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# Ethics and Critical Conversations: Challenges and Strategies for Interacting with Family Members and Patients

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# Today's Presenter

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- Director of the Donnelley Ethics Program at Shirley Ryan AbilityLab.
- Faculty member at Northwestern University's medical and law schools.
- National educator in healthcare ethics, consent, and decision-making.
- Works closely with clinicians and care teams on complex, real-world ethics cases.



# Purpose

- Focus on understanding and examining ethics issues and tensions during critical conversations with claimants and family members.
  - Didactic and case-based discussions used to describe ethics frameworks and methods.
  - Discussion of skills and best practices to address tensions, conflicts and dynamics that can play into critical conversations.

# Objectives

At the conclusion of this presentation, participants will be able to:

- Recognize how to apply framework for ethical decision making during critical conversations with claimants and families.
- Identify at least two barriers and two facilitators to effective communication related to critical conversations with claimants and families.
- Select key strategies and tools to leverage inter-professional collaboration and ethics during critical conversations.



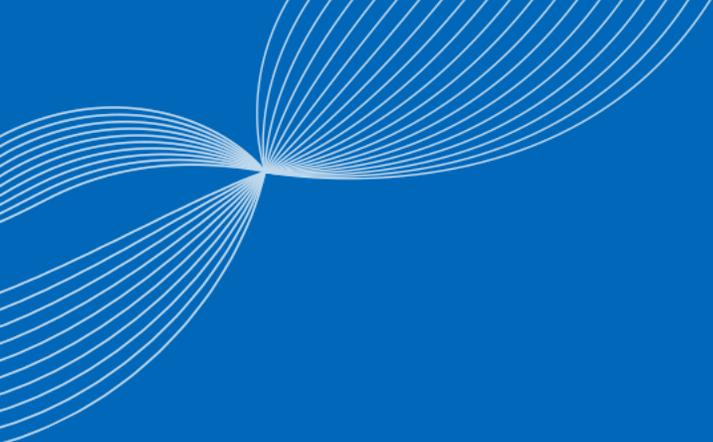
# Ethics Defined

Ethics are moral principles that govern a person's behavior or activities.

Ethical dilemmas in claims adjusting arise when professionals must choose between competing values, responsibilities, or interests—often under pressure from stakeholders, legal requirements, or organizational goals. These dilemmas test the adjuster's integrity, fairness, and commitment to both the insurer and the claimant

# Case 1: Dilemma regarding information request

- 54-year-old man with SCI and mild TBI
- Inpatient rehabilitation with waxing and waning decisional capacity
- Wife of 23 yrs is surrogate decision maker for complex medical decisions
- Claimant was having an affair and was involved in the accident when he was with his lover. Wife and children not aware of affair but starting to wonder what is going on.
- Getting ready to think through discharge planning; claimant is assenting to going home with wife.
- **Family starting to ask nurses and care managers, adjuster what happened and was going on at the time of the accident...What do you do?**



What concerns come to mind?

Name one or two?



An abstract graphic on the left side of the slide, composed of various geometric shapes and overlapping human figures in shades of orange, yellow, and red. The figures appear to be in various poses, some with hands raised, suggesting a collaborative or thoughtful environment. The background of the entire slide is a solid, vibrant orange.

# Ethics Frameworks and Concepts

# Ethics

Various theories and frameworks can be used to analyze ethical considerations, including a focus on

- Principles
- Relationships
- Virtues
- Consequences
- Rules
- Process

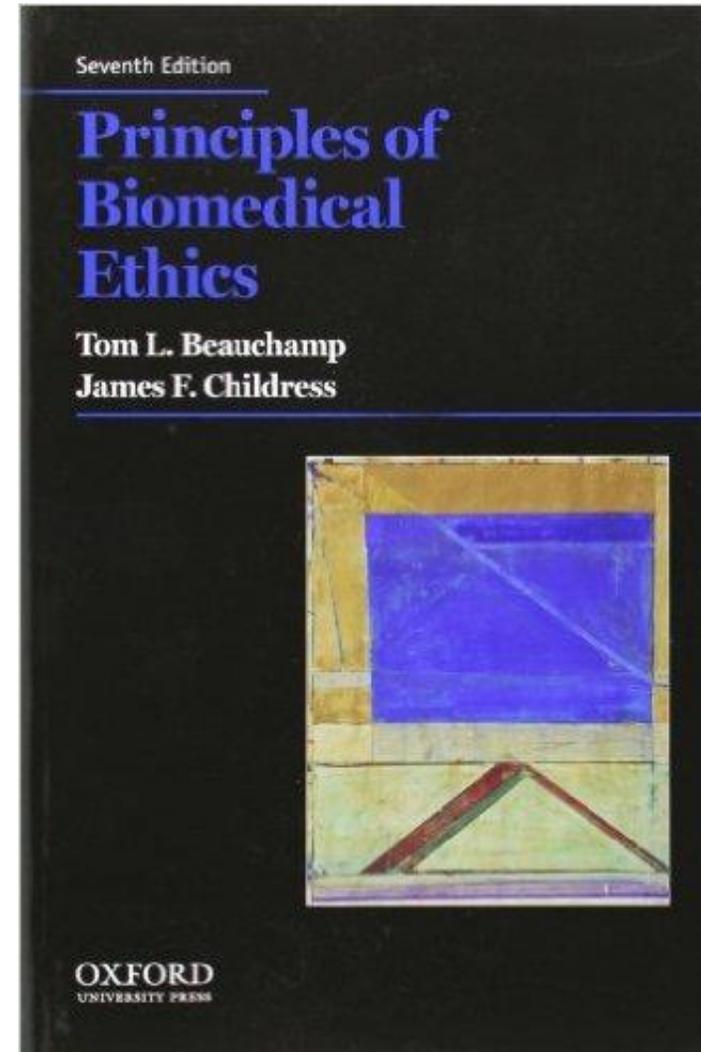


Mukherjee, D. (2011). Ethical Considerations. In Zollman F. (ed). *Management of Traumatic Brain Injury*.

# Core Principles of Biomedical Ethics

- **Beneficence**: providing benefit and balancing risks to bring forth the best results
- **Respect for Autonomy**: fostering self-determination and respecting individual differences
- **Nonmaleficence**: doing no harm
- **Justice**: upholding concepts of fairness and equity

Beauchamp TL, Childress JF. Principles of Biomedical Ethics, 7th ed. New York: Oxford University Press; 2013.



# Common Ethics Issues in Care Management

- Decisional-capacity
- Surrogate decision-making
- Informed refusals/ AMA discharge
- Truth-telling
- Advance care planning
- Disclosure of confidential information
- Goals of care
- Abuse and neglect
- End-of-life decision-making



Is it ever okay to not to share information requested with a family member who is a surrogate decision-maker?



# Disclosures of Sensitive Information can be Tricky

Is there ever a duty to disclose personal health information about claimants to others?

How can we balance our duty of confidentiality and respect for privacy with our commitment to provide sufficient information for medical decision-making?

What about the commitment to “do no harm”?

What factors should be considered in deciding when to disclose sensitive information?



# Informed Consent

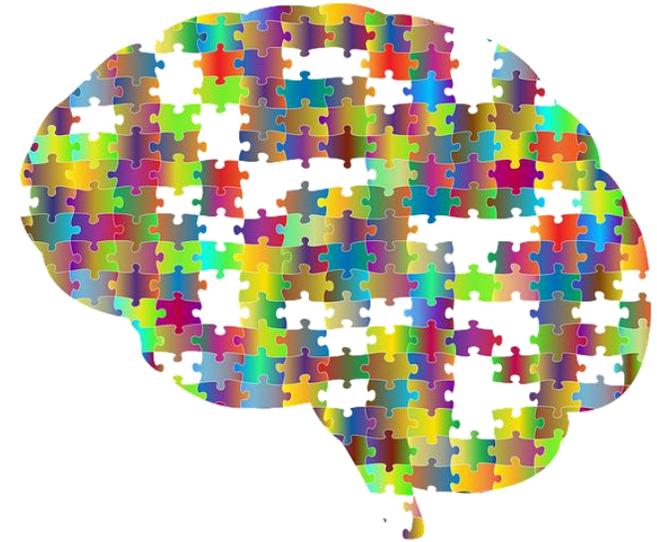
- “Patients have the right to receive information and ask questions about recommended treatments so that they can make well-considered decisions about care.” – American Medical Assoc., 2021
- Elements of consent:
  - Disclosure of relevant information
  - Ability to make a decision (either patient or surrogate)
  - Voluntariness



<https://code-medical-ethics.ama-assn.org/ethics-opinions/informed-consent#:~:text=Informed%20consent%20to%20medical%20treatment,well%2Dconsidered%20decisions%20about%20care.>

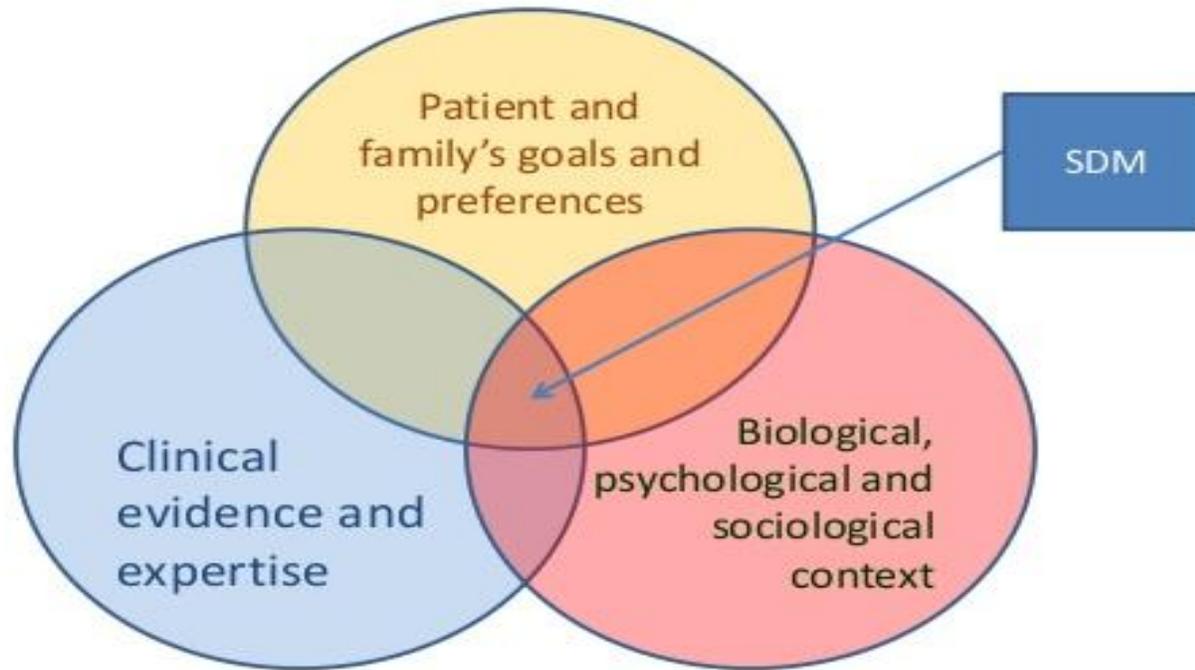
# Decision-Making Capacity

- Medical **decision-making capacity** is the ability of a patient to make their own medical decisions
- **Capacity** is the basis of informed consent
- Patients with **capacity**:
  - can **consent** to medical care
  - have the **right to refuse** unwanted (even life-saving) medical care



# Medical Shared Decision Making

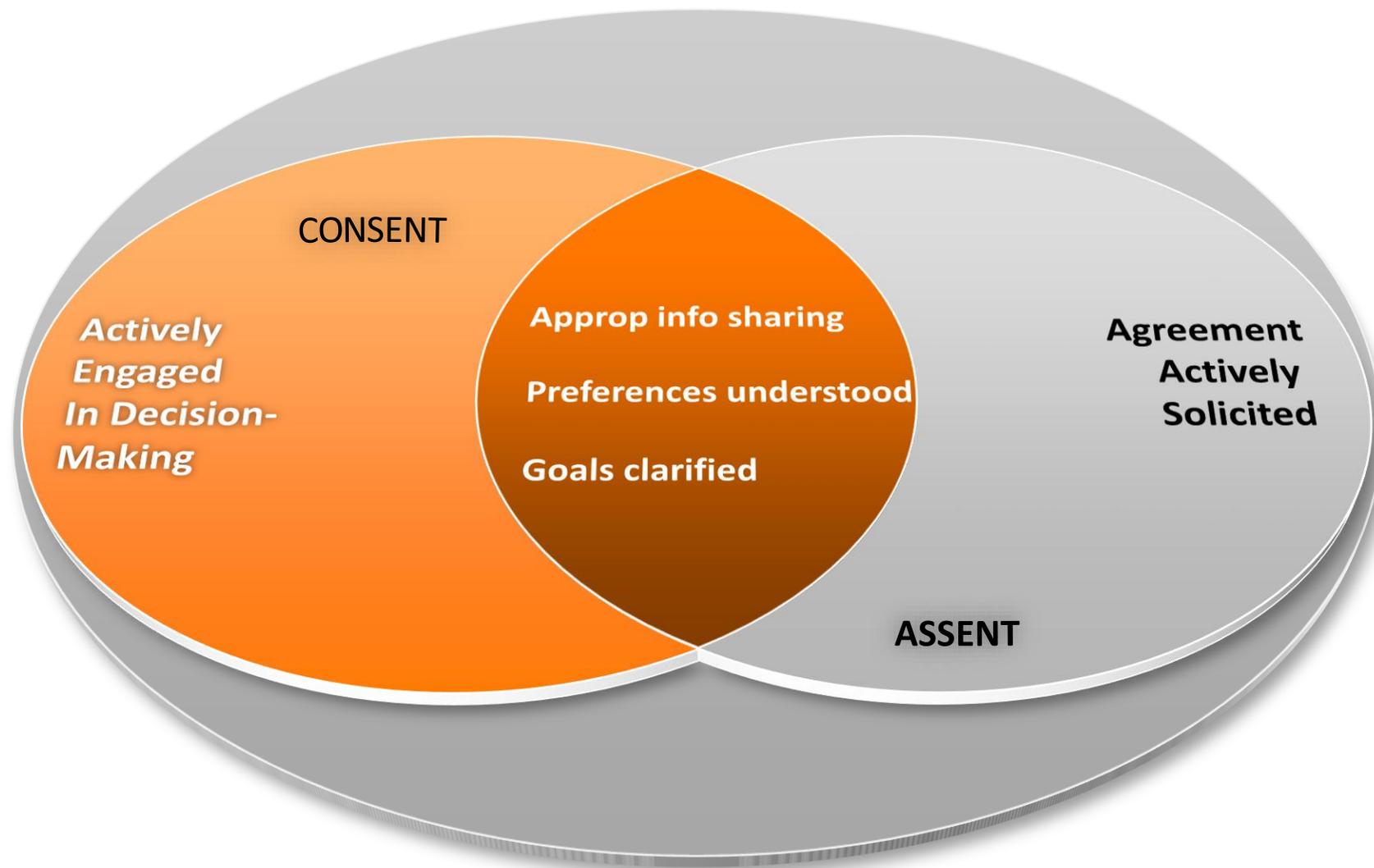
## Decision-making process



<http://www.cincinnatichildrens.org/>

# Consent and Assent

Areas of overlap and points of distinction



# Patients Perspective & Relational Autonomy

- Close social relationships matter & shape patient preferences
- Health care decision-making is thereby naturally influenced (not unduly influenced) by family members' motivations and concerns

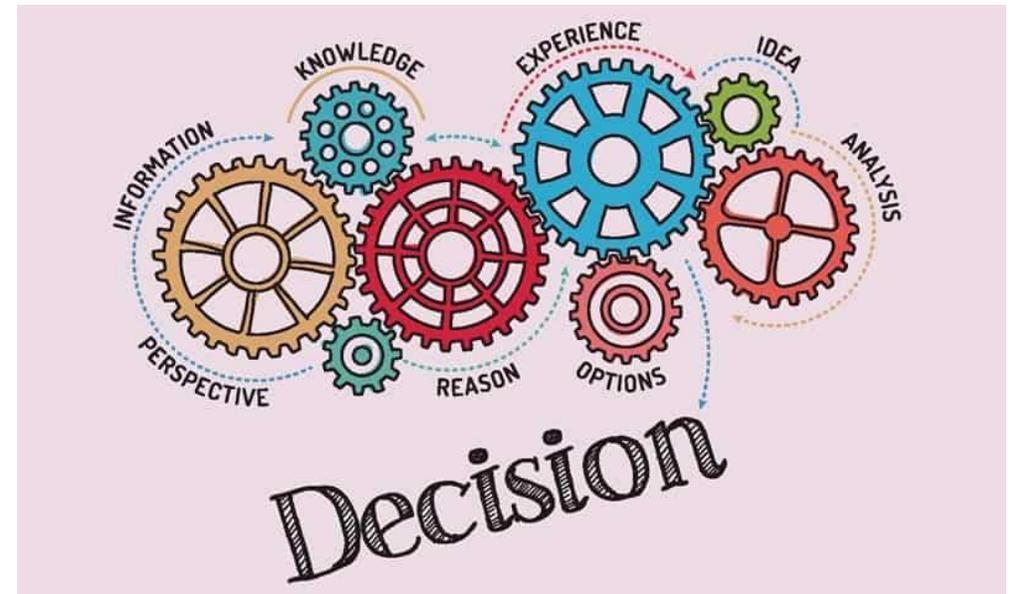


Gilbar, R. Miola, J. One Size Fits all? On Patient Autonomy, Medical Decision-Making and the Impact of Culture, *Med. Law Review*, 2015;23(3):375-99.



# Complex Choices in Rehabilitation

- Treatment consent/refusal – e.g., code status
- Goals of care
- Discharge
- Research opportunities



# Rehabilitation Setting



Patients recovering capacities over longer length of stay

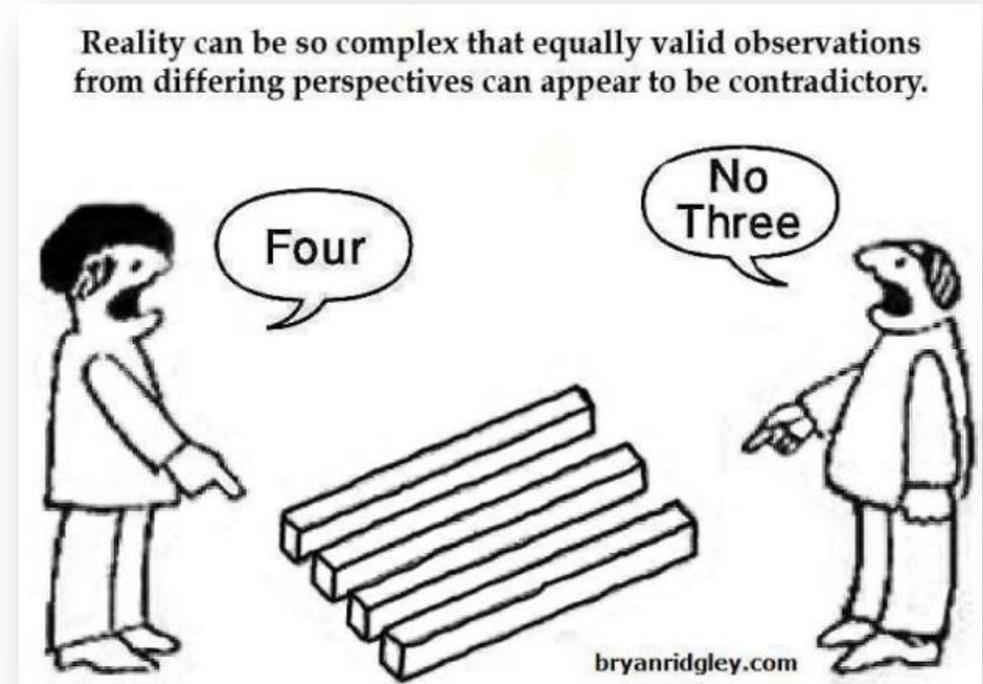
Need for patient engagement

Discharge questions loom large at outset

Multi-disciplinary team model

# Conflict and Different Perspectives

- Differing perspectives - multiple truths?
- Conflict present more often than we would like to admit – identifying & addressing conflict is important



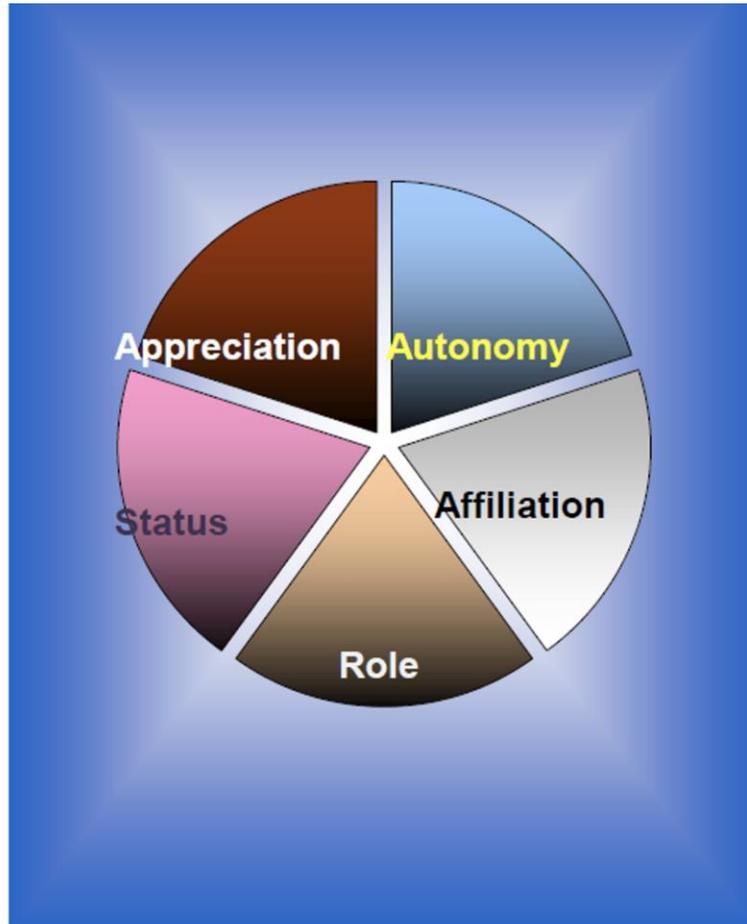
Team members caring for patients may have different views of what could be most helpful



# Core Concerns Framework

# Turn Your Attention to 5 “Core Concerns”

The Five Matters that We *Really* Care About



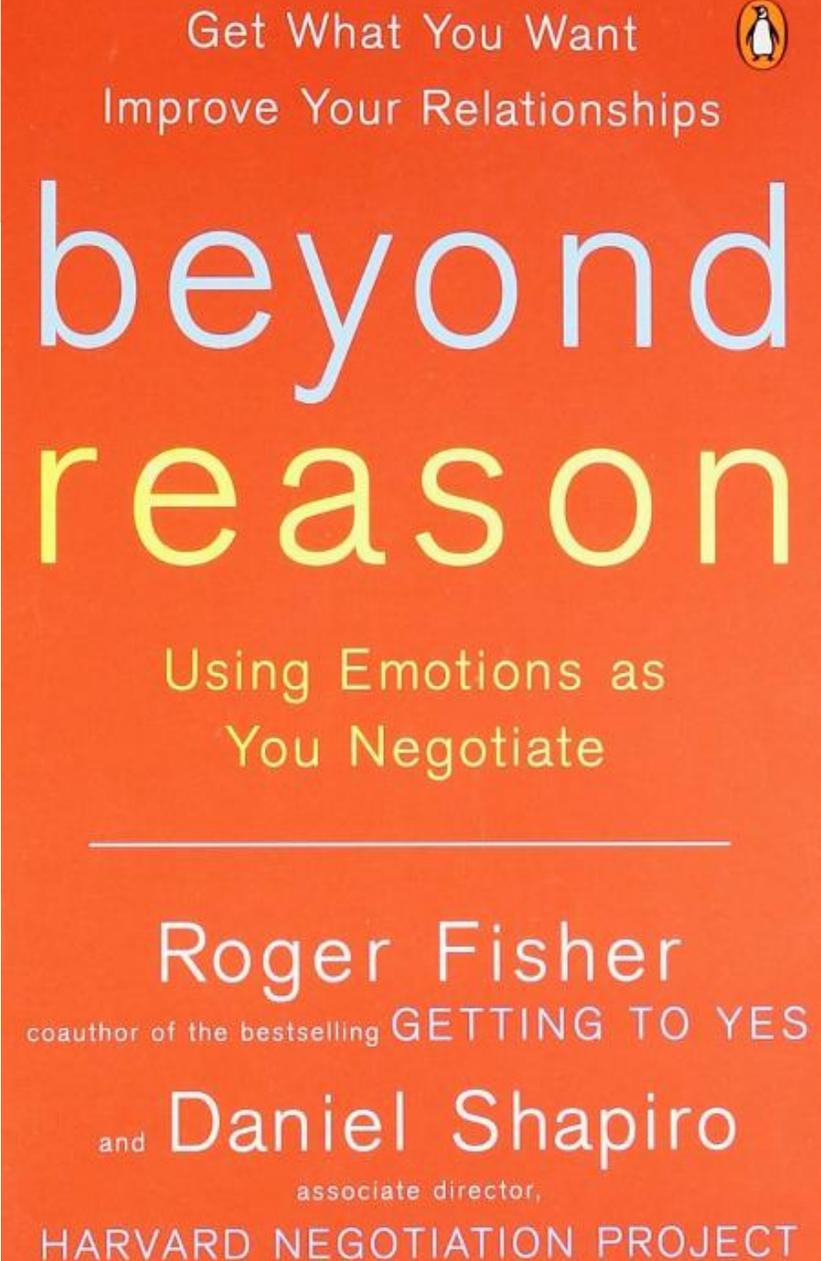
<u>Emotions</u>			
Anger	Guilt	Overjoyed	Comfort
Rage	Shame	Satisfied	Fondness
Fury	Remorse	Content	Pride
Outrage	Humiliation	Gratified	Hope
Wrath	Embarrassment	Pleased	Awe
Indignation	Mortification	Carefree	Wonder
Irritation	Shy	Jubilant	Relief
Annoyance	Regretful	Thrill	Calm
Hatred	Sadness	Exuberant	Tranquil
Spite	Anguish	Exultant	Serene
Impatience	Hopelessness	Enthusiastic	Relaxed
Fright	Gloom	Blissful	Patient
Anxiety	Unhappiness	Cheerful	Comfortable
Horror	Grief	Playful	Humbled
Fear	Woe	Amused	Envy
Unease	Misery	Glad	Jealousy
Apprehension	Melancholy	Gleeful	Disgust
Worry	Blue	Jolly	Revulsion
Alarm	Down	Jovial	Loathsome
Dread	Devastated	Delighted	Repulsion
Panic	Heartbroken	Euphoric	Sickened
Awe	Mournful	Ecstatic	Resentment
	Forlorn	Elated	Contempt
	Gloomy	Enraptured	Happiness
	Despair	Triumphant	Joy
	Sorrow	Love	Liking
	Apathy	Affection	
	Nostalgia	Adoration	
		Passion	

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# Core Concerns Framework

1. Express Appreciation
2. Build Affiliation
3. Respect Autonomy
4. Acknowledge Status
5. Choose a Fulfilling Role

*Fisher, R & Shapiro, D. Beyond Reason: Using Emotions as You Negotiate. New York, NY: Penguin Books, 2005.*



# 1. Express Appreciation

## Prepare to Appreciate Others.

- Active listening
- Listen for context & meta-messages
- Role reversal exercise, ask open ended Qs

## Help Others Appreciate You.

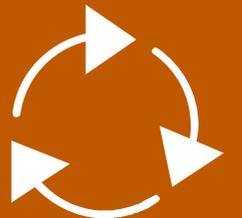
- Propose time limit for them to listen to you
- Limit yourself to a few big points
- Tailor your message
- Ask others to find merit in your point of view

REMEMBER:

Logistics

And

Language Matter



## 2. Build Affiliation (Connectedness)

### Build

Review chart ahead of time to build links

Start the discussion regarding points of commonality

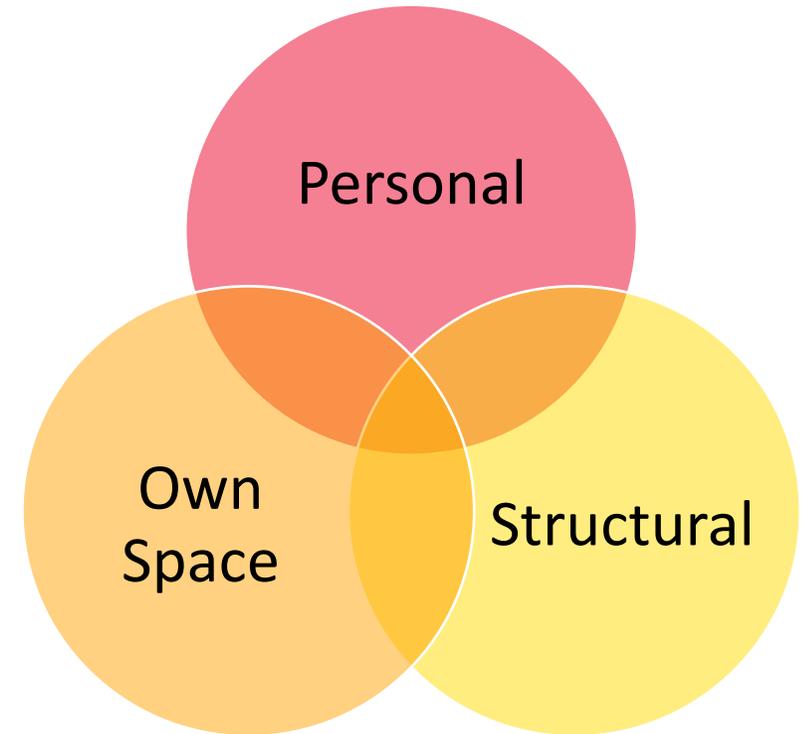
Set up times to connect

### Keep

Exclude with care and keep in contact

### Remember

Affiliation  $\neq$  Manipulation



# 3. Respect Autonomy

- Establish decision-making guidelines (inform vs. consult vs. negotiate joint agreement)
- Decide who to invite input from and who to inform
- Give away your own autonomy sometimes; limiting yours can elevate others
- If impinge, genuinely apologize and try to self-correct



## 4. Acknowledge Status

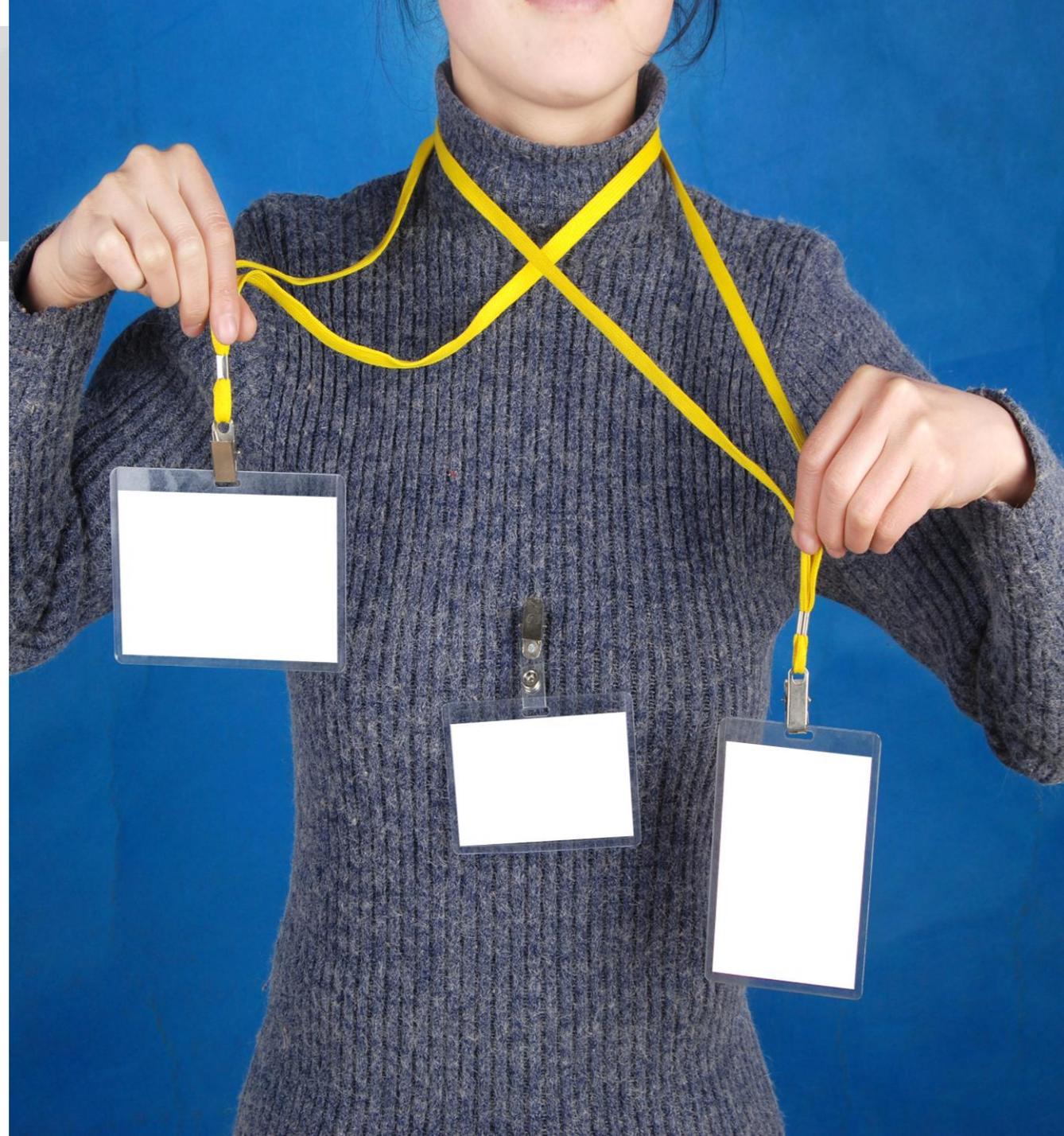
- Recognize their status by asking advice re: their particular area of expertise
- Appreciate your areas of high status
- Use checks and balances to avoid status spillover
- Raise your status by doing your homework, preparing for discussions



Status is Not fixed. It can be acquired.

## 5. Choose a Fulfilling Role

- Listener
- Problem solver
- Devil's Advocate
- Brainstormer
- Advisor





# Discussion and Take Aways

# Case 1: Dilemma regarding information request

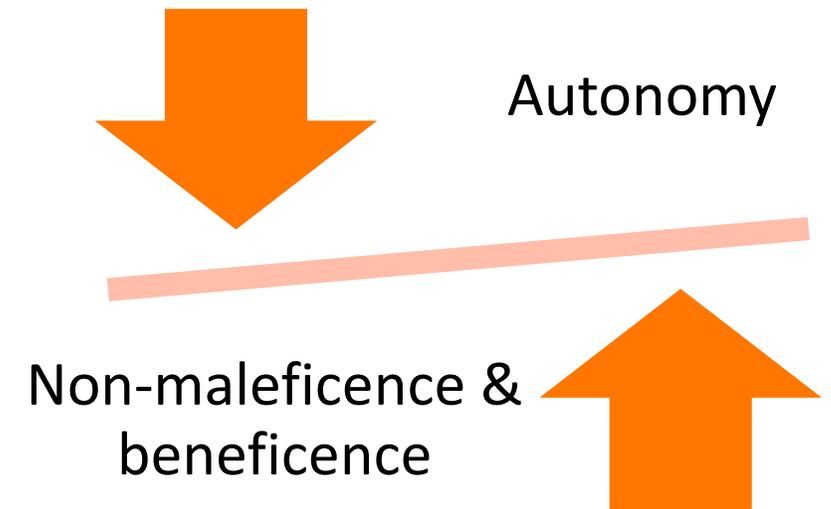
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- Inpatient on the rehabilitation service with waxing and waning decisional capacity
- Wife of 23 yrs is surrogate decision maker for complex medical decisions
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- Getting ready to think through discharge planning; patient is assenting to going home with wife.
- **Family starting to ask nurses and care managers what happened and was going on at the time of the accident...What do you do?**

What additional concerns do you have about this case? (Name one or two words that come to mind)

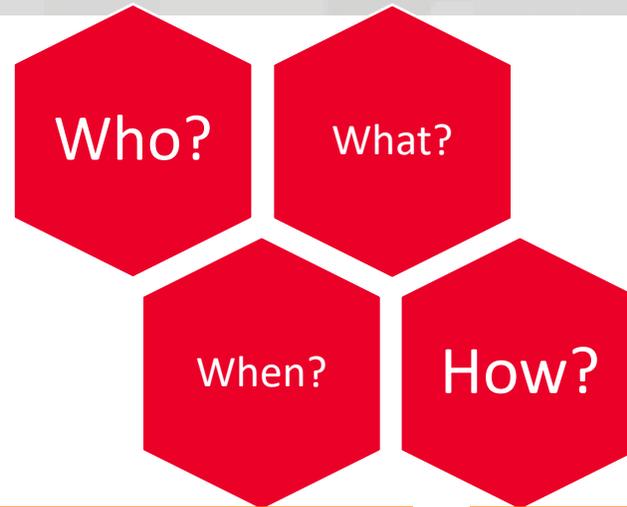
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# Considerations for info Requests from Surrogates

- Respect for patient privacy
- Duty of confidentiality
- Respect for autonomy
- Commitment to non-maleficence
- Benefits vs. harms



# Factors and Approaches to Consider – Disclosures of Sensitive info to Others



WHAT?	WHEN?	WHO?	HOW?
<ul style="list-style-type: none"><li>Minimally necessary, relevant info</li></ul>	<ul style="list-style-type: none"><li>Risk/benefit favors disclosure*</li></ul>	<ul style="list-style-type: none"><li>Legally authorized rep (HCPOA or surrogate)</li></ul>	<ul style="list-style-type: none"><li>Privately and sensitively; explore prior knowledge; plan supports, including supporting patient to disclose**</li></ul>

\*often d/t direct, foreseeable harm to affected individuals

\*\*ideal to support patient to disclose directly

# Article Discussion Case

<https://onlinelibrary.wiley.com/doi/full/10.1016/j.pmrj.2015.05.021>



Ethical Legal | [Free Access](#)

## Surrogate Decision Making and Truth Telling in a Rehabilitation Case

Carol Levine MA, Jeanne M. Hoffman PhD, ABPP, Jason Byron MA, Robert Arnold MD, Andy Kondrat MA, Debjani Mukherjee PhD [✉](#)

First published: 16 July 2015 | <https://doi.org/10.1016/j.pmrj.2015.05.021>

Disclosure: nothing to disclose  
Disclosure: board member, Vital Talk

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### Feature Editor Introduction

Surrogate decision making is a critical bioethical issue that has been addressed by courts, policies, and medical practices. Most states have laws that dictate to whom clinicians should go if a patient lacks the capacity to make decisions; in Illinois, for example, a hierarchical list of surrogates guides clinicians in the absence of a durable power of attorney for health care. However, the context and complexities of family and surrogate relationships can make the process of surrogate decision making very complicated. In fact, navigating psychologically and socially complex relationships that are under stress as a result of a traumatic injury can lead to a host of ethical, moral, and sometimes legal issues for clinicians. The importance of

[10.1016/j.pmrj.2015.05.021](https://doi.org/10.1016/j.pmrj.2015.05.021) | not be overstated in the rehabilitation setting, which includes many

# Thank You & Contact Info

**THANK YOU!**

Comments, Questions?

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<https://www.sralab.org/services/donnelley-ethics-program>

