assessing legal issues and accessing appropriate advice is essential and will be specific
- Palliative care team should include access to paralegal and legal advice and support

Common legal issues

- Making a will
- Protection of vulnerable adults
- Protection of children
- Protection of assets including land and property
- Medico legal decision making

Making a Will: terminology

- **Will**
 - written witnessed document stating management of property after death
- **Assets**
 - money, property, possessions, business
- **Beneficiary** and heir
 - **a person or organization** one leaves something to in their will
- **Estate**
 - everything one owns at death
- **In testate**
 - dying without a will
- **In estate**
 - dying with a will
- **Testator**
 - person who writes a will, author
- **Executor**
 - person who oversees the distribution of your assets in accordance with your will.
- **Guardian**
 - looks after children and property until they become of age
- **Codicil**
 - update to will

Making a Will: importance

- It makes sharing property more straightforward:
 - It ensures that people will only be given what is allocated to them in the will
 - Avoids questions and quarrels among relatives
 - It gives one a chance to give away all property even to those not known by relatives
 - Protects vulnerable members from having property and assets taken over

How to Write a Will

- A will should be made in writing, typed or hand-written.
- If the person making the will cannot write, he/she can ask another trusted person to write what they tell them.
- A lawyer can also assist in writing a will on payment of a fee.
- Should be age of consent and of sound mind with witnesses and aware of writing the will

Making a will; contents

- Testator details
 - name, date and place of birth, place of origin, tribe, names of his/ her parents
 - postal address, residential address, including village and country where the patient ordinarily lives
- Details of family members.
- Details of any other beneficiaries
- List of all property and other assets
- Witnessed signatures
 - testator, witnesses
- Details of where will is kept

Making a will, challenges

- Why is it important to write a will?
- Why don't people write wills?
- What can health workers and caregivers do to help patients write wills?
 - Doctors
 - Nurses
 - Social workers
 - Health Educators
 - Community volunteers
 - Caregivers, family members

Group Work

- *Use your local scenario to give experience of will writing or other legal issues*

- These resources are developed as part of the THET multi-country project whose goal is to strengthen and integrate palliative care into national health systems through a public health primary care approach
 - Acknowledgement given to Cairdeas International Palliative Care Trust and MPCU for their preparation and adaptation
 - part of the teaching materials for the Palliative Care Toolkit training with modules as per the Training Manual
 - can be used as basic PC presentations when facilitators are encouraged to adapt



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