

# Ethical Perspectives on Paternalism and Autonomy in Living Donor Acceptance Criteria

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# Learning Objectives

Increase participants' understanding of paternalism in living donation

Increase participants' understanding of autonomy in living donation

Facilitate participants' comfort level with balancing ethical principles in service of LD autonomy and best interests



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# Outline



Overview of Living Donation,  
Paternalism and Autonomy in Bioethics

How Paternalism and Autonomy Relate to Living Donation

Balancing Interests



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**POPULATED PLACES**

25,000 – 99,999 • Portland  
 24,999 and less • Millinocket  
 State capital ★ Augusta

**TRANSPORTATION**

Interstate; limited access highway   
 Other principal highway   
 Railroad   
 Ferry 

**PHYSICAL FEATURES**

Streams   
 Lakes   
 Highest elevation in state (feet) +5267  
 The lowest elevation in Maine is sea level (Atlantic Ocean).



# MaineHealth

- 12 Hospitals
- 200 Specialty and Primary Practices
- Serves 1.1 million Maine & NH residents



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# Maine Coon Cat



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# New England LKD 2022

## Living Kidney Donors



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# Living Donor Acceptance

Shared  
Decision  
Making



Transparent



In Practice:  
Complex



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# Donor Centered Shared Decision Making

(Thiessen et al., 2015)

- A donor-centered approach to declining a donor would entail informing the donor about the extent to which medical uncertainty persists. Discretionary donors should be advised that other centers may use different criteria for accepting living donors.
- Possibility of Optimizing for donation
- Example: Non-ideal donors with BMI > recommended could be coached in optimization of diet, exercise, lifestyle as in DonateWell at USC.



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# First successful living donor transplant 1954



**“I’m here, and I’m going to stay, and that’s it,” Ronald wrote to his brother on the eve of the surgery when Richard urged him to back out.’**

(Boston Magazine; AP photo)

- Side note: Ronald spent his life in Maine as a math teacher and farmer until his death in 2010 at age 79.



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# Paternalism and Autonomy: Practical Considerations in Tension

(Thiessen et al., 2015; Chen et al., 2019)

- Respect for Living Donor Self-Determination
- Recipient Need
- Potential impact of poor donor outcomes on center certification status
- Public opinions about living donation
- Professional standards
- Provider conscience



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# Is LD ever morally or ethically obligatory?

(Beauchamp & Childress, 2019)

- Living Organ Donation is a ***supererogatory*** act

**Supererogatory: beyond what is obligatory**

***From a medical ethics perspective, living organ donation is not a moral obligation; “praiseworthy but optional”***

*From Tuesday Keynote: Donor shortage/ethical imperative to find LD*

*Response: yes but careful to not conflate ethical imperative to find qualified LD with an ethical imperative to donate*



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# History of Paternalism (fatherly, paternal)

Intentional overriding of one person's preferences by another. The action appeals to the goal of benefiting the person or preventing or mitigating harm



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# Paternalism in Medicine: tends toward power imbalance

Paternalism in medicine is the tendency to view the medical provider as possessing greater knowledge, training, expertise and experience thereby granting authority on what constitutes a patient's "best interests"



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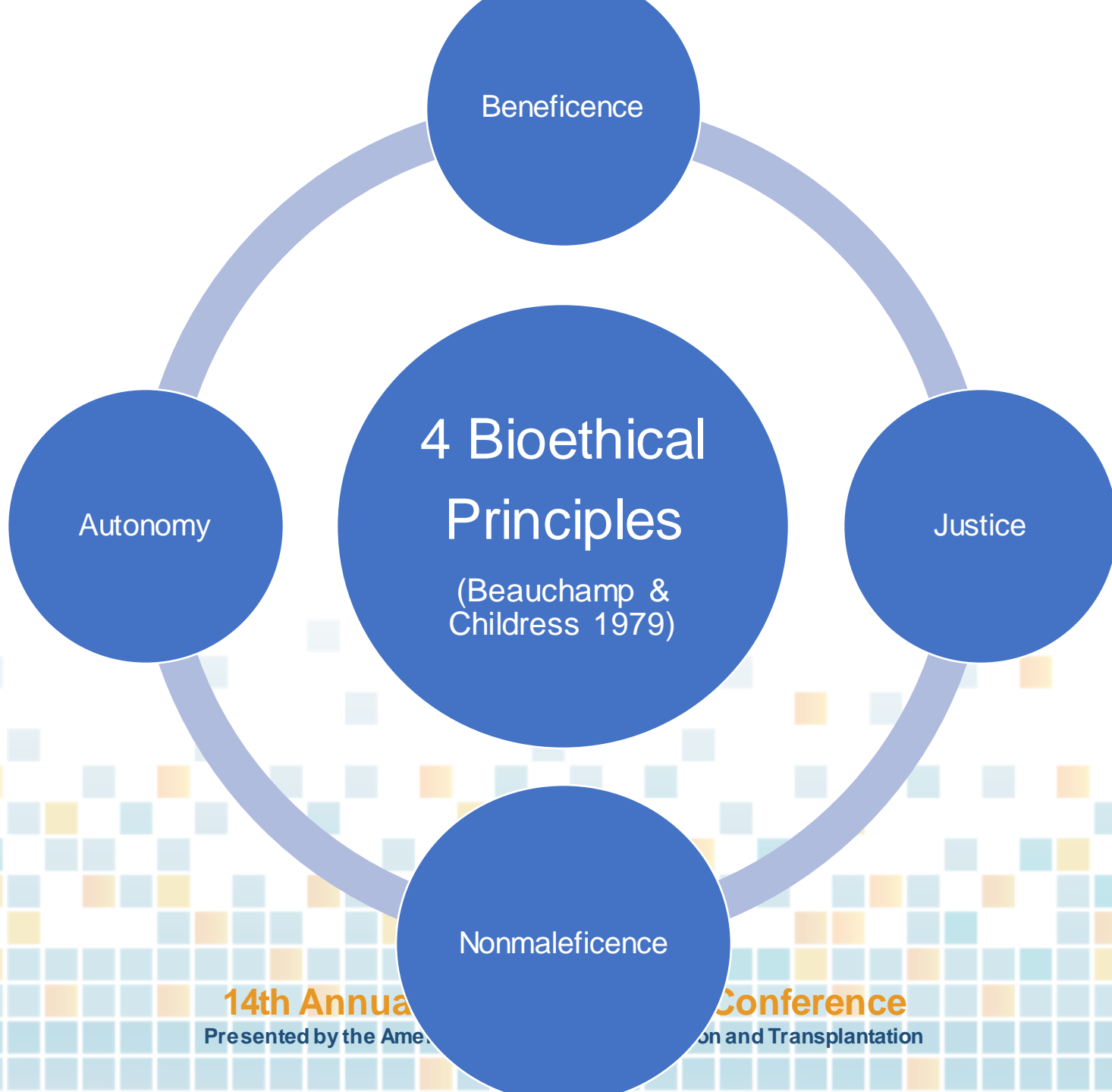
# Karen Ann Quinlan 1976

(Photo used with permission: Fair use, <https://en.wikipedia.org/w/index.php?curid=7659862>)



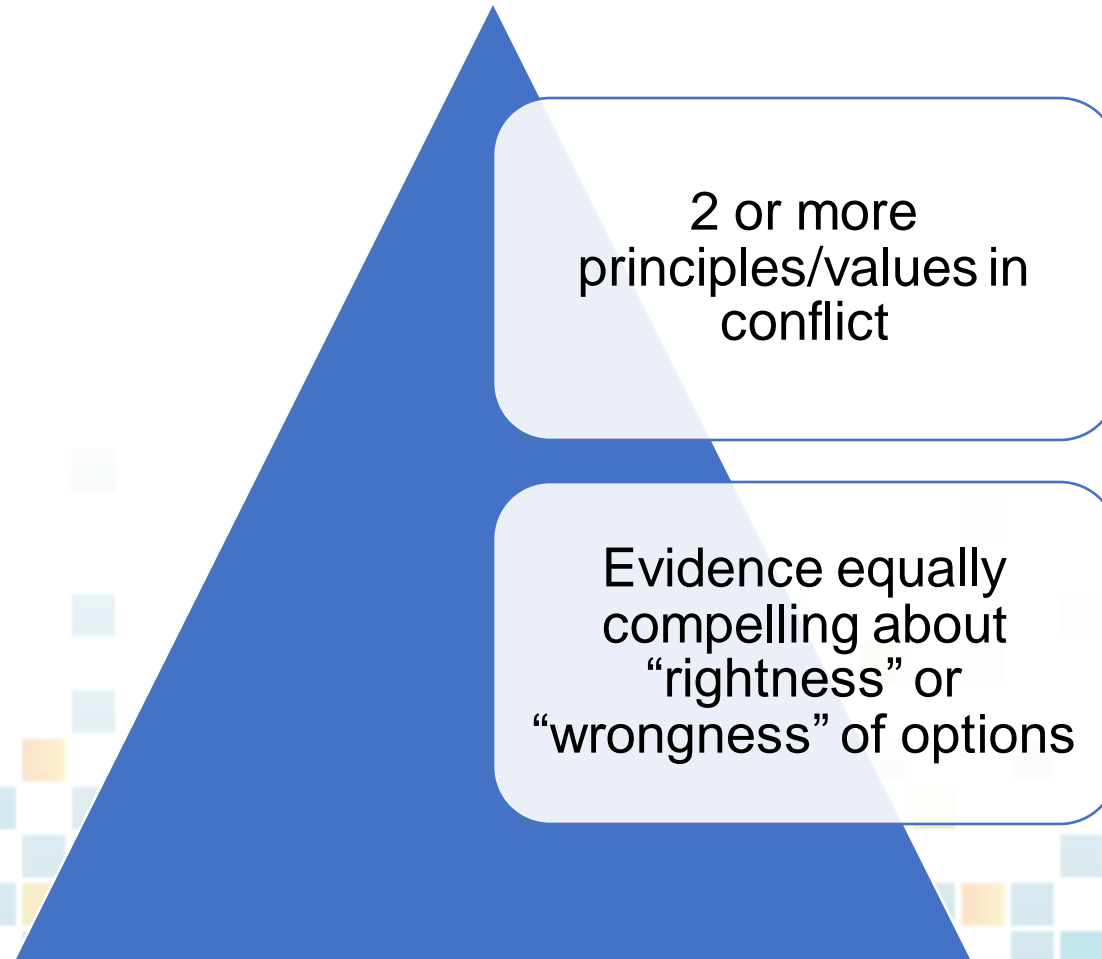
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# When do we have an ethical dilemma?



# Respect for Autonomy

(Beauchamp & Childress 2019)

Includes BOTH the obligation to establish that necessary conditions are present for autonomous action AND acknowledge right of the person to hold views, make choices, and take actions based on their beliefs and views.



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# What Guides Us? Conditions Necessary in Autonomous Decision Making

The action is intended

Understanding  
(informed consent)

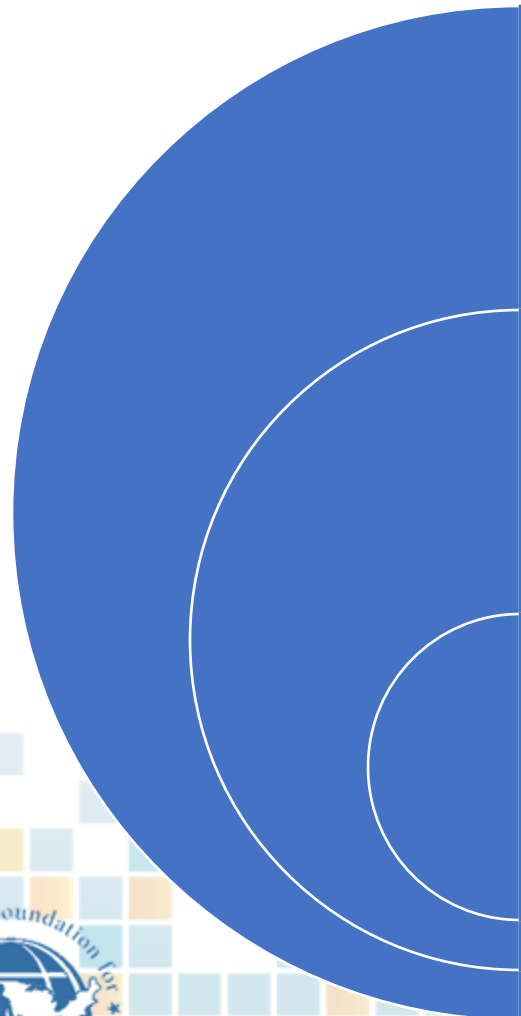
Free of undue pressure  
(internal and external)



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# LD Exclusion Criteria

	<h2>Undue Pressure/Inducement</h2>	<ul style="list-style-type: none"><li>• persuading someone to donate by using incentives/pressure that distort a person's judgment</li></ul>
	<h2>Exploitation</h2>	<ul style="list-style-type: none"><li>• person who bears the risk is in a weaker or more vulnerable position and receives unequal benefits for the burdens undertaken; the recipient clearly benefits at the expense of the donor</li></ul>
	<h2>Coercion</h2>	<ul style="list-style-type: none"><li>• a threat that makes you worse off no matter which outcome you choose</li></ul>



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Obligations to respect  
autonomy do not extend to  
persons who cannot be  
rendered autonomous  
because they are:



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# Hard vs. Soft Paternalism in Bioethics

(Beauchamp & Childress)

## Hard Paternalism

Usurps autonomy  
Restricts information

Overrides decisions that are:  
-informed  
-voluntary

## Soft Paternalism

Intervenes on grounds of  
Beneficence or  
Nonmaleficence

Goal:  
prevent nonvoluntary conduct



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# Can We Balance These Considerations?

## The “non-ideal donor”: 2 perspectives

“Donor consent and autonomy is [*sic*] necessary, but not sufficient, to proceed to kidney donation. Medical evaluation and concurrence is essential. Donor autonomy does not overrule medical judgment and decision-making” (Thiessen et al., 2015)

“The magnitude of the harm [to donor] to be prevented does not outweigh the benefits to recipients to a degree that would permit the overruling of the non-ideal donor’s autonomy.”

(Weightman, Coghlan, & Clayton, 2022)



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# Balancing of Ethical Concerns

**Autonomy**

Must be informed, have capacity,  
not under duress

Goal: Ensure Robust Consent

**Soft Paternalism**

Intervenes on grounds of  
Beneficence or  
Nonmaleficence

Goal:  
Prevent nonvoluntary conduct



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# Acceptance Criteria and the “non-ideal donor”

Amy is a 23 year old electrical engineer working at her first job at Ford Motor Company in Detroit. Her twin sister Abby is a nurse in Boston. Abby has ESRD due to acquired cystic kidney disease and will likely need to start dialysis soon. As soon as Amy heard of Abby’s need she describes feeling an immediate and profound desire to donate a kidney to her sister. Amy contacted 3 transplant centers who told her that their minimum age requirement for living donation is 25.

Is the policy a form of Paternalism? Hard or Soft?  
Is Amy capable of making an autonomous decision?



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# How Can We Balance Autonomy and Harm Avoidance/Paternalism?

(Weightman, Coghlan, & Clayton, 2022)

**Empower LD  
to participate  
in SDM**

**Understand  
individual risk  
threshold:  
leave room for  
case-by-case**

**Understand  
how LD  
balances risks  
with  
motivations**

***Tensions will  
and should  
remain***



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# Thank You!



# Questions?



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