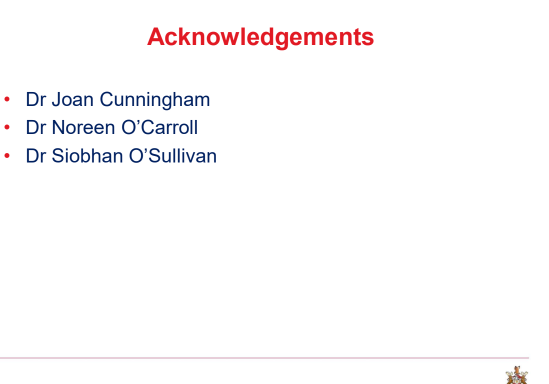
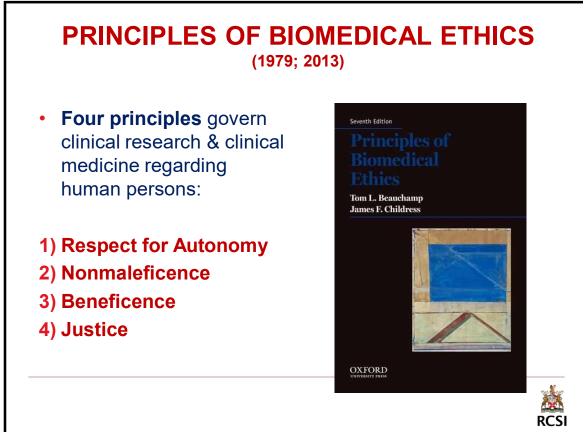
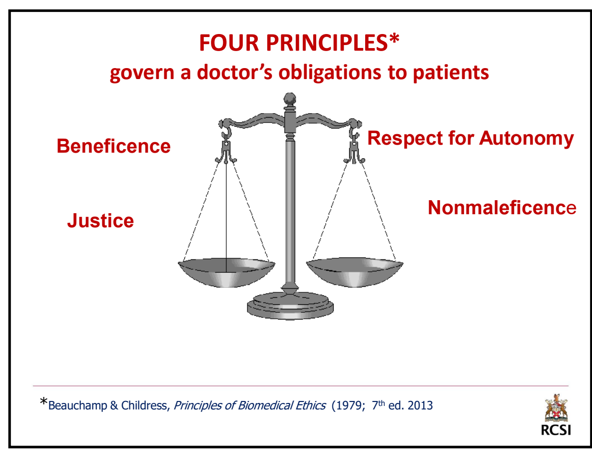






RESPECT FOR AUTONOMY

- **Etymology**: The word *autonomy* derives from the Greek words ***autos* = self and *nomos* = rule, governance, law**
- **Definition of Autonomy:**
- The right of persons to make authentic choices about what they shall do, and what shall be done to them and, as far as is possible, what should happen to them.
- Deliberate self rule is a special attribute ascribed to all moral agents

The principle of RESPECT FOR AUTOMONY

The principle of Respect for Autonomy incorporates two aspects:

(i) **Respect for Autonomy** – which requires that those who are capable of deliberation about their personal choices should be treated with respect for their capacity for self determination.

(ii) **Protection of persons with impaired or diminished autonomy** – which requires that those who are dependent or vulnerable be afforded security against harm or abuse.

RESPECT FOR AUTONOMY

DOCTOR'S OBLIGATIONS	PATIENT'S RIGHTS
The obligation to maintain patient confidentiality.	The right to have one's medical information kept confidential.
The obligation to presume the capacity of the patient to consent/refuse treatment, OR if indications to the contrary, *to assess incapacity.*	The right to *self-determination* through choice and action i.e. to make an autonomous choice.
The obligation to provide all *necessary information* for informed consent.	The right to receive all the *information* necessary for decision-making.
The obligation to get *consent / refusal* prior to treatment.	The right to *consent/refuse* examination, procedures etc.

The principle of BENEFICENCE

- ***Principle of Beneficence*** refers to a statement of moral obligation to act for the benefit of others.
- Principle of Beneficence requires that an agent take positive steps to help others, not merely refrain from harmful acts.
- Attending to the welfare of patients – not merely avoiding harm – embodies medicine's goal, rationale, and justification.

Beauchamp & Childress (2013) *Principles of Biomedical Ethics*: 202ff.

BENEFICENCE

- The principle of Beneficence refers to **a moral obligation to act for the benefit of others.**
- The traditional Hippocratic moral obligation of medicine is to provide net medical benefit to patients with minimal harm, that is, beneficence with non-maleficence.
- To do this we must respect the patient's autonomy for what constitutes benefit for one patient may be harm for another.
- Beneficence is vital in all medical and health care professions.

BENEFICENCE v PATERNALISM

BENEFICENCE

- The ethical obligation to act for the benefit patients.

PATERNALISM

The intentional overriding of a patient's preferences by:
- ❑Manipulation of information
- ❑Nondisclosure of information
- ❑Deception
- ❑Lying
- ❑Coercion

and justifying this action by:
- Reference to the patient's best interests;
- Preventing harm to the patient;
- Mitigating harm to the patient.

THE PRINCIPLE OF NONMALEFICENCE "Do no harm"

DUE CARE	ABSENCE OF DUE CARE
✓Taking sufficient and appropriate care to avoid causing harm, as the circumstances demand of a reasonable and prudent person.	❑**NEGLIGENCE** – intentional or unintentional. ❑**PROFESSIONAL MALPRACTICE** – not following professional standards of due care.

NONMALEFICENCE "Do no harm"

The concept of harm

- Hippocratic Oath
- "I will use treatment to help the sick according to my ability and judgement, but I will never use it to injure or wrong them."

NONMALEFICENCE

- What do we mean by harm?
- In medical terms, pain, disability, suffering, death
- Specification of non-maleficence might mean
  - Do not kill
  - Do not cause pain or suffering
  - Do not incapacitate
  - Do not cause offence
  - Do not deprive others of the goods of life

The principle of JUSTICE

The principle of justice refers to the obligation to provide fair, equitable and appropriate treatment to patients.

BUT: By which principle of justice should healthcare be distributed?

Distributive justice – concerned with who ought to get what goods. Very Important in Healthcare.

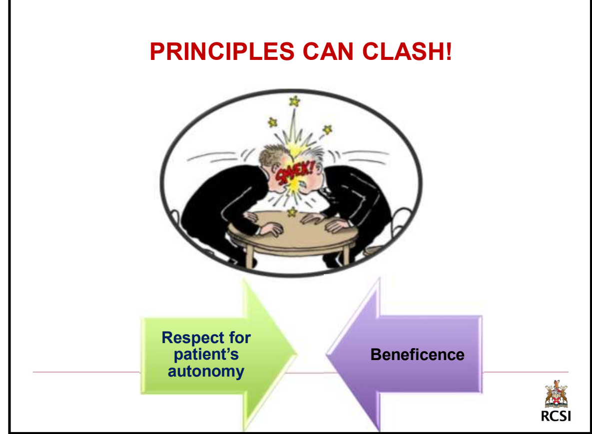
DISTRIBUTIVE JUSTICE TYPES OF ALLOCATION

- Partitioning the comprehensive social budget
- Allocating within the health budget
- Allocating within the health care budget
- Allocating scarce treatment for patients

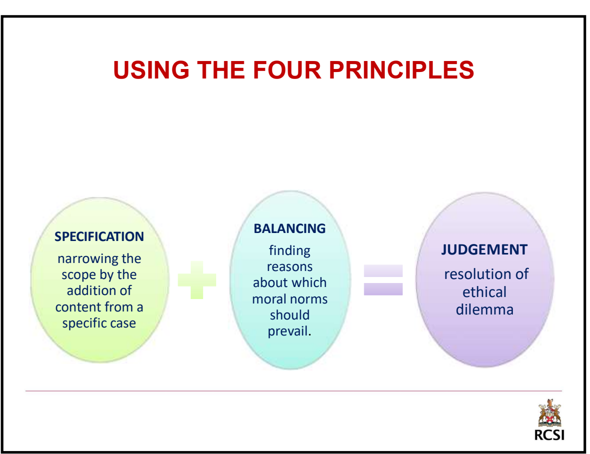
RATIONING – AS CRITERIA FOR ALLOCATING

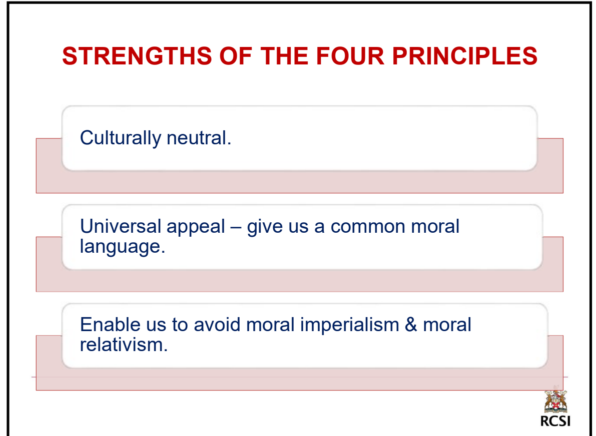
- Rationing of healthcare to those who cause their own ill health
- Smokers
- Obese People
- Over consumption of alcohol
- Risky sexual behaviour
- Risky activities in life
- Known genetic predispositions

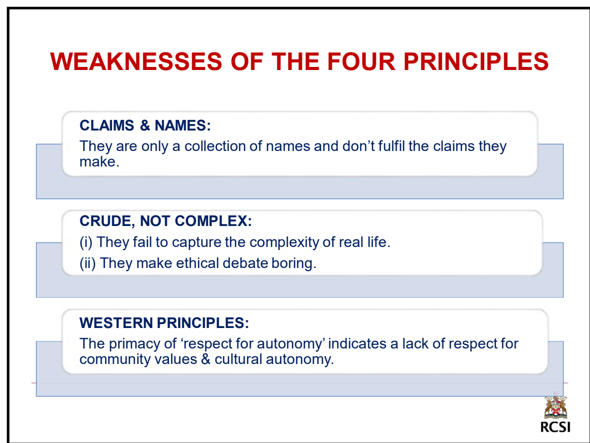
PRINCIPLES CAN CLASH!

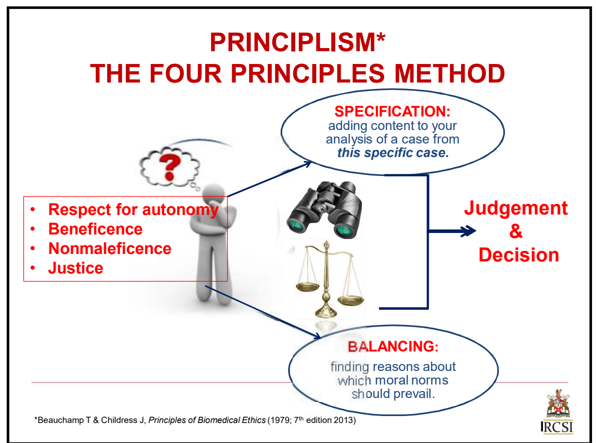


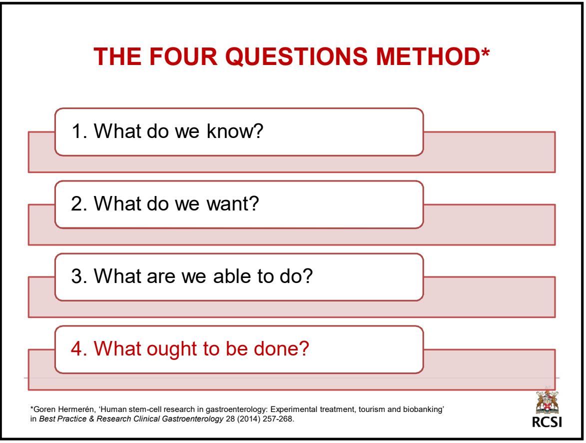
USING THE FOUR PRINCIPLES









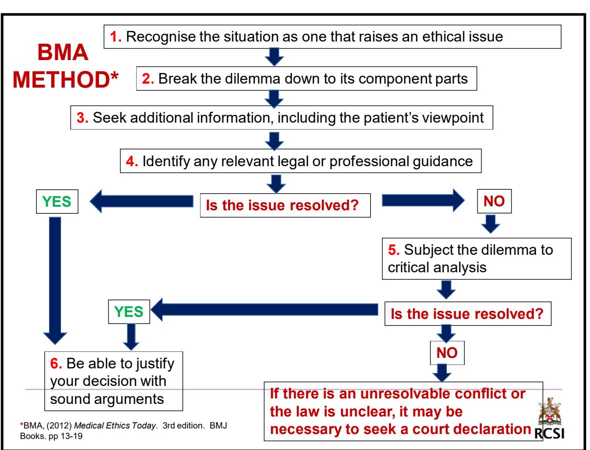


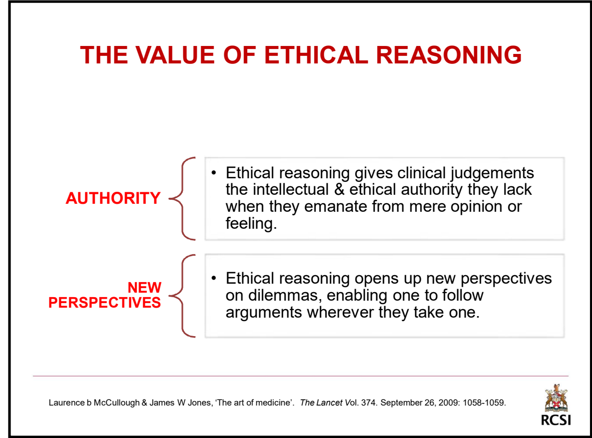
The Four-Topic Paradigm

Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, 7th ed. New York: McGraw-Hill, 2010.

- **Medical Indications**
- **Quality of Life**
- **Patient Preferences**
- **Contextual Features**

RCSI





Professionalism

Guide to Professional Conduct and Ethics for Registered Medical Practitioners – 2016

- **Section 46:End of Life Care**
  - *"When patients are nearing the end of life, it is your responsibility to make sure they are comfortable, suffer as little as possible and die with dignity. You should treat them with kindness and compassion"*
- **46.2**
  - *"Communicating with patients & their families is an essential part of good care.*

Professionalism

Guide to Professional Conduct and Ethics for Registered Medical Practitioners – 2016

- **46.3**
  - *" Usually you will give treatment that is intended to prolong a patient's life. However, there is no obligation on you to start or continue treatment, including resuscitation, or provide nutrition & hydration by medical intervention, if you judge that treatment:*
    - *Is unlikely to work*
    - *Might cause the patient more harm than benefit or*
    - *Is likely to cause the patient pain, discomfort or distress that will out weigh the benefits it may bring*
- **46.9**
  - *"You must not take part in the deliberate killing of a patient."*

RCSI

An Bord Altranais:

- 4. In end of life care, you should support the person to die with dignity and comfort. This extends to ensuring the respect for the patient in the period after their death, taking into consideration the cultural norms and values of the patient and their family.
- 5. You should respect an individual's advance healthcare directive, if you know they have one

Communication

- Breaking bad news can cause distress to the patient, family & the caregiver
- Reluctance to tell the truth/break bad news?
- Fear of
  - The patient's reaction
  - Destroying the patient's hope
  - Causing the patient stress
- Clinician perspective:
  - Own inadequacy & General discomfort discussing death
  - Lack of training
  - Lack of time
- Family request

Communication

- How does one respond to:
  - *"Don't tell him doctor, the truth will kill him!….we know him better than you!" " we'll sue you if you tell him"*
  - *"Don't tell him he's in the hospice"*
  - *"Don't tell him he's got cancer"*
  - *"Don't tell him the cancer is back"*
  - *"Don't tell him he's not going to get better"*
  - *"Don't tell him he's going to die"*

Withholding & withdrawing treatment

- Movement towards "proportionate" (Beneficial) & "non proportionate" (Non-beneficial) treatment
- *"Is this treatment in keeping with the current clinical goals of this individual?"*

Requests for life prolonging treatment in palliative care setting

- Potentially ethically challenging situations arise when competent patient requests active treatment with goal of life-prolongation, while the doctor suggests supportive care only
- How do we resolve this?

Artificial Hydration & Nutrition in Palliative Care

- Hydration & nutrition are considered essential components of good medical care
  - Provided with the primary intention of benefiting the patient
  - Role in the care of the terminally ill patient is not so straightforward
- Anorexia & decreased oral intake of calories are natural accompaniments of terminal illness

Artificial Hydration & Nutrition in Palliative Care

- Some health care professionals regard artificial hydration as central part of the management of the dying patient:
  - Perceive that artificial hydration is essential component of end of life care in maintaining patient comfort
- Others disagree, saying that it adds to patient suffering

Do Not Attempt to Resuscitate Orders

- Decisions about CPR must be made on the basis of an *individual* assessment of each patient's case
- Advance care planning, including making decisions about CPR, is an important part of good clinical care for those at risk of cardiorespiratory arrest
- Communication and the provision of information are essential parts of good quality care

Do Not Attempt to Resuscitate Orders

- Palliative care patients frequently articulate to their medical team that they do not want to be resuscitated
- CPR is generally not appropriate in patients with terminal illness as it is unlikely to be successful
- Clear, sensitive communication with the patient +/- family essential to explain goals of management

Ethical issues in caring for the child with a life limiting illness

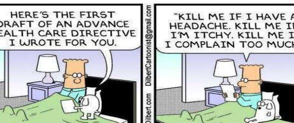
- Unique ethical challenges in paediatric setting
  - Consent
  - Withholding & withdrawing treatment
- Beneficence "Best Interests"
- Parents usually are the substituted decision makers
- The parents, with the clinicians are expected to act in the best interests of the child
- Clinicians are ethically & legally responsible for ensuring decisions are made in the child's best interests
- **Is this the right way to resolve issues like this?**

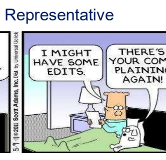
Advance Healthcare Directives

- Useful to know thoughts about specific issues as relevant to each individual's case:
  - Admit to hospital in event of deterioration or keep comfortable at home
  - Cardiopulmonary resuscitation/Ventilatory support
  - Hydration
  - Antibiotics (IV or oral)
  - Transfusions
  - Dialysis
  - Organ Transplantation
  - Further chemotherapy

Advance Healthcare Directives

- Treatment refusal
  - [A]n advance expression made by the person … of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity
- Treatment request
  - Must be taken into account
- May also appoint Designated Healthcare Representative





Advance Healthcare Directives

- ***Definition***: an adult's written statement setting out type & extent of treatment to which adult consents to or refuses if adult losses capacity to make treatment decisions
- AHCD is an expression of autonomy & provides a patient with a mechanism to record refusal of treatment
- Two types of AHCD
  1. Instructional directive i.e. *directions for treatment &*
  2. proxy directive i.e. *designated person is allowed to communicate patient's treatment choices*

Advanced Healthcare Directives

- **'A refusal of treatment set out in an advance healthcare directive shall be complied with if:**
  a. at the time in question the directive-maker **lacks capacity** to give consent to the treatment;
  b. the **treatment** to be refused is **clearly identified** in the directive;
  c. the **circumstances** in which the refusal of treatment is intended to apply are **clearly identified** in the directive.'
  - *Pr. 8 S.84(2)*

Advanced Health Care Directives

- *Assisted Decision Making (Capacity) Act 2015* defines treatment as '*an intervention for a therapeutic, preventative, diagnostic, palliative or other purpose related to patient's physical or mental health, including life-sustaining treatment*'
- *2015 Act* defines AHCD purpose as twofold
- Enable a patient to be treated according to his/her will & preferences
- Provide clinicians with information about patient's treatment choices

Advanced Health Care Directives

- ***2015 Act* Guiding Principle for AHCD – *Refusal of treatment must be accepted even if refusal appears to be unwise, appears not to be based on sound medical principles, or, may result in patient's death***
- Treatment refusal must be followed if three conditions are satisfied:-
  1. Patient had capacity at time of making AHCD
  2. Treatment to be refused clearly identified in AHCD, &
  3. Circumstances in which refusal of treatment is intended to apply are clearly indicated in AHCD

Research in palliative care

- Progress is made through advances in basic science & clinical research:
  - Is as applicable to palliative care as any other area of medicine
- Research is essential
  - For maintaining standards
  - Advancing knowledge
  - Improving practice

Research in palliative care

- Ethics of research in palliative care
- Unique challenges:
  - Life-limiting conditions
    - Unpredictable illness trajectories
    - Issues with competency
  - Vulnerable patients:
    - Frequently distressed by their symptoms
    - Specific groups incl. elderly/paediatric/learning disabilities
    - May feel obliged to participate

Research in palliative care

- Palliative care is relatively new specialty there may be difficulties in finding data collection tools
- Small pool of potential patients
- Problems of randomisation/RCT

The Ethics of Sedation for Intractable Distress in the Dying

- Defined as:
  - *"The use of sedation to control refractory symptoms in patients who are in the terminal phase of their illness"*
- **Aim is to induce deep unconsciousness, when all other means have failed**

The Ethics of Sedation for Intractable Distress in the Dying

- **Ethical concerns:**
  - Decision to render patient unconscious
  - Possible shortening of patient's life?
  - Frequent association with the simultaneous withdrawal/withholding of hydration/nutrition
  - Is it a form of euthanasia?
  - Does it disregard respect for the sanctity of human life principle?

The Ethics of Sedation for Intractable Distress in the Dying

- Ethical justification?
- Discussion usually includes reference to principles of:
  - Proportionality
    - A therapy of last resort in the face of intolerable suffering, when all other therapies have been expended or are inappropriate
  - Autonomy (the patient)
  - Beneficence (the palliative care team)

The Ethics of Sedation for Intractable Distress in the Dying

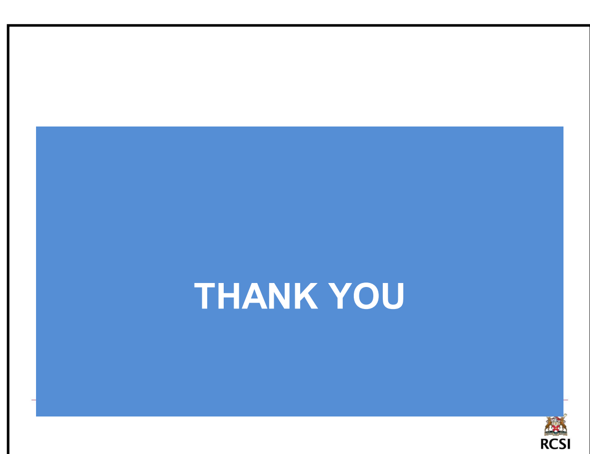
- Principle of Double Effect
  - ❖ Act itself must be morally good/at least indifferent
  - ❖ Agent must not positively will the bad effect, but may permit it. If he could attain the good effect without the bad, he should do so
  - ❖ Good effect must flow from the action at least as immediately as the bad effect, ie the good effect must be produced by the action, not by the bad effect
  - ❖ Good effect must be sufficiently desirable to compensate for allowing of the bad effect

The Ethics of Sedation for Intractable Distress in the Dying

- **All 4 conditions are fulfilled:**
  - ■ Relief from intractable symptom
  - ■ Intention is the relief of suffering, although theoretical hastening of death may be an unavoidable consequence
  - ■ Good effect achieved through the sedative, not through the death of the patient
  - ■ Relief of intractable suffering is sufficiently desirable to compensate for putting patient at risk of earlier death

Allocation of Resources

- Criteria
- Government Policy
- Hospital policy – macro –level
- Individual patients – micro -- level



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