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# Informed Consent is not Enough

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# Disclosures

- None to declare

# Living Organ Donation: Values & Principles

- Justice
- Transparency
- Autonomy
- **Beneficence**
- **Non-Maleficence**
- **Trust**
- Partiality
- Altruism



Fast Policy Facts: Living Donation [www.cntrp.ca](http://www.cntrp.ca) 2015

# Autonomy vs. Beneficence

- We do NOT agree to all patient requests
- **First do No Harm**
- Body Integrity Identity disorders:
  - Wish to be disabled
  - Xenomelia: feeling that a limb does not belong



# Paternalism

- Assumes the professional knows best course of action for the patient
- Based on the values & clinical judgment of the professional
- May be counter to the values of the patient
- BUT may also reflect beneficence, non-maleficence

# Healthcare Professionals' Duty to Care

- Professional colleges: Codes of Ethics
- No abandonment of the patient
- Refusal to provide care should be explained to the patient
- Referral for 2nd opinion

# CMA Code of Ethics

## Fundamental Responsibilities:

- 1. Consider first the well-being of the patient.**
2. Practise the profession of medicine in a manner that treats the patient with dignity and as a person worthy of respect.
3. Provide **for appropriate care** for your patient, even when cure is no longer possible, including physical comfort and spiritual and psychosocial support.

# CMA Code of Ethics: contd.

**4. Consider the well-being of society in matters affecting health.**

5. Practise the art and science of medicine competently, with integrity and without impairment.

6. Engage in lifelong learning to maintain and improve your professional knowledge, skills and attitudes.



# College of RNs of Nova Scotia

Code of Ethics includes:

- Providing safe, compassionate, competent and ethical care
- **Promoting health and wellbeing**
- Promoting and respecting informed decision-making
- Promoting Justice
  - Nurses promote justice by safeguarding human rights, equity and fairness and **by promoting the public good**

# Autonomy of the Healthcare Team

- Health Care Professionals are Moral Agents
- Bring their own ethical standards to the transplantation process (personal, cultural, professional)
- Need to feel they are practising within ethical norms
- OR they can experience burnout & moral distress



# Individuals and Society

- Moral Hazard
- Separation of decision-making from responsibility for bad consequences
- Healthcare system: will provide care post donation
- Consequences for all others in that community
- Resources need to be distributed fairly & responsibly

## 1954: Kidney Transplant from a Living Donor to twin

- Dr Joseph Murray, Boston, December 1954  
*“the first time in the history of medicine a procedure is being adopted in which a perfectly healthy person is injured permanently in order to improve the well-being (not of himself but) of another”*

Moore FD: New Problems for Surgery. Science 1964:144:388.



- Warnings in using one person for the benefit of another: means to an end



# Case

- Mr. B, 57, diabetes, led to ESRD, needs a kidney
- Daughter, Mary, 35, mother of 2
  - gestational diabetes x 2 pregnancies
- Mary wants to give her father a kidney
- Glucose tolerance test: positive

# Ethical Issues

Conflicting values, beliefs, goals or difficult alternatives

Uncertainty re what to do or why to do it

Concerns that rights are violated or persons not respected

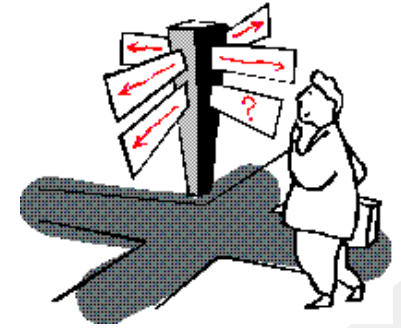
Conflicting obligations or responsibilities

Concerns with fairness or justice



# Ethical Dilemma

- Most ethical course of action is unclear
- Strong moral reason to support each of several positions
- Decision must be made based on the most right or least wrong choice of action.





# Living Donation: Risks & Benefits

## *Risks:*

- medical
- psychological
- stress for family
- stress of non-donation
- coercion / manipulation
- commercialization

## *Benefits:*

- helps recipient
- reduces waiting list
- donor self esteem
- improved relationships
- tangible benefits
- helps society

# Positives of Non-Donation

- Protects the non-donor's health
- May protect the intended recipient from harms of bad outcome for the donor
- Maintains trust in the transplant system
- Less moral distress for HCPs
- Optimizes health overall



# Donors and Recipients

- Relationships involve self interest
- Donors can help the recipient in many ways
- Non donation does not mean lack of support or caring
- Healthcare teams can **manage donor expectations** throughout the evaluation

# Outcome

- What does outcome entail?
  - Length of time the organ lasts in the recipient
  - Long term health of the donor
  - Maximum satisfaction for the recipient & donor
  - Quality of Life of the recipient & donor



# Principles: Beneficence & Non-Maleficence

- Total benefit must outweigh harm
- Donor benefit essential
- Beneficence to donor:
  - protect donor health / interests
  - support best decision for the donor
  - provide necessary information
  - maintain confidentiality
  - follow up care

# Trust

- Organ donation depends on Public Trust in the:
  - organ donation system
  - healthcare system
  - healthcare professionals
- We must aim to maximize overall benefit
- Not achieved if the donor's health is compromised



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# Acknowledgments

- Daniel Buchman PhD